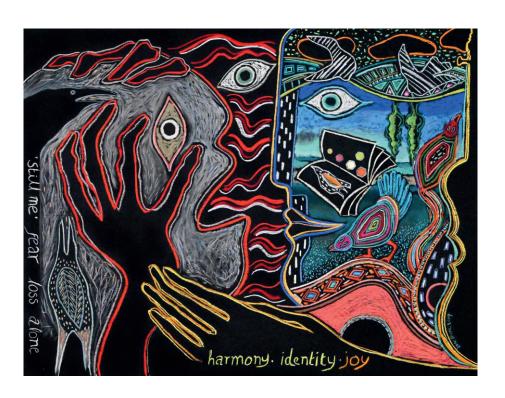
# A.R.T.S. for Brain Health

Social Prescribing transforming the diagnostic narrative for dementia

From Despair to Desire



Veronica Franklin Gould



# A4D speakers 2019-21

#### The Rt. Hon. Andy Burnham, Mayor of Greater Manchester:

'You have got to start with the person not the patient, prioritise social, cultural and creative interventions to prevent the risk of cognitive decline. In a 21<sup>st</sup> century NHS we need to turn things around. Social prescribing needs to be at the heart of the system. It has got to be about that wider holistic support for people with dementia, not just post-diagnosis, but from the onset of symptoms. I think 'care' is helping people do what they love to do, allowing them to connect with their passions, what animates them in life. Empower them to do what they love doing. That is the starting point for dementia care. It is about the vision of promoting independence, creativity, empowering people to interact and enjoy activities to preserve their brain health.'

#### Baroness Greengross, Co-Chair of the All-Party Parliamentary Group on

**Dementia**: Many people think that if you have a diagnosis of dementia, it's the end of a decent life. Arts 4 Dementia has inspired us to understand a new sort of life is just beginning, and it can be inspirational, because the arts can inspire us. They can put us on a different footing, learn to appreciate new things better, in depth, in a way we couldn't do before perhaps. This is part of social prescribing, a prescription that can improve, enhance and in fact create a quality of life we imagined was gone for ever.

Dr Michael Dixon, Chair of the College of Medicine & Co-Founder of the National Social Prescribing Network: The important thing is not only to stimulate the mind, but also to create a social experience. We must ensure that people with dementia can access social prescription at a very early point, because that enables us firstly to delay the onset of any deterioration but also to make sure that they are already linked to those arts interventions, familiar with the group at an early stage which might be more difficult as the disease progresses. It also gives their carer a support; and speaking as a GP gives patients another way of improving their lives and improving their health.

#### Professor Martin Marshall, Chair, Royal College of General Practitioners:

We have been working closely with the National Academy for Social Prescribing, supporting the rollout of the link worker role in general practice. We are seeing great examples of social prescribing helping GP teams to support and refer patients at the onset of dementia. These are shared decision-making processes with the individual, their family and carers. The shift for us in general practice is not just engaging with those medical activities which are core, but to engage with social activities, and make sure the two are aligned.'

#### Dr Charles Alessi, Senior Advisor, Public Health England:

We know now more than ever that both social isolation and cognitive inactivity are risk factors towards people developing cognitive decline, especially as they grow older. It is fundamentally important for people to retain meaning and purpose and I know no better way than to maintain contact with the arts and the community to achieve this

#### Keith Oliver, AS Ambassador, living with Alzheimer's disease:

It is crucial to make the prescribed arts intervention early — at the point of referral to the memory service. I remember how worried my wife and I were, wondering if I were to have dementia during the testing period of seven to eight months back in 2010. I did feel at a cliff edge and I needed something positive, constructive, rewarding and stimulating to fill the vacuum and anxiety that the condition, the tests and the diagnosis were generating.

#### Alexandra Coulter, Director of the National Centre for Creative Health:

That issue of anxiety, waiting to find out whether you have dementia is really emotive. Arts-based processes and activities can have a positive impact on cognition, attention, stimulation, enhanced communication and engagement and we need to make these arts-based activities accessible to people everywhere.

Georgia Chimbani, Dementia Lead Association of Directors of Adult Social Services: Social prescribing arts for people affected by dementia fits very much with the local authority agenda in terms of early intervention - Prevent, Reduce, Delay.

#### Dr Jenny Elliott, Chief Executive, Arts Care, Northern Ireland:

What we have found increasingly working in this field of arts and dementia and arts predementia, has just been the many benefits that the arts can bring in terms of quality of life, self-value, self-confidence, and the management of a healthy life.

# A.R.T.S. for Brain Health

# Social Prescribing transforming the diagnostic narrative for dementia From Despair to Desire:

Findings from Arts 4 Dementia's two-year programme to help advance social prescribing at the onset of dementia symptoms

'We must promote the use of arts as soon as diagnostic tests begin. This will protect against cognitive decline and the strains of dementia and will empower people to preserve cultural interests, especially music, and enjoy quality of life in the community for years longer'

Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia.

Of all engagements, the work of Arts 4 Dementia is for me most important. It has been remarkable to see our social prescribing campaign advancing, with doctors referring patients to music and the arts when symptoms occur - the only remedy to slow down the uncurable condition.

HSH Dr Donatus, Prince von Hohenzollern.

September 2021









Participants with mild cognitive impairment hold sketches inspired by Dame Elizabeth Frink CH DBE RA at Dorset County Museum.

#### Foreword

The creative health movement is reaching across boundaries, from the NHS to the arts and voluntary sector, and demonstrating the power of collaboration to prevent ill health and enhance health and wellbeing.

The NHS Long Term Plan launched in January 2019 placed a new emphasis on prevention with social prescribing central to the strategy and the arts central to social prescribing.

At the Creative Health conference at the Southbank Centre in June 2019, Simon Stevens, then CEO of NHS England, for the first time affirmed the acceptance by the NHS of the important contribution that the arts could make to the promotion of health and wellbeing, leading to better outcomes.

Under new policy we are to be liberated into collaboration. Health, Social Care, Local Government and the voluntary and community sector are at last to be brought together in place-based, shared endeavour to improve health and wellbeing.

Arts Council England's ten-year strategy, *Let's Create* (2020) committed to partnership working for arts and health. The *Creative Health* report of the All-Party Parliamentary Group on Arts, Health and Wellbeing recommended establishing a UK strategic centre, independent of government, to support the advance of good practice, collaboration and delivery, and the National Centre for Creative Health is now up and running. The Department of Health has established the National Academy of Social Prescribing (NASP).

The role of the arts in combating loneliness and cognitive decline is now widely recognised as providing vital benefit to patients. GPs are also recognising that engagement by their patients with the arts eases the pressure on them. Working with social prescribing link workers, GPs can look to cultural and creative organisations to empower their patients at the onset of dementia – earlier than ever before. The arts help patients to preserve their brain health, and keep active, connected and inspired in community life for years longer.

The Rt. Hon. Lord Howarth of Newport CBE, Chair, National Centre for Creative Health Co-Chair, All-Party Parliamentary Group on Arts, Health and Wellbeing

# A.R.T.S. for Brain Health – Terms of Reference

#### Arts 4 Dementia (arts4dementia.org.uk)

Arts 4 Dementia (A4D) was founded in 2011 to co-ordinate what is now the national social prescriber arts and wellbeing web directory for brain health and dementia and to help develop weekly programmes at arts venues, with training, as cognitive, mental, social and physical rehabilitation for people with early-stage symptoms of dementia and their carers). A4D has worked towards arts being offered to counteract shock on diagnosis.

Now thanks to the NHS Long Term Plan (2019) introducing social prescriber link workers (SPLWs) available to GPs to help support patients' wellbeing, they can be referred to arts from the onset of symptoms. Referral to an SPLW at the same time as referral to memory assessment will empower people to choose arts and wellbeing programmes to maximise brain activity, preserve sense of purpose, identity and joy in the community

This report, informed by A4D's two-year campaign, aims to establish social prescribing (SP) referral to cultural and creative activity as natural practice at the onset of dementia – to bridge the gap from the onset of symptoms, through the confusing, fear-filled months leading to memory assessment and diagnosis, whether mild cognitive impairment (MCI) or a dementia.

#### Terms of Reference for A.R.T.S. for Brain Health

A.R.T.S. – **A**ctivities to **R**evitalise **T**he **S**oul – represents wide-ranging stimulating opportunities to cover the arts and nature prescribing.

Professor Brian Lawlor's Global Brain Health Institute podcast (2020) Dementia is Global established the trajectory of our campaign to transform the narrative of dementia from one of tragedy, to hope through arts engagement.

How cognitive impairment can increase the risk of loneliness and vice versa is discussed in Campaign to End Loneliness report, 2020, *The Psychology of Loneliness: Why it matters and what we can do.* and DCMS (2018) *A Connected Society: strategies for tackling Loneliness* 

Studies by Dr Daisy Fancourt, detail the role and impact of cultural and creative engagement, notably in World Health Organisation (2019), What is the evidence on the role of the arts in improving health and well-being? Health Evidence Network Synthesis Report 67. Participatory arts referenced by Dr Rebecca Gordon-Nesbitt in Older and wiser? Creative ageing in the UK 2010-19 (King's Fund and Baring Foundation) and the Creative Health Inquiry (2017) for the All-Party Parliamentary Group on Arts, Health and Wellbeing. Cutler's Ageing Artfully: Older People and Professional Participatory Arts in the UK (2009). Professor Helen Chatterjee guides arts prescription evaluations.

For modifiable risk factors for dementia, WHO (2017) Global Action Plan on the Public Health Response to Dementia 2017-2025 (2019) Risk reduction of cognitive decline and dementia: WHO Guidelines, Livingston G. et al (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission' Lancet 390(10113) 2673-2734 and Increase your Brainability and Reduce your Risk of Dementia (2021).

Dr Marie Polley has provided many informed studies on SP.

### **Abbreviations**

A4D Arts 4 Dementia

A4D Conf21 A4D Best Practice Conference, Arts for Brain Health: Social

Prescribing as Peri-Diagnostic Practice for Dementia, 2021.

A4D Conf19 A4D Best Practice Conference, Towards Social Prescribing

(Arts & Heritage) for the Dementias, 2019.

ACE Arts Council England
AD Alzheimer's Disease

AHNS Academic Health Science Network
APPG All-Party Parliamentary Group

A.R.T.S. All arts, performance, nature, sports, wellbeing activities

CCG Clinical Commissioning Group.

EMIS System used to manage electronic patient records and

prescriptions

GPCOG GP Assessment of Cognition.

HLP Healthy London Partnerships

ICS Integrated Care System.

MDT Multi-Disciplinary Team

NASP National Academy for Social Prescribing.

NHSE/I NHS England and NHS Improvement.

OAP Old Age Psychiatrist

OPMH Older People's Mental Health

P&C Person/patient and companion/carer

PCN Primary Care Network.

SPLW Social prescriber link workers, social navigators

SPN Social Prescribing Network

UCL University College London

WHIS World Health Innovation Summit

WHO World Health Organisation

VD Vascular Dementia

### Report Authors

#### Arts 4 Dementia (arts4dementia.org.uk)

Arts 4 Dementia (A4D) was founded in 2010, with a double purpose, to coordinate by website arts events for dementia in the community – now the national social prescriber arts and wellbeing directory for dementia – and to help develop weekly workshop programmes at arts venues, with training, as cognitive, mental, social and physical rehabilitation for people with early-stage dementia and their carers. A4D workshops aim to stimulate participants to bypass the stressful symptoms, confusion and loneliness of dementia, to restore self-esteem, focus, sense of purpose and social wellbeing together in the community. (Reawakening the Mind, 2013; Music Reawakening, 2015, Reawakening Integrated: Arts & Heritage, 2017).

#### Veronica Franklin Gould, President

Veronica, founder of A4D's re-energising arts practice to bridge the provision gap for early-stage dementia, is a passionate campaigner for formally embedding arts and health programmes into The Well Pathway for Dementia, to underpin a better quality of life from the outset to end-of-life. Veronica is a member of the Royal Society of Art and Associate Member of the Royal Society for Public Health; and this year was nominated a finalist Social Prescribing Innovator of the Year.

The Rt Hon Alan Howarth, Co-Chair of the All-Party Parliamentary Group on Arts Health and Wellbeing and Chair of the new National Centre for Creative Health has kindly written the report Foreword.

Heike Fanelsa, Project Manager, Self-Care and Prevention Team, NHS Gloucestershire CCG, has kindly written an account on data reporting for the Creative Health Consortium, Gloucestershire CCG.

Cicely Ryder-Belson, Social Prescribing Co-Ordinator on this programme has written the guidance on Zoom set-up for workshops, ArtsPAL prepared text for our Southwark programme.

This report is informed by the testimony of over 450 speakers at our two national and 15 regional SP conferences, quoted within.

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# **Executive Summary**

### A.R.T.S. for Brain Health - Social Prescribing for Dementia

Everyone has the right freely to participate in the cultural life of the community.' Yet, referral to A.R.T.S. (Activities to Revitalise The Soul support for dementia requires a diagnosis. For people in the lonely, fear-filled months/years awaiting memory assessment and diagnosis, the right to A.R.T.S. participation has been hard to access – until now. GPs can at the onset of symptoms refer them to their practice social prescribing link worker (SPLW) for non-medical support – i.e., for re-energising A.R.T.S to help preserve their brain health, relieve fear and nurture their resilience in the community. If people are engaged in a social arts group when diagnosis comes, their sense of identity, purpose and belonging can continue, despite dementia – for years longer.

Over 200,000 people are diagnosed with a dementia each year in the UK. One-third more will not receive a diagnosis, either due to personal or cultural fears – the word 'dementia' itself and associated stigma is a deterrent. Of those referred to memory services for assessment for their cognitive challenges, one-third will not have a dementia diagnosis<sup>2</sup>. All would derive cognitive benefit and enhanced wellbeing through participating in A.R.T.S. programmes to preserve their brain health.

The report, informed by 400 speakers at A4D's two national conferences and 15 regional cross-sector meetings throughout the UK, leaders in dementia prevention, creative ageing, social prescribing, culture, health and wellbeing, people with lived experience, GPs, memory services and local authorities, includes

- How engaging in A.R.T.S addresses modifiable risk factors for dementia and protects against the advance of cognitive decline.
- Current diagnostic practice for dementia, with case studies from patients, how GPs and memory services offer or plan to offer SP.
- SP, creative ageing and A.R.T.S. for brain health, with case studies.
- Models for collaborative practice, for arts organisations to raise awareness to SPLW and achieve sustainable A.R.T.S. programmes.

#### Preventing well – A.R.T.S. modifying risk factors

As one-third of cases of dementia could be prevented, risk factors and how A.R.T.S. protect against the advance of dementia are examined.

#### Learning vs lack of education

Learning music, poetry or drama, exploring works of art, discovering the artist's intention, challenges the brain to create new neural

<sup>&</sup>lt;sup>1</sup> Universal Declaration of Human Rights, 1948. United Nations, Article 27.

<sup>&</sup>lt;sup>2</sup> Alzheimer's Research UK; Tim Sanders, Commissioning Lead for Dementia, Leeds City Council and Leeds CCG quoted other memory assessment outcome as 35% at A4D Yorkshire SP meeting, also quoted by Dr Frances Duffy, Consultant Lead Clinical Psychologist, Northern Health & Social Care Trust, at A4D Northern Ireland SP meeting.

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connections and pathways that can compensate for reduced activity in other regions. Opening the door to new discovery and engaging interest is the essence of cognitively stimulating A.R.T.S. workshop programmes run through arts organisations' learning or community teams, as well as community arts hubs or healthy living centres. Cocurating A.R.T.S. programmes heightens sense of identity, purpose and connectivity as members of a resilient, socially active group.

#### Social contact vs loneliness and isolation

The social connectivity involved in person-centred A.R.T.S. plays a vital role protecting people at this vulnerable cusp, across all social backgrounds and cultural ethnicities. A.R.T.S. fulfil their core psychological need, nurture social bonding, personal identity through collaborating in creative endeavour.<sup>3</sup>

#### Dance movement vs physical inactivity, obesity and depression.

Dance offers a joyous route to health and wellbeing, more effective than an exercise class in reducing body fat, fall prevention and, through the role of music, in improving mood, reducing stress and helping to maintain attention. Learning new steps, to lead and follow, enhances hand-eye coordination.<sup>4</sup>

#### Music vs depression

As we age, music-making provides a tool for a total brain workout, improves plasticity in the cortex, which enhances the ageing brain's cognitive abilities – perception, motor function, working memory – improves cardio-vascular strength. It allows creative self-expression, reducing stress and giving a joyful sense of accomplishment.<sup>5</sup>

#### Connecting actively with nature vs physical inactivity

Group activities for wellbeing and camaraderie in nature help protect against obesity, sleep deprivation, anxiety, depression and social isolation.

#### Diagnosing well - The patient journey

According to GPs, it takes several years from the start of symptoms to get a dementia diagnosis and the wait for a memory assessment appointment can be three to fourteen weeks, or more. Memory services who hitherto proposed arts as post diagnostic support now advise patients awaiting appointments to take up A.R.T.S. – this is partly due to our supporter the Dementia Change Action Network, who attended our regional meetings, then including this guidance in their new Next Steps website.

#### Supporting well – social prescription

Introduced through the NHS Long Term Plan in 2019, there are now 1,500 SPLW around the UK available to every GP – who has only ten minutes per

 $<sup>^{3}</sup>$  WHO (2019), What is the evidence on the role of arts, pp.9-10.

<sup>&</sup>lt;sup>4</sup> Ibid, p. 6 and Creative Health (2017), pp.12 and 90.

<sup>&</sup>lt;sup>5</sup> Ibid. p.24; Korte et al, 2013; Särkämö et al, 2013; Sutcliffe et al, 2020.

### **Executive Summary**

appointment – and can now refer patients to their SPLW for non-clinical, psychosocial sources of support, such as A.R.T.S., whatever is of greatest interest to the patient. If it doesn't exist locally, they may well have contacts, community builder who can help support its set up. SPLW are trained and supported by the social prescribing network's regional learning coordinators.

#### Living Well – A.R.T.S. to preserve brain health

Thanks to GPs' easy access to SPLW, A.R.T.S. can be offered at the onset of symptoms and, in so doing, transform the diagnostic experience, reduce anxiety and preserve resilience for the individual and their partner together in the community for years longer. The Culture Health and Wellbeing Alliance disseminates innovative models through regional and national conferences. The type of arts we propose for brain health is weekly participatory activities, challenging but achievable, designed to re-energise and inspire, with arts teams informed by early-stage dementia training to give insight into the challenges people face as early symptoms of mild cognitive impairment and the various dementia subtypes arise. There is no sense of dementia here – except that it is understood and if a diagnosis is confirmed, participants remain part of the group, co-curating, improvising, inspiring each other, as regional case studies and the A4D web-listing for brain health and for dementia illustrate.

#### ArtsPAL

To enable individuals to access A.R.T.S. prescription programmes, and accompany them in creative endeavour, A4D has set up a cultural and creative befriender network ArtsPAL, by region.

#### The Way Forward

For sustainable A.R.T.S. programmes, we highlight the National Academy for Social Prescribing (NASP)'s place-based Thriving Communities Fund, which established the an ideal model for sustainable A.R.T.S. programmes. The Fund is now closed. We feature examples of programmes it is supporting; and we urge NASP, in partnership with Arts Council England and other national bodies to continue the Thriving Communities Fund.

The World Health Innovation Summit has agreed to fundraise to further this programme, in particular, longitudinal academic research, starting in September 2022.

We propose an amendment to the NICE guideline 97 for Dementia, 1.2 Diagnosis: Initial assessment in non-specialist settings, page 15: to insert before 1.26 a recommendation to social prescribing for brain health.

#### Arts 4 Dementia Social Prescribing Programme 2019-21

Our conference Towards Social Prescribing (Arts & Heritage) for the Dementias (2019), Southwark Social Prescribing pilot and D-IAGNOSIS campaign picture and tour are discussed. A4D SP Conference 2021 talk links. 'Arts for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia.

# A.R.T.S. for Brain Health – Introduction

Over 200,000 people are diagnosed with a dementia each year in the UK. There is no cure and when symptoms set in, anxiety, fear that their brain is degenerating, feelings of shame and stigma become overwhelming. Those figures and associated care costs are expected to rise substantially in the coming decades, unless new treatments – including health-giving arts – enable the progression of the condition to be prevented or slowed. A.R.T.S. – visual, decorative and performance arts, heritage, wellbeing, nature, sports Activities to Revitalise The Soul – offered as post-diagnostic support, need to be offered earlier, during those isolating months, years, leading to diagnosis.

Since Arts 4 Dementia (A4D) addressed the NHSE Preventing Well agenda in our *Reawakening Integrated Arts & Heritage* 2017 and with the introduction, through the NHS Long Term Plan (2019), of social prescriber link workers (SPLW) to whom GPs can refer patients for non-medical A.R.T.S. support (see page 33), A4D has campaigned to advance referral to social prescribing (SP) at the onset of dementia. Bridging the support gap, this will reduce strain in the period leading to diagnosis and empower people to take up re-energising weekly arts activity to preserve their brain health.

Meanwhile, the Lancet Commission's Dementia prevention, intervention and care (2020) reinforced risk factors that can be modified by healthy and creative ageing activity (see page 17). The World Health Organisation (WHO)'s scoping review What is the evidence on the role of the arts in improving health and well-being? (2019) endorses the robust impact of the arts on mental and physical health, with multimodal benefits for people with cognitive challenges and dementia, advocates including arts and humanities education in training health-care professionals and the use of SP schemes to strengthen lines of referral from health and social care to arts programmes (see page 16). WHO Guidelines (2019), mindful that social isolation and cognitive inactivity are risk factors, calls for the implementation of interventions that can slow cognitive decline or delay dementia. This year, The NeuroArts Blueprint, Advancing the Science of Arts, Health and Wellbeing was launched in the USA to provide scientific evidence to measure and map how art changes the brain and the body and advance wellbeing.

There are now 1,500 SPLW nationwide, available to every GP. Learning from leaders in culture, health and wellbeing, SP, creative ageing, dementia prevention, people with lived experience, GPs, psychiatrists and psychologists, local authorities and the student SP scheme (see page 298) at our A4D SP conferences 'Towards Social Prescribing (Arts & Heritage) for the Dementias (2019, see page 196) and 'Arts for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia (2021, see page 208) and 15 regional cross-sector meetings informs this report. *A.R.T.S. for Brain Health* reports findings from A4D's two-year campaign, which is already taking effect as more doctors, mindful that each later stage means worsening private strain at home and with easy access to SPLW, refer patients to health enhancing A.R.T.S.

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<sup>&</sup>lt;sup>6</sup> Wittenberg et al., (2020), 'Projections of care for older people with dementia in England: 2015 to 2040', *Age and Ageing*, vol.49, 2, March 2020, pp.264-69.

# A.R.T.S. for Brain Health – Chronology

# Context: Creative Health, NHS policy change and SP development, 2017-21

'The time has come to recognise the powerful contribution the arts can make to our health and wellbeing', The Rt. Hon. Lord Howarth of Newport, Co-Chair, of the All-Party Parliamentary Group on Arts, Health and Wellbeing (wrote in the Foreword to *Creative Health: The Arts for Health and Wellbeing* 

#### **2**017

- July: Creative Health published, huge impact throughout the UK and beyond, acknowledged the role of culture and creativity in improving health outcomes. Led to policy change.
- O September: A4D *Reawakening Integrated Arts & Heritage* report addresses prevention, in regional framework to integrate arts into dementia care in Dorset.

#### 2018

- o Aesop 'National Arts in Health Conference and Showcase',
- November: King's Fund Conference, Social Prescribing: Coming of Age: Rt. Hon. Matt Hancock, Secretary for Health and Social Care, announced the creation of a National Academy for Social Prescribing (NASP). (See page 73).

#### 2019:

- January: NHS Long Term Plan launched with an emphasis on prevention, announcing the introduction of SPLW to be available to every GP – there are now 1,500 SPLW – to whom GPs can refer patients for non-medical support (see page 72)
- May: A4D Best Practice Conference, 'Towards Social Prescribing (Arts & Heritage) for the Dementias.
- June: Southbank's first Creative Health Conference: NHSE CEO acknowledges importance of the arts to promote social connection, improve health and positive health and wellbeing.
- November: Baring Foundation review by Dr Rebecca Gordon Nesbitt, Older and wiser? Creative ageing in the UK 2010-19.
- December: Creative Ageing Development Agency, (CADA) based at Manchester Museum, launched to develop, support and advocate for creative ageing across the UK.

#### **2**020:

- January: Arts Council England's, Let's Create, ten-year strategy committed to harness the arts in the service of health
- January: A4D launches national D-IAGNOSIS! Arts to Preserve Wellbeing Campaign at Tate Exchange, regional SP meeting tour, opens at Canterbury.
- November: NASP announced the Thriving Communities cross sector initiative and fund to support A.R.T.S. (see below) prescription programme.

#### **2**021:

- o March: National Centre for Creative Health (NCCH) launched to advance practice, inform policy and promote collaboration.
- May: A4D Best Practice Conference: Arts for Brain Health, Social Prescribing as Peri-Diagnostic Practice for Dementia.
- June: Culture Health and Wellbeing International Conference.

### Aims of A.R.T.S. for Brain Health, 2019-21

Everyone has the right freely to participate in the cultural life of the community. Yet, referral to A.R.T.S. support for dementia requires a diagnosis. For people in the lonely, fear-filled months/years awaiting memory assessment and diagnosis, the right to A.R.T.S. participation has been hard to access – until now. Thanks to the availability of SPLWs, GPs can at the onset of symptoms refer them to A.R.T.S to preserve their brain health, relieve fear and preserve resilience in the community. If people are engaged in a social arts group when diagnosis comes, their sense of identity, purpose and belonging can continue, despite dementia – for years longer.

The aim of our SP programme 2019-21 was to debate transformation of the diagnostic experience, to embed referral to A.R.T.S. to preserve brain health as GP practice from the onset of symptoms, on or before referral to memory assessment.

#### Our deliverable aims involved:

- A4D Best Practice Conference 2019 'Towards Social Prescribing (Arts & Heritage) for the Dementias' (The Wellcome Collection). Leaders in academia, SP, culture, health, social care, arts practitioners for dementia presented evidence, raised cross-sector issues. (See page 195)
- SP dance and drama weekly workshop programme in the London Borough of Southwark (see page 200) to pilot the referral process from GP to SPLW and arts organisation, establish the annual cost and involve medical and neuroscience students with arts students, interacting with participants with early symptoms of dementia.
- Co-ordinating the <u>ArtsPAL</u> cultural and creative befriender network through the A4D website (see page 179), to enable individuals living alone to access and enjoy together A.R.T.S. prescription programmes to preserve brain health.
- Commissioning a campaign picture *D-IAGNOSIS! From Despair to Desire Arts to Preserve Wellbeing* (see page **204**).to show how engaging in A.R.T.S. overrides diagnostic fear its dual purpose to hang at museums and stimulate A.R.T.S. programmes for brain health and to inform health and SP teams to refer patients, through
- Fifteen cross sector museum-hosted meetings in every NHSE region, Scotland, Wales and Northern Ireland, chaired by professors of cognitive health, dementia and its prevention and addressed by leaders in culture, health and wellbeing, SP, creative ageing, arts for health practitioners, local authority cabinet leads and the patient journey from GP to memory service (See page 27), with verbatim reports to inform ongoing research; and A.R.T.S. opportunities for brain health nationwide mapped on the A4D website.
- A4D SP Conference 2021 'Arts for Brain Health: SP as Peri-Diagnostic Practice for Dementia (See page 207).

<sup>&</sup>lt;sup>7</sup> Universal Declaration of Human Rights (1948). United Nations, Article 27.

# Aims of A.R.T.S. for Brain Health report, 2021

Our report aims to provide information for the future practice, commissioning and design of SP programmes to preserve brain health, and to inform a potential amendment to the NICE Dementia Guideline 97: 1.2 Diagnosis, to recommend referral to SP for A.R.T.S. to preserve brain health (see page 192). The report includes

- How engaging in A.R.T.S addresses modifiable risk factors for dementia and protects against the advance of cognitive decline.
- Current diagnostic practice for dementia, with case studies from patients, how GPs and memory services offer or plan to offer SP.
- SP, creative ageing and A.R.T.S. for brain health, with case studies.
- Models for collaborative practice, for arts organisations to raise awareness to SPLW and achieve sustainable A.R.T.S. programmes.

# Rationale for SP to A.R.T.S. for brain health – from despair to desire

There is no cure for dementia and many tests and months of worry before diagnosis that unlocks arts support. As confusion and anxiety make people fearful about leaving the safety of home, the strain on them and their family partners increases; and isolation as friends and colleagues drift away may exacerbate fears of stigma or shame adding to worries about their future.

The first step in the NHS Transformation Framework, The Well Pathway for Dementia is Preventing Well. The availability of SPLW to GPs can at last facilitate this. Engaging in A.R.T.S. at an early stage empowers people to take positive action, to choose with their SPLW activities that will inspire them to lead happy, healthier, more confident lives together, connected to people and programmes of interest in their community. Having a weekly activity to look forward, so vital when they are undergoing memory tests and diagnosis and for years after diagnosis of a dementia., becomes a lifeline of interest and joy and is take the best action to protect against cognitive decline.

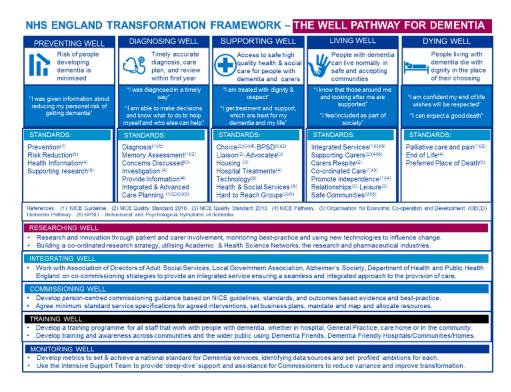
#### Outcomes

The aim is for SP to A.R.T.S. to address modifiable risk factors for dementia, reduce isolation, help ameliorate symptoms, improve quality of life, nurture health, wellbeing and resilience. Short-term and medium-term outcomes might include – for both individual and family partner:

- Loneliness and fear eased by community involvement.
- People empowered to address risk factors and preserve brain health.
- Cultural interests, sense of purpose social interaction restored.
- Joy and achievement in learning, co-curating, performing together.
- Improved health and wellbeing through A.R.T.S.
- Sense of failing tests counterbalanced by A.R.T.S. achievements.
- Improved memory and speech (See page 31).



### 1 Preventing Well



'Preventing Well', the first step along the NHS Transformation Framework 'The Well Pathway for Dementia' calls for the risk of developing dementia to be minimised by raising individual awareness of risk factors and the significance of physical activity, social engagement, detailed in the WHO (2017) Global Action Plan on the Public Health Response to Dementia 2017-2025 and (2019) Risk reduction of cognitive decline and dementia: WHO Guidelines.

In 2020 Brain Health Scotland was founded to establish services to improve brain health across the life course, with drop-in brain health clinics to help identify personal risk and encourage healthy lifestyle with or without dementia; and the international public health experts Charles Alessi, Larry Chambers and Muir Gray, Director of the Optimal Ageing Programme at The University of Oxford, have set up The Brainability Programme and published a positive and enticing book *Increase your Brainability and Reduce your Risk of Dementia* (2021).

Through neuroarts – or neuroaesthetics, pioneered by the UCL neurobiologist Semir Zekis – a growing body of research is establishing how the human brain responds to arts experiences, the mechanism in the brain (in the medial prefrontal cortex) that engages with beauty, whether sorrowful or joyful, whatever the culture or art form. The NeuroArts Blueprint, Advancing the Science of Arts, Health and Wellbeing launched this year by John Hopkins University and the Aspen Institute in the USA seeks to provide scientific evidence to measure and map how art changes the brain and the body and advance wellbeing.

<sup>8</sup> Zeki, S. (1999) Inner Vision: An Exploration of Art and the Brain.

#### 1.1 Modifiable risk factors

According to World Health Organisation (WHO) Guidelines, (2019), modifying lifestyle related risk factors helps prevent or delay dementia by reducing neuropathological damage and increasing and/or maintaining cognitive reserve. The *Lancet* Commission on Dementia Prevention, Intervention and Care 2020 report and new guidelines reinforced risk factors highlighted in 2017. Of the twelve identified - less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, air pollution and disrupted sleep – weekly re-energising A.R.T.S. programmes for brain health can help reduce are social isolation, physical inactivity and obesity, depression, lack of education.

The rhythm of cortisol levels, the primary stress hormone, vital to regulating mood, blood pressure and sleep cycles, is disrupted by dementia, resulting in increased frailty, agitation and cognitive decline. A University of Canberra study (2019) of participants with dementia, viewing, experiencing and discussing masterpieces of art at the National Gallery of Australia, demonstrated through saliva tests, improvements in cortisol levels, that symptoms of depression had subsided and that their working memory skills and verbal fluency had increased.

# 1.2. Modifying multiple risk factors through A.R.T.S.

The WHO Health Evidence Synthesis Report on the role of arts (2019), explains A.R.T.S. as multimodal interventions combining multiple healthpromoting components, involving aesthetic engagement, the imagination, stimulating experiences, sensory activation, evocation of emotion, learning and cognitive stimulation, as well as social support and interaction and physical activity. These trigger psychological, physiological, social and behavioural responses that address the complex challenges associated with cognitive decline and help build cognitive reserve. Inner individual response to a new or beautiful experience, and creative expression – both individual and interacting with the group – motivates and inspires participants to override feelings of stigma and trauma, enriching the sense of wellbeing.9 A.R.T.S. transcend cultural boundaries, are socially inclusive and allowing the flexibility to develop new art forms, but for those more comfortable celebrating wideranging ethnicities celebrate the A.R.T.S. of their own culture (see page 173). For people already experiencing cognitive decline, A.R.T.S. participation can help prevent it worsening.

Dr Daisy Fancourt of University College London (UCL), author of the WHO report, affirmed at A4D's 2019 SP conference the vital health outcome of prescribing A.R.T.S.: 'What is key is the idea of cognitive reserve – one can build the resilience of the brain against decline.'

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<sup>&</sup>lt;sup>9</sup> WHO (2019) pp.2-5 and 25.

<sup>&</sup>lt;sup>10</sup> Speaking at A4DConf19.

# 1.2.1 Physical activity vs physical inactivity, obesity, depression and lack of sleep.

Brainability specifies three positive strategies, showing how healthy and creative ageing can reduce the risk of dementia:

- Protect the brain tissue: Stress and inactivity cause inflammation, a contributory factor for dementia. Engaging in A.R.T.S. as a social and inspiring activity relieves loneliness (see page 26), reduces fear and stress, preserves identity and revitalises participants. Musical rhythm raises the level of the neurotransmitter serotonin and, as A4D has found, the sense of wellbeing may last for days.<sup>11</sup> Playing music can ease sleep patterns and in so doing protect the brain tissue.
- Keep the blood and oxygen flowing: Physical activity stimulates the body to produce endorphins, feel-good chemicals that relieve stress and pain. Heightened by music and dance, it improves blood flow to the brain. The Bronx Aging Study of 469 people over 75 has shown that those who frequently played a musical instrument or danced were associated with a reduced risk of dementia.12 According to the Academy of Medical Royal Colleges report Exercise – the Miracle Cure (2015), taking 30 minutes exercise reverses brain atrophy in the hippocampus - crucial to memory - and frontal lobe of the brain, so delaying the progression of the disease. Harvard Medical School's Walking for Health (2015) reports that walking helps maintain brain volume and reduces memory problems in people with mild cognitive impairment (MCI) or Alzheimer's disease.'13 WHO risk reduction guidelines recommend adults with MCI aged over 65 years to do at least 150 minutes of moderate-intensity aerobic physical activity per week.14
- **Keep engaged, positive and with a purpose**: Neuroplasticity of the brain and nervous system means that tackling the challenge of a new skill, the stimulation of learning even with dementia, enables new networks of nerve cells to develop. For example, learning to dance the tango, additional nerve cells are produced to help carry out the steps. Existing neurons form new connections to other existing neurons, creating new networks; and dancing with a partner, in a dance group, is positive, purposeful and preserves social contact.<sup>15</sup>

<sup>11</sup> A4D, Reawakening the Mind (2013) p.25.

 $<sup>^{12}</sup>$  Verghese et al (2003). Leisure activities and the risk of dementia in the elderly'  $348(25),\,\mathrm{pp.}\ 2508\text{-}16.$ 

<sup>&</sup>lt;sup>13</sup>. Alessi et al. (2021). Increase your Brainability and reduce your risk of dementia, pp.57-58.

<sup>&</sup>lt;sup>14</sup> WHO (2019). Risk Reduction of Cognitive Decline and Dementia, p.14.

<sup>&</sup>lt;sup>15</sup> Sir Muir Gray, speaking at A4D Conf21, Thursday 20 May.

# 1.2.1 Physical activity vs physical inactivity, obesity, depression and lack of sleep.

Connecting Actively with Nature (CAN), a nature partnership run by Active Devon<sup>16</sup> to support people aged over 55, addresses multiple risk factors – social isolation, obesity, sleep deprivation, anxiety, depression, mental health, through walking, Nordic walking, wellbeing walks, running, pilates, gardening, wild swimming, visiting beautiful places of environmental and historic interest. Being in the fresh air, in nature, improves mood, relieves stress, improves sleep. Being physically active in nature adds fitness to the mix, improves blood flow to the brain and doing so in a social group, connected and engaged, all help to delay the advance of cognitive decline.

Forest bathing for example, at The Lost Gardens of Heligan or picking and rolling in their wildflower meadows, can improve sleep quality, mood and lower cortisol levels - this primary stress hormone plays an important role in regulating mood, cycle of sleep and blood pressure.

Men's Sheds, introduced all over the UK to counteract loneliness and isolation and restore personal identity post retirement, encourages men to share skills and knowledge – woodworking, metalworking and restore sense of purpose and involvement in community projects, such as restoring village features, helping maintain parks and green spaces. In a fantastic partnership with Swansea City Opera, the local Men's Shed, co-produced an energetic scene with chorus 'Shoulder to Shoulder' (see page 165), their shed leader never having sung before.

# 1.2.2 Dance movement vs physical inactivity, obesity and depression.

As physical activity clothed in imagination and creativity, dance offers a joyous route to health and wellbeing, more effective than an exercise class in reducing body fat, fall prevention and, through the role of music, in improving mood, reducing stress and helping to maintain attention. Learning new steps, to lead and follow, enhances hand-eye coordination.<sup>17</sup>

An 18-month German study comparing the effect of dance with endurance training among volunteers aged around 68 years, showed that while both showed an increase in the hippocampus region of the brain associated with agerelated decline, only dance was shown to improve balance. This was attributed to the extra challenge of learning new dance routines each week. A dance class, whatever the style – tango, jazz, rock and roll, ballet, ballroom, line dancing, Scottish dancing, country dancing, Morris dancing, hip hop and more



partners to transform lives through sport and physical activity. <sup>17</sup> WHO (2019) p. 16 and *Creative Health* (2017) pp.12 and 90.

931. OF YOUR HEALTH IS BASED ON WHAT YOU DO IN YOUR DAILY LIFE!

F.A.T. Studio at A4D SP Southwark pilot launch October 2019

<sup>&</sup>lt;sup>18</sup> Rehman et al. (2018).

# 1.2.2 Dance movement vs physical inactivity, obesity and depression.

- brings all the benefits of music (see page **20**) with the added vigour of movement, throughout life and for years after dementia sets in.

Fergus Early, Artistic Director of Green Candle Dance, recalls that in the 25 years its 'Spinoff' group for people aged over 55 has been running, only three out of 200 participants have had a positive dementia diagnosis.

Dance calls on brain power, memory and in its freestyle improvisational form, involves creativity, decision-making, negotiating space and movement with others, calculating relationships at speed, while emotionally offering the opportunity for expression, for feelings to emanate through the whole body. <sup>19</sup> It is the most physically expressive art form, integrating several brain functions at once – kinaesthetic, rational, musical and emotional. Increasing neural activity and hippocampal volume, it offers powerful protection against the risk of dementia and generates cognitive reserve. <sup>20</sup>

Bisakha Sarker, Artistic Director of Chaturangan South Asian Dance explains that what art proposes may not be a cure, but it gives 'precious, fleeting maybe



moments of happiness, a sense of regaining control. The art can give the gift of a few moments away from the grip of fear. In between the treatments and diagnosis, much autonomy is lost. A session of dance and movement can allow all to put aside sufferings, to enter another space.

Bisakha, who ran a South Asian dance programme in partnership with A4D and Akademi, highlights its rich vocabulary of hand gestures with which participants experimented creatively each week. As her *Dancing Moments* resource demonstrates: 'The storytelling element can open the scope of improvisation and a journey into one's vision, connecting the body and mind.' <sup>21</sup>

Dance offers the opportunities for inclusivity across cultures, who also celebrate their own culture in dance, for example, Keneish Dance in Birmingham, founded by Keisha Grant, West Midlands Arts Champion of the Culture Health and Wellbeing Alliance. In China, a specially designed aerobic dance routine on people affected by MCI showed improvement in cognitive function, especially episodic memory and processing speed.<sup>22</sup>

Whatever the dance form, participants value exercising the whole body and especially, the mind, releasing tension to allow the flow of movement. Their later comments express exhilaration. Improvisation, requiring much thought

It is a feeling of freedom which you are able to experience using your whole body – it is elating!

<sup>&</sup>lt;sup>19</sup> Speaking at A4D Conf21, Thursday 20 May.

<sup>&</sup>lt;sup>20</sup> New England Journal of Medicine (2010).

<sup>&</sup>lt;sup>21</sup> Speaking at A4D Conf21, Friday 21 May.

<sup>&</sup>lt;sup>22</sup> Yi Zhu et al. (2018). 'Effects of a specially designed aerobic dance routine on mild cognitive impairment', *Clinical Interventions in Aging* (2018) 13, pp.1691-1700.

# 1.2.2. Dance movement vs physical inactivity, obesity and depression.

about the music, dance type, the character, the space and co-ordination to interact with other dancers and retain the flow, however spontaneous. Improvisation featured in each dance programme A4D has partnered with over the years – Rambert Dance, English National Ballet, Green Candle Dance, Pavilion Dance South West; and Siobhan Davies Studios in addition encourages the use of other art forms to inspire their contemporary dance practice. (For 'Dance for the Brain' see page 204 and 230).

BUPA's Keep Dancing: The health and wellbeing benefits of dance for older people (2011) found that not only was dance beneficial for people with dementia, but that taking part improved their mental health and cognitive performance, the social aspects helped overcome feelings of social isolation and depression and that ballroom dancing reduced the chances of getting dementia by 76%.

Nottingham City Arts, who have a long track record of arts and health, are experimenting with exercise for those with early cognitive challenges, connecting with nature, walking and mindfulness as well as the creative arts. dance, music, puppetry, poetry, carnival and outside events.

### 1.2.3. Music vs physical inactivity and depression

The impact of music-making - especially in a group with other singers or musicians - experiencing a performance and even listening to music, on the physical and emotional health of people experiencing symptoms of cognitive decline, is substantial in its protection against onset and slowing the advance of dementia.

Engaging with music, its emotional and rhythmic, interactive power<sup>23</sup> improves plasticity in the cortex, which enhances the ageing brain's cognitive abilities – perception, motor function, working memory – improves cardio-vascular strength, allows creative self-expression, reducing stress and giving a joyful sense of accomplishment. <sup>24</sup>

Singing in a choir, musical theatre, an opera group, playing an instrument, listening, learning new music, performing and improvising, engages the whole brain and promotes neuroplasticity, thereby increasing resistance to agerelated neurodegeneration. As we age, music-making provides a tool for a total brain workout.

The various aspects of music – pitch, rhythm, tempo, timbre, dynamics and meaning – recruit different parts of the brain, tapping into multisensory integration, learning, reward and cognition.

Interventions that encourage older adults to play a musical instrument have been found to improve or preserve their general cognition, processing speed and memory. Since the Bronx Aging Study of 2003 and 2014 study of twins

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<sup>&</sup>lt;sup>23</sup> Franklin Gould, V. (2015).

<sup>&</sup>lt;sup>24</sup> WHO (2019) p.24; Korte et al, 2013; Särkämö et al. (2013); Ginsborg, J. 'Music and Memory', A4D Music Reawakening conference (2015); Sutcliffe et al. (2020) pp.479-91.

# 1.2.3. Music vs physical inactivity and depression.

linking musical instrument playing as protective against cognitive impairment and with a reduced risk of dementia,<sup>25</sup> the 2019 Heriot-Watt University has shown that people taking up music in older age had better abstract reasoning and memory than non-musicians. Orchestras have opened up participatory opportunities for those wishing to restore musical instrument playing, notably, Bournemouth Symphony Orchestra's Rusty and Not So Rusty Musicians.

Making music with a group, practising or singing together each week, social bonding occurs faster than with other art form. Synchronization, exertion and endogenous opioid release<sup>26</sup> have been identified as key mechanisms underlying music-led bonding. The social interaction reduces loneliness and depression, increases emotional wellbeing, maintains competence and identity.

Participants at Breathe Arts Health Research's evidence-based participatory Singing for Stress Relief programme, delivered at the new Tessa Jowell Health Centre in Dulwich in the London Borough of Southwark were referred through SP. Led by a professional singer, the choral workshops enabled participants to learn new skills and provided a safe space to try singing for the first time. Uplifting, fun and engaging, they aimed to improve breath control, relieve stress and make people laugh. For a calmer choice the City of London Sinfonia performed Mindful Music.

Musical improvisation, known to enhance memory function, requires mental agility, is practised by organists, jazz players and in eastern music. If this ad lib playing goes well it is a thrilling experience, full of spontaneity and excitement, inspiring to the player and a bolster to his confidence. <sup>27</sup>

Dr Nina Kraus, Professor at Northwestern University in Illinois, USA, investigating the neural encoding of speech and music, has concluded that humans are biologically bound to sound, which the body requires to survive, which is why the brain processes auditory stimuli faster than visual.

Her study on relationship between sound waves and brain waves, found that if the brain is stimulated with certain musical notes, it reacts with an electrical wave that mirrors that very note, and when stimulated with a familiar song extract, brainwaves fire to complete the rest of that song.

Musicality and musical memory remain strong after diagnosis of dementia. Tackling the challenge of playing, indeed learning music together heightens brain activity and becomes a joy. The emotional and rhythmic powers of music energise our being, from our minds to our posture, fingers and toes. Music enhances mood, movement and speech. A compelling musical project restores sense of purpose.

<sup>&</sup>lt;sup>25</sup> Verghese et al (2003) 348(25), pp. 2508-16. Balbag et al. (2014).

<sup>&</sup>lt;sup>26</sup> The endogenous opioid system plays a vital role in regulating myriad physiologic functions like pain relief (analgesia), euphoria induction, stress resilience, cardiovascular protection, food intake control, and many more.

<sup>&</sup>lt;sup>27</sup> Shuckburgh, J. (2009). Harmony and Discord: The Real Life of J S Bach (London: Old Street Publishing) p.p24–25.

#### 1.2.4 Social contact vs loneliness and isolation

A third of cases of dementia could be prevented by addressing risk-factors in early life. Professor Chris Drinkwater, Chair of Ways to Wellness, advises that in our 40s and 50s we should prepare for active old age, build up our social networks and acquire new skills and interests. Doing something new and challenging keeps us active, engaged and involved. Keeping up this pro-active approach preserves resilience and brain health.<sup>28</sup>

Cognitive impairment, however, increases the risk of loneliness (how someone feels) and social isolation (the position they find themselves in or choose to be) and vice versa. Loneliness and social isolation can have an impact on cardiovascular disease, stroke, the progression of frailty, anxiety and depression, and cause cognitive decline.<sup>29</sup>

Fear of worsening memory loss, deterioration of the brain, a dementia diagnosis can make people wary of social situations or perceive interactions with others more negatively. Loneliness, as the psychologist Carl Jung pointed out, inhibits the ability to express what matters most to them.<sup>30</sup> Social embarrassment, helplessness, shame, fear of leaving the safety of home, trauma and stigma<sup>31</sup>, lead to reduction of social networks. This is why continuing to engage in or take up new A.R.T.S., maintaining social life, learning skills in the community, preserving identity and sense of purpose is so important.

Especially at the challenging onset of symptoms of a dementia, feelings of loneliness can create a downward spiral, when colleagues and friends drift away, causing the person to become more fearful, sense rejection and withdraw into themselves, aware that this is just the beginning of life with dementia.<sup>32</sup>

Dr Michael Dixon, National Clinical lead for Social Prescription at NHSE/I and Chair of the College of Medicine, speaks of the paradox of loneliness, that scientists have shown how lonely people are twice as suspicious of a stranger than those who are not lonely. 'There is a paradox, those who are most lonely and want to socialise find it most difficult. That is where social prescription comes in, that's where social prescription in the early stages of dementia can give people that boost in confidence, that socialisation which is so crucial.'

The social connectivity involved in person-centred A.R.T.S. plays a vital role protecting people at this vulnerable cusp, across all social backgrounds and cultural ethnicities. Overriding their fall into social isolation and loneliness, A.R.T.S. fulfil their core psychological need, preserve their sense of belonging and identity in the community, a key aspect of health and wellbeing. A.R.T.S. nurture social bonding, heightened in nature, prosocial behaviour, shared sense of success, collaborating in creativity. A.R.T.S. participation allows self-expression, even to express the inexpressible.<sup>33</sup>

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<sup>&</sup>lt;sup>28</sup> Speaking at A4D's Tyne & Wear SP meeting, 24 September 2020.

<sup>&</sup>lt;sup>29</sup> DCMS (2018) p.18.

<sup>&</sup>lt;sup>30</sup> Jung, C.G. (1961). Memories Dreams and Reflections: An Autobiography, page 356.

<sup>&</sup>lt;sup>31</sup> Alzheimer's Disease Int. (2019). World Alzheimer Report 2019: Attitudes to dementia.

<sup>&</sup>lt;sup>32</sup> Campaign to End Loneliness report (2020); Kalpa Karicha, plenary debate, A4D-SPC21; International Longevity Centre, 2018. pp.10-19.

<sup>33</sup> WHO (2019), What is the evidence on the role of arts, pp.9-10.

# 1.2.5. Learning vs lack of education

It is about the vision of promoting independence, creativity, empowering people to interact and enjoy activities to preserve their brain health.

The Rt. Hon. Andy Burnham, Mayor of Greater Manchester

It's given me a new zest for life and a new determination that I can do things for myself if I try. I'm a different person, more able, more confident. (MeetMe member)

Dominic Campbell, Artistic Director of Creative Ageing International, warns against over-protecting a person who is living with gradual deterioration. In removing risk, 'we take away the risk that accompanies learning. If we take away risk, we take away elements of learning and neuroplasticity and ultimately, we take away joy – we are not doing care, we are doing control.' More effective, he advises, is to use art as a scaffold for change, a mechanism for transition – 'creativity to create the system of care . . . to propagate joy. Working with participants to co-curate bespoke programmes to generate creative responses to local conditions and issues, and to develop tools to measure, evaluate and codify, for scaling practice.<sup>34</sup> Learning music, poetry or drama, exploring works of art, discovering the artist's intention, challenges the brain to create new neural connections and pathways that can compensate for reduced activity in other regions.

Opening the door to new discovery and engaging interest is the essence of cognitively stimulating A.R.T.S. workshop programmes, run through the learning or community departments of larger arts organisations, as well as community arts hubs or social groups run by Age UK, creative ageing and culture specific organisations. Co-curating A.R.T.S. programmes, heightens sense of identity, of purpose in creative endeavour and connectivity as members of a resilient, socially active group. A.R.T.S. workshops, designed to be challenging, but achievable and rewarding for all, nurture learning. For those experiencing cognitive decline, looking at and discussing fine and decorative arts and architecture, painting classes, creating poetry, theatre scenarios, the sense of enlightenment, opening their eyes to things they may not have noticed before, whether in fresh air, a class or studio, the opportunity to volunteer – all offer intellectual opportunities and thereby encourage neurogenesis, the development of new brain cells; and through enhancing motor learning, dance classes, can improve memory, learning and attention.<sup>35</sup>

Over the years at A4D, we have observed participants continuing to benefit from compelling programmes, designed to re-energise and inspire new creative learning, for some three years post diagnosis – a figure also quoted by Henry Simmons, Chief Executive of Alzheimer Scotland.<sup>36</sup>

Even in lockdown, thinking about transforming everyday objects into poetry, a drama scenario or art, draws on the intellect and imagination. This has literary and art historical precedence, notably, in the work of Marcel Duchamp's Fountain (1917) urinal or Salvador Dali's lobster telephone. Improvising requires mental agility, whether as a performance exercise or instantaneous scenario. Museums Health. An A4D Southwark Playhouse drama participant filled the Zoom screen posing in voluptuous bunches of grapes as earrings, while another speedily drew a face on an upside-down cup as a dancing partner for a fellow participant's solar powered dancing hula-girl Lulu, triggering instant responses from each other to market their ideas across the screens.

<sup>&</sup>lt;sup>34</sup> Speaking at A4D Conf 21, Friday 21 May.

<sup>&</sup>lt;sup>35</sup> WHO, (2019). *ibid*, p.25/

<sup>&</sup>lt;sup>36</sup> Speaking at A4D SP meeting, 15 February 2021

### 1.2.5. Museums, learning and social inclusion

Museums, churches and heritage venues foster an environment of social inclusion and inspirational learning through art, architecture, decorative and historic collections, bringing people together into uplifting healing spaces in the heart of their communities, which – the National Alliance for Museums, Health and Wellbeing reports – enhances their physical and mental health at every stage of life. As such, they are a powerful force to enable us to preserve brain health. Their learning teams engage diverse participants in lively, innovative A.R.T.S. programmes for wellbeing and healthy ageing and now offer innovative interactive weekly opportunities by Zoom (see page 216).

Dr Daisy Fancourt's English Longitudinal Study of Ageing (2018) involved a large, multidisciplinary cohort study of 4,000 people aged over 50, who were dementia free at the start of the ten-year study. Nine or ten of 1,000 developed dementia, but for those who went to museums, galleries or theatrical or musical performances, this was reduced to three or four per 1,000, indicating that cultural engagement, even monthly, can generate cognitive reserve.<sup>37</sup>

Museums on Prescription (2014-17), the project led by Professor Helen Chatterjee of UCL, with Professor Paul Camic of Canterbury Christ Church University as Co-Investigator, referred lonely and isolated older people, through SP, to ten weekly sessions of museum-based talks, behind-the-scenes tours, gallery visits, object handling and discussion, collection-inspired creative activities and the co-production of exhibitions and museum guides. The project endorsed museums as community resources providing engaging A.R.T.S. to improve wellbeing and social inclusion for older people, as cross-sector partnerships with health and social care providers.

That year, 2017, A4D piloted a County Museum model to re-energise and inspire people to override symptoms of MCI and early stage dementia. Referrals were not yet through social prescription. Sessions from a different museum department each week began with discussion on the Jurassic Era, Roman mosaics, natural history, rural Dorset, Thomas Hardy, museum founders, textiles and women sculptors, with art sessions in the galleries, where conversations continued to engage participant interest.

Pallant House Gallery in Chichester, addressing the issue of loneliness and isolation, offers a Partners in Art scheme, whereby individuals access the art world on an equal footing, with a volunteer partner who shares their passion, enjoying arts experiences whether viewing or creating in the Gallery or outside it. (For creative and cultural befrienders, see ArtsPAL page 181).

The National Alliance for Museums, Health and Wellbeing (f.2015) survey quoted in Desmarais et al (2018) reports that older people and those with dementia accounted for half of all museums' health and wellbeing projects. Museums provide generous and versatile spaces for performance arts as well as activities inspired by their own collections. A valuable resource for health and social care professionals, *Museums, Health & Social Care service* created in 2020 by Tyne & Wear Archives & Museums and Northumbria University, details ways in which their museums can engage people's interest (see page 121).

It opened doors for me, you gave us the opportunity to explore things that we wouldn't have done by ourselves. Normally I would never have dared come here'

I particularly like that you get up close and personal with the early discoveries. Meeting up with long deceased animals.

That was magical!

<sup>&</sup>lt;sup>37</sup> Fancourt et al. (2018); A4D Conf19.

## 1.2.7. Drama and Poetry

Going to the theatre is immediately engaging. Actors projecting their voices to involve the audience with the drama, energises the mind and heightens emotions as we imagine the outcome, keeping us on the edge of our seats. Participating in a drama class or amateur dramatic group has been found to improve memory and executive function. This requires concentration and interactivity; and with team support, learning lines, working towards a production, offers splendid cognitive exercise to delay onset.<sup>38</sup>

Acting in a way different from usual requires the brain to respond to a novel set of stimuli, causing new neurons to develop and adapt. In a 2012 Harvard Medical School study of the effect of drama on brain function, the neuropsychologist Dr Sigmund Hough highlighted this process of becoming different interesting to the brain because of its 'inherent ability to make change serve a new purpose'. He affirmed drama's protective qualities against cognitive decline and even suggested that elements could be explored to halt Alzheimer's. <sup>39</sup>

Poetry, with its sense of rhythm, appeals to similar parts of the brain as song. Joining a poetry circle, book group or Shared Reading scheme generates ideas and sense of purpose between participants. The neural processing of language when reading complex texts - reciting Shakespeare, whose vocabulary surprises both reciter and listener and catches the brain off-guard - can stimulate brain pathways and influence emotional networks and memory function, with the potential to bypass cognitive challenges.<sup>40</sup>

An Illinois study of 2007 invited 124 older adults aged 60-86 to participate in nine 90-minute sessions over a month, of either visual art or theatre training, or no training, with cognitive tests at the beginning and end. The theatre group's test scores were found to have improved significantly more than the visual arts group for problem solving and wellbeing.<sup>41</sup>

Creating and enacting scenarios with a drama group, in allowing individuals to improvise and develop amusing experiences together, can act as a medium to alleviate depression. Indeed, an A4D participant, who had been struggling with depression, found that drama restored his confidence, as his friends observed. He went on to create hilariously imaginative scenarios across screens in our 20200 Southwark Playhouse drama programme 'Muse of Fire' (see page 204).

The octogenarian actors, Sir Anthony Hopkins and Dame Sheila Hancock have both expressed determination to keep learning lines to protect against cognitive decline. Indeed, Sir Richard Eyre, the director and patron of A4D, advises: 'I've known several actors who have had problems with remembering their lines – not always connected with the onset of Alzheimer's Disease. In every case I would recommend continuing the discipline of learning lines. There's no better way of exercising the brain.'42

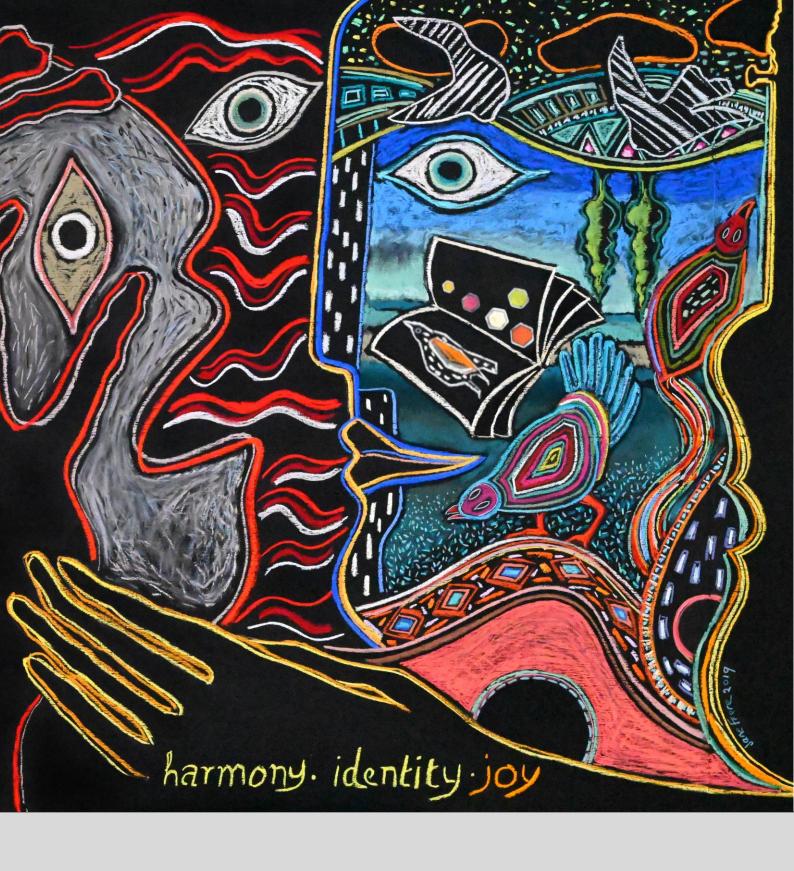
<sup>38</sup> WHO (2019), p.24.

<sup>&</sup>lt;sup>39</sup> Hough, B.H. and Hough, S., 2012, p.455.

<sup>40</sup> Creative Health (2017), 108.

<sup>&</sup>lt;sup>41</sup> Munger D. (2007).

<sup>42</sup> Franklin Gould, V. and Vella-Burrows, T. (2017) p.81.



# Diagnosing Well

# 2 Diagnosing well – The patient journey, from first GP appointment to Diagnosis.

Over 200,000 people in the UK are diagnosed with a dementia each year. A third more will not receive a diagnosis, either due to personal or cultural fears – the word 'dementia' itself and associated stigma is a deterrent. Of those referred to memory services for assessment for their cognitive challenges, one-third will not have a dementia diagnosis.<sup>43</sup>. All would derive cognitive benefit and enhanced wellbeing through participating in A.R.T.S. programmes to preserve their brain health.

For a rounded picture of patients' diagnostic experience in order to ascertain the most effective point for GP referral to their SPLW for re-energising A.R.T.S., we consulted:

- GPs and memory service teams in each NHSE region, Scotland, Wales and Northern Ireland, to outline the tests they offered patients and time frame to referral to memory service and diagnosis.
- SPLW as they came into place.
- A4D participants to discuss their own lived diagnostic experience.

# 2.1 Individuals' diagnostic experience

A4D workshop practice is to identify in advance each participant's diagnosis, date of diagnosis, symptoms, career and arts interests (keeping medical data private). For our 2020 Southwark SP dance and drama workshop programme (see page **204**), our aim was to attract those awaiting memory assessment and diagnosis or – as this was the start of arts prescribing in Southwark, as early as possible post diagnosis.

To present the lived diagnostic experience below, we have consulted our Southwark participants, individuals invited to speak at our 2019 and 2021 conferences and the regional meetings, our A4D trustee whose wife is living with frontotemporal dementia and A4D trustee, who is himself living with Alzheimer's disease.

Ten have kindly agreed to share their experiences, from the onset of symptoms.

CASE STUDIES show each person's diagnostic experience and the effect of their arts participation to help preserve quality of life. All except Keith Oliver had retired from their careers when symptoms prompted their visits to the GP.

<sup>&</sup>lt;sup>43</sup> Alzheimer's Research UK; Tim Sanders, Commissioning Lead for Dementia, Leeds City Council and Leeds CCG quoted other memory assessment outcome as 35% at A4D Yorkshire SP meeting, also quoted by Dr Frances Duffy, Consultant Lead Clinical Psychologist, Northern Health & Social Care Trust, at A4D Northern Ireland SP meeting.



Keith Oliver A primary school head teacher, visited his GP in March 2010 after a series of falls, fatigue and inability to concentrate. The GP, suspecting a brain tumour, referred him for a brain scan, which, three weeks later, a neurologist suggested may indicate early onset Alzheimer's disease (see page 39). Always proactive, Keith fulfilled his role as headmaster while continuing tests, each one recorded in his now published diary. In September, his GP signed him off work for two months and on his first day off, Keith and his wife overrode

health issues by taking a Canterbury Arts Society day trip to the artist John Constable's Flatford Mill. On 31 December, after nine months' neurological testing, Keith was formally diagnosed with Alzheimer's, which, on his retirement, opened the door to a major new role as founder of the National Young Onset Dementia Network and international ambassador for the Alzheimer's Society and exploring art and photography. Keith spoke at our Oxford SP meeting and national conference.

I did feel at a cliff edge. I needed something positive, constructive, rewarding and stimulating to fill the vacuum and anxiety that the condition, the tests and the diagnosis were generating.

Involvement in the arts builds resilience which is absolutely necessary if one is able to live as well as possible with dementia.

### Anastasia and Alphonse

Baptiste. Since 2010, Alphonse, 83, a dustman, had been experiencing memory loss, lack of sleep and showed signs of behavioural change. Drinking masked symptoms until an out of character event in 2014 led him to the GP. He was referred for memory assessment and partly due to difficulties with communication,



a year later vascular dementia was diagnosed. Anastasia, 81, a cleaner, has early symptoms of Alzheimer's disease, which began in 2018. She has no diagnosis, but their daughter brought both parents to A4D 'Dance for the Brain' at Siobhan Davies as a result of meeting David at Rambert Dance.



Paul Bowdage, 74, an analytical planner, experienced memory issues for some years, but his mathematical expertise and political interests enabled him to pass the cognitive tests.

In 2017, his GP referred him for memory assessment; and after a lumbar puncture in 2018, Alzheimer's disease was diagnosed. A keen rambler, he and his wife joined A4D drama in 2020.

<sup>&</sup>lt;sup>44</sup> Oliver, K. (2019). Dear Alzheimer's: A Diary of Living with Dementia. (JKP).

I'm really excited about being an art student on this project. I thought my first drawing experience was so enjoyable and it did such a great job bringing what I term as therapeutic calm, to my Brain. While on the workshop I literally forgot the stress related issues, which have been occupying my mind.

I would never have put art, objects and music together, so (A4D at Central Saint Martins) has opened my eyes.

I can't do numbers anymore, I can't do letters, I can't read, but I can now do painting and music and I think this has been fantastic.

Music helps me cope.

Difficulties are eased.

As the notes float away, so do my cares.

I like the comradeship. I felt part of it straight away. I'm accessing skills I'd thought had gone. I haven't looked at a bass clef since 1975.

Dementia hasn't got me. I'm still in charge!



Ronald Amanze, 58, musician and poet, had had a stroke, experienced loss of memory and blocked arteries due to brain injury and found difficulty in expressing feelings. In 2013 he visited her GP. After five MRI scans, he was diagnosed with Alzheimer's disease in 2015. He felt culturally stigmatised, so he used to disguise symptoms through songs. In hospital he started doodling, which developed into art. A trustee of A4D, he uses poetry, art and music to help raise awareness of happiness that can be generated

through involvement with the arts and joined our Central Saint Martin's student art programme.

Chris Maddocks, 71, a police officer, retired from the Environment Agency due to ill health in 2016. Having had three strokes, she was told her symptoms would recover, but instead experienced depression, anxiety, extreme fatigue, memory problems and difficulty in decision making. Chris felt lost She went to her GP, who said she was here for her physical not mental health 'I'd refer you to the memory team if I thought you needed it, but you don't.' She thought she was going



mad. After a further stroke in May 2016, she was taken back to hospital and was diagnosed with vascular dementia. (See page 40). Chris, who spoke at the A4DConf19, took part in A4D at Central Saint Martin's,

Chris Norris, 67, started his working life when he joined the army as a musician in HM Life Guards Mounted Band. On leaving, he joined the Kent Police and was a founder member of their band. In 2004, he became a Driving Examiner but on professional advice after a third heart attack in 2009, he gave up playing. In 2012 he was having difficulties processing the sequential order of the Driving Tests and visited his GP, who initially thought this due to depression, which Chris knew was not the



case. Following further problems and GP visits, Chris was eventually referred to the local memory clinic where, that December, aged 58, he was diagnosed with Frontotemporal dementia (FTD, see page 38), whereupon Chris resumed his tenor horn playing. In 2015 he joined A4D's programme where English Chamber Orchestra musicians and London College of Music students worked with him on sequences and transposition which had been challenged by FTD. Together they performed in a concert at the Wigmore Hall in London. Chris continues to play in Brass Bands and presented at A4D's 2020 Kent Meeting.



David Parsons, 70, a retired actuary, had been concussed seven times playing rugby and had memory issues for ten years, but would pass GP cognitive tests. In 2018, his memory declined more noticeably. He returned to the GP. In December 2019, he was diagnosed with Alzheimer's. The GP immediately referred him to A4D 'Muse of Fire' drama at Southwark Playhouse, A4D 'Dance for the Brain' with Siobhan Davies Dance and 'Dance for Dementia' at Rambert.

Sue Treacy, 70, a food hygiene teacher, had a mini stroke that affected her memory and ability to read and write. She was referred for memory assessment at her local hospital and her GP gave her a diagnosis of vascular dementia in 2017. Sue took up art at the Hart Club in Lambeth, which champions neurodiversity in the arts and created a witty range of characters in our A4D drama (see page 204). Her memory and reading have



since considerably improved. Handwriting remains a challenge. Even though a new GP confirmed in 2021 that she does not have dementia, Sue continues drama with Southwark Playhouse and 'Clay for Dementia' at the Garden Museum.



Eugenie Johnson, age 82, a hospital dietitian, has no diagnosis yet. Signs of memory loss and high blood pressure began in 2017. Her GP memory test indicated problems and due to COVID19, her GP carried out the assessment and arranged for blood tests in September 2020. Still awaiting results, her daughter encourages a good diet and exercise. Eugenie's naturally active lifestyle has been curtailed by lockdown, which lowered her mood and exacerbated symptoms. The surgery SPLW referred her to A4D 'Dance for the Brain' (see page 204), which cheers and is important to her.

Ron Bennett, 61, a French polisher, was suffering from lack of sleep, low mood, trauma, anxiety, hernia, leg pain and was about to go for memory assessment when his GP referred him to A4D drama (see page 204), to raise his morale. There, the camaraderie and creating person-centred comedic scenarios restored his confidence and proved life-transforming. Despite no dementia diagnosis and believing drama wasn't for him, he acts with relish, continuing the drama with others who do have a diagnosis. His confidence and



sense of purpose has returned, and he is consciously using his brain more.

Despite time lag - chiefly due to ensuring that all reversible causes are examined before referral to memory assessment, and now with extended delays due to the pandemic - we know through all the GP and memory teams we met through our regional meetings how very caring, person-centred and assiduous memory assessment is.

All value highly participating in A.R.T.S. activities, to which in the early days of Southwark link workers, four were referred prior to diagnosis. One is assumed to have vascular dementia and was referred to our dance programme by her SPLW to raise her morale, and another who was experiencing low mood, lack of sleep, anxiety and attended Alcoholics Anonymous, who was referred by his mental health nurse. Both continue dance and drama on Zoom. Another who came after diagnosis with vascular dementia, through an arts volunteer, had stroke damage that affected her memory and the ability to read. found that arts and drama had restored her reading to the extent that she could now follow a recipe and enjoy reading a book. So energising and free flowing are A.R.T.S, inspiring participants to contribute ideas to enact, design and perform, that she too continues drama with the group in the early stages of dementia and their companions.

# 2.2 Diagnosing well – The GP Perspective

The Patient Journey was a central part of A4D's 15 regional SP meetings 2020-21. Our aim was to learn and share the diagnostic process from the patient's first presentation to their GP of symptoms of a potential dementia, the tests carried out, timeframe to referral for memory assessment, the memory assessment process and timeframe to diagnosis.

Our aim was to open the conversation to establish the most natural time to refer patients to empowering A.R.T.S. to preserve their brain health.

### 2.2 The GP Perspective:

According to GP leads for later life mental health and dementia, it takes several years from the start of symptoms to get a diagnosis of dementia. The period from first patient appointment with GP to referral to memory service could be a speedy three weeks pre-COVID19, but we found this to be generally 12-14 weeks. For some participants initial GP assessments took a year or more, partly due to people passing the basic memory screening tests time and again, despite memory and behaviour concerns This stage would be a helpful time for referral to the SPLW for referral to A.R.T.S. (see pages 85 ff).

Each case is individual. Patients may present with very early memory impairment, or quite severe end-stage memory impairment. It is generally family or friends who bring their concerns to the GP. These may involve loss of memory, confidence, sleep, reading ability, or anxiety, depression, behaviour change, speech or movement difficulties or other unusual symptom but may not actually be caused by a dementia, so a GP needs time to examine reversible causes.

Unless the dementia is advanced, in which case, after initial assessment, a GP may offer the patient an early referral for memory assessment, the longest wait in the diagnostic journey tends to be pre-referral.

With only ten minutes per appointment, GP may call the patient back for several appointments. Each of these present an opportunity to refer the patient to the surgery SPLW for A.R.T.S. to preserve their brain health.

#### 2.2.1 Information gathering and reversible causes:

The GP needs to establish the type of problem, to look at preventable risk factors, whether it is a brain disease related to a neurological problem or related to a stroke or a reversible condition. Patients may present with depression fearing they may be developing a dementia. The GP looks firstly at:

- The patient's capabilities how well they function; how difficult symptoms are impacting their daily living or quality of life; their relationship; when they first noticed symptoms; what they like doing; if they are struggling or need help with care and need to be referred to social services.
- 2. The friend or family member's perspective a collateral history, to discuss what is happening at home; how symptoms affect their partner or friend in daily life; do they make up stories as coping mechanisms to cover up memory lapse?

# 2.2 Diagnosing well – The GP perspective

- 3. The patient's medical records looking for vascular issues; diabetes; histories of strokes; heart attacks; high blood pressure.
- 4. A short memory screening test either the Six Item Cognitive Impairment Test (6CIT), or the GPCOG Screening Test or Mini Mental State Examination adapting to suit patients whose first language is not English. These can be helpful in assessing whether the patient is normal or mildly or severely impaired, but responses can also mislead as some patients pass the tests and slip through the net for a time. Results one week.
- 5. Eliminating reversible causes the GP will screen the patient for depression, delirium, anaemia, vitamin deficiencies, liver and kidney function, find out about medication for example pain medication can affect memory; and arrange a collection of blood tests for biochemical signs of thyroid, low folic levels that can present like a memory problem.
- Patient appointment with nurse for blood tests and urine sample.
- The GP meets with nurse to discuss gather data and results.
- Patient appointment with GP, either at the surgery or virtually, to address reversible causes if one has been found, and for example prescribe folic acid if their foliates are low.

#### 2.2.2 Referral for memory assessment:

If there is no reversible cause, the GP seeks consent to refer the patient for memory assessment and can at the same time discuss what the patient can do to improve their brain health.

If the impairment is mild, GP may suggest monitoring them and meeting again in six months.

In view of the lengthy wait for memory assessment in Northern Ireland -12-18 months - in the interim, Dr Laura McDonnell GP, Regional Clinical Lead at the Western Integrated Care Partnership, explains to patients that they are being referred for their brain health and there are things the patient can do to manage stress, optimise their cardiovascular health, blood pressure, cholesterol and address lifestyle, notably referral to SPLW to take up re-energising A.R.T.S.

A4D's supporter, the Dementia Change Action Network (DCAN), having attended our regional SP meetings, has produced a helpful guide, *Living Well While Waiting for an Assessment* on their Next Steps website., which encourages people awaiting memory assessment to engage in A.R.T.S.

# 2.3 Diagnosing well – Memory Assessment

Referrals to the memory service, chiefly by GP, also from the rapid response liaison psychiatry team, are triaged by memory assessment nurses, placed on the waiting list and patients receive a letter, asking whether they would like their appointment face to face, by video or telephone.

Appointment waiting times have lengthened due to COVID19 from two or three months to as much as 18 months. Mindful that for 35% of patients the diagnosis will not actually be identified as a dementia, the patient's life history and cognitive developments and effects are studied in greater depth. The timeframe to diagnosis varies from a one-stop-shop – all tests including scan and diagnosis in a single day – to months or years depending on the individual, nature of impairment, the pandemic and memory assessment waiting times.

At each stage, where fears of a dementia diagnosis are naturally rise, referral to SPLW for re-energising A.R.T.S. offer both person and family partner empowering opportunities to override their fear and despair through creative expression and social interaction.

Memory services aim at early diagnosis, but the earlier you try and diagnose dementia, the more difficult it is, and this can give some problems in achieving a 100% diagnosis rate' says Professor Tom Dening, a Consultant Old Age Psychiatrist (OAP) and Professor of Dementia Research at the University of Nottingham.

# How memory assessment takes place:

Memory services are set up variously, either according to tradition the consultant OAP sees every patient or, in view of the greater number or people being referred, the assessment service is more likely to be led by a senior specialist nurse in consultation with the multi-disciplinary team (MDT) of psychiatrists, clinical psychologists, neurologists. Assessment usually takes place at the hospital-based memory clinic, jointly run by neurology and psychiatry. Pre-COVID19 all tests and diagnosis could be organised as a one-stop-shop in a single day, but this also depends on the individual. More often now, assessments take place over a period of time. A consultant may hold a specialist clinic in a GP surgery, and sometimes GPs with a special interest in dementia will undertake diagnostic assessments. But where there is a need for more intense investigation and assessment, especially for people with young onset dementia, this will take place in the memory clinic.

# 2.3.1 Pre-Assessment Counselling

In a conversation either at the patient's home, by video or phone, a Senior Nurse Specialist team leader explains to the patient, together with the family member or close friend, the reason for the assessment, what it involves, to prepare the patient for the possible outcomes – MCI, depression or a dementia. They look at the pros and cons of receiving a diagnosis, so that the patient together with their companion can give informed consent and decide how the patient would like the assessment to begin – face to face at the clinic, or virtually. The nurse may advise the patient to preserve their brain health by keeping physical and mentally active, to maintain social activities and even refer them to an SPLW. If the patient is happy to proceed, the next step is.

# 2.3 Diagnosing well – Memory Assessment

#### 2.3.2 Clinical assessment

Two to three months later, the assessment revolves around patient's story, the history, examination and investigations:

# History

- More in-depth history of the patient's life, strengths, hobbies, interests, likes, dislikes.
- Current medication: this impacts on their mental and physical state and can affect new treatment.
- Clinical history: development of symptoms, how they have affected the
  patient and in which order they appeared; what they are able or unable
  to do; their strengths and weaknesses.

#### Examination

- Detailed cognitive testing, the 25-minute pen and paper Addenbrooke's Cognitive Examination (ACE3) looking at memory, language, visuo-spatial function, orientation in time and place, problem solving. Translators can be on hand to interpret.
- The companion will also complete questionnaires.

# Investigations

A CT or MRI brain scan may be arranged

# Multi-Disciplinary Team meeting:

 The consultant or nurse presents assessment report to MDT colleagues, who may come to a provisional diagnosis, or a final diagnosis.

# 2.3.3 Diagnosis:

As early as possible – but the wait may be eight to twelve weeks – the consultant or nurse will feedback the assessment outcome to the patient in a 75-minute appointment and make a treatment plan, including A.R.T.S. lasting powers of attorney etc. If no diagnosis yet, the memory team will monitor patients for a further three to six months, during which a diagnosis will be made, whether of a dementia, depression, MCI.

If the diagnosis is MCI, memory clinics will continue to follow their progress over the next couple of years, to identify reversible causes and provide occupational therapy and psychological support. As a result of our East of England meeting, the Peterborough nurse has set in train referral to SPLW on diagnosis of MCI.

If the diagnosis is a dementia, this will be given in accordance with their wishes, to the patient and family carer. They are given time to digest the diagnosis, ask questions and discuss the diagnosis, what it means. In

Social prescribing would be really useful when people come with fears about the diagnoisis and communication difficulties, when people struggle to express themselves.

It would be useful even before they come to the clinic, which will make their journey to the clinic a bit bitter.

However early we can, we need to link people so we can guide them alone the journey and help them live well, even with the diagnosis.

Dr Chitra Srinivasan, Associate Clinical Director, Consultant Psychiatrist, Devon Partnership NHS Trust

# 2.3 Diagnosing well – Memory Assessment

some cases, tablets can be given immediately. They return home with printed guidance and will be sent a copy of the memory service letter to the GP. If the patient does not wish to know a dementia diagnosis, treatment and support is given without naming the diagnosis.

# 2.3.4 Early post-diagnostic period:

A comprehensive care plan is arranged; and this is where A.R.T.S. are currently offered, as well as peer support – often some weeks after diagnosis and years after symptoms began. Despite the compassion with which patients will have been treated, life at home will have been increasingly stressful.

At our regional meetings GPs and consultant OAPs, nurses, psychologists, senior professorial chairs and SPLW all sought ways to involve SPLW more closely in the pre-diagnostic and assessment process, keen to change the focus of A.R.T.S. from nice to do, to core and essential to patients' wellbeing.

# 2.3.5. Diagnosis – cognitive outcomes – dementia subtypes

The outcome for 65% of patients referred to memory assessment will be a dementia, a clinical syndrome which affects memory, thought processes, judgement and decision-making and social behaviour.

Mild Cognitive Impairment (MCI), a common diagnosis, is characterised by objective cognitive impairment, less severe than a dementia and without significant impact on daily activities or discernible progression over time. Though, like dementia, MCI can affect more than memory. In general, over three years, a third of patients with MCI improve a third stay the same and a third progress to dementia. For those who improve, likely causes may have been depression, anxiety or physical illness, <sup>45</sup> all of which can be effectively addressed by engaging in re-energising weekly A.R.T.S.,

Alzheimer's Disease (AD), the most common subtype of dementia, begins with mild memory loss, some confusion, forgetting names and mislaying possessions, difficulty finding the right word, reasoning and following conversation. People may become withdrawn and experience mood swings. As the disease progresses, their ability to read and write may be affected. Ability to perceive music and musical emotions remains relatively intact; and music, dance and drama can reduce anxiety and improve cognitive functioning.

Vascular Dementia (VD), caused either by stroke, transient ischaemic attack (TIA) or by poor blood supply to the subcortical, neural formations deep within the brain. It may affect vision, train of thought, concentration and cause confusion. Parts of the brain that control awareness may still function and can cause depression. Symptoms may begin suddenly, remains stable or possibly improve at first. Further TIAs and strokes advance the condition in a stepped progression. The diagnosis may be Mixed, a combination of AD and VD.

<sup>&</sup>lt;sup>45</sup> Barrett, E. & Burns, A. (2014), Dementia Revealed What Primary Care Needs to Know: A Primer for General Practice (June 2014, Department of Health), pp. 6-10.

# 2.3 Diagnosing well – dementia subtypes

Dementia with Lewy Bodies: Tiny deposits in the brain's nerve cells bring symptoms similar to AD and to motor problems associated with Parkinson's disease. Subtle at first, symptoms vary each day. People may find it hard to remain alert and to plan ahead. Longer term difficulties affect thinking, language, orientation, comprehension, calculation, judgment, memory and learning capacity, sleep, and spatial awareness, and bring hallucinations and elusions of persecution.

Frontotemporal Dementia: Subtle at first, damage to the frontal lobes of the brain, which control behaviour, emotions and language, may gradually lead to inappropriate and aggressive behaviour, even in mild-mannered people. Despite loss of inhibitions and speech difficulties, their memory may be unaffected; and they are likely to be aware of what is happening to them.

Every individual's experience with dementia is unique. In the early stages, the changes that people experience frequently engender feelings of fear, helplessness, loneliness and depression. The joys of engaging with A.R.T.S. can override these symptoms and restore their resilience, identity, sense of purpose and social wellbeing for longer, so much so that Sue (see page 30), whose memory problems and ability to read were restored after active participation in art and drama. Her diagnosis of VD was reassessed as the result of her stroke.

While the mental deficits associated with dementia are indeed serious, the mind can circumvent these difficulties and improvise through well-functioning facilities. It is widely acknowledged that the arts have enormous potential to deliver health improvement. People with cognitive challenges can discover new facets of creativity and interest and develop a surprise passion – like Ron, for drama, or Ronald for poetry, or Eugenie, for dance – and continue to do so, with or without dementia.

Over the years, we have observed that A4D's weekly programmes keep people confident and energised in the community for some three years after diagnosis – these are effectively A.R.T.S. to preserve brain health, workshops of real interest, for healthy ageing, led by artists, musicians, dancers, actors trained to understand their challenges, their existing skills and how best to access them (see Appendix 1 page 215).

# 2.4.1 LONDON BOROUGH OF TOWER HAMLETS

Professor Sir Sam Everington GP, Bromley by Bow Partnership, Chair, Tower Hamlets CCG, Clinical Lead, East London Health Partnership, Deputy Chair, Tower Hamlets Health and Wellbeing Board.



Sam Everington is one of four GPs attached to the Bromley by Bow' Partnership's three health centres and their healthy living centres offering SP services in partnership with the Bromley by Bow Centre. A pioneer of the SP movement, he and his colleagues at Bromley by Bow – where creativity and design in architecture, garden paths, fun and sociability permeates – have long referred patients, informally, to weekly A.R.T.S. to inspire them above health and wellbeing challenges (see pages 109 and 139).

Their Single Universal Referral Form, with specific sections for older people, wellbeing and social care support and weight, allows space for free descriptions to address needs including risk factors for dementia.

# Consultant Old Age Psychiatrist: Dr Nick Bass Senior Nurse Practitioner: Jana Mikova Diagnostic Memory clinic – Tower Hamlets, East London NHS Foundation Trust

Consultant old age psychiatrist screen referrals daily, acknowledge receipt to GP and allocate the nurse who

- Telephones the patient within four to six weeks to:
  - o Explain the assessment process.
  - Seek consent for neuroimaging, ideally an MRI which is more efficient, but there is currently an up to six-month waiting time, otherwise a speedier CT scan.
  - Discuss dates for the first memory assessment appointment which could be one week or within the post-COVID19 target of two months from receipt of referral.
  - Advise the patient to keep mentally and physically active and socialise, to preserve their brain health.
- The patient receives a letter giving the date and time of their appointment at Mile End Hospital, enclosing a memory assessment leaflet, with guidance about what to expect, a link to the <u>Next Steps</u> website advising participation in activities for wellbeing, and links to local A.R.T.S. opportunities, as at the Bromley by Bow Centre and Green Candle Dance.
- There may be more assessments and brain scan.
- Diagnosis, followed by post diagnostic support.



Our patients relieve stress by devoting their mind to painting poetry., ceramics or dancing.

Some now talk about their latest creative achievements rather than their medical worries.

# 2.4.2. SOUTH-WEST: GLOUCESTERSHIRE Dr Simon Opher GP, Walnut Tree Practice, Dursley and founder of <u>Artlift.</u>

Dr Opher engaged an artist in residence in a special therapeutic room at the Walnut Tree Practice in 2001, to refer patients who he noticed were anxious or stressed, to creative activity - initially pottery for its malleability - then fine art, poetry and dance. Weekly activities were offered over a 10-12-week period.

Taking up arts so cheered them, soon replacing their weekly GP visits, that in 2007 Dr Opher founded the aptly named Artlift to provide arts on prescription to patients at eight Gloucestershire surgeries, each with their art room. Artlift expanded into Wiltshire, funded by Arts Council England (ACE) and Gloucestershire County Council. With happier patients and 30-35% drop in GP consultations, Gloucestershire CCG set up a Cultural Commissioning Board, funding Artlift which is now a partner in the Gloucester Creative Consortium.

Walnut Tree patients with memory worries become transfixed by arts, happily engaging in local healthy ageing community activities, such as the Prema Arts Centre, history society, allotments, running, cycling and cricket clubs. Their Memory Assessment Service is based in Dursley.

# Managing Memory Together, Gloucestershire Health & Care NHS Foundation Trust

Kathy Holmes, Engagement and Involvement Manager, explains that memory assessment service triages the patient's referral details to ascertain need. The patient then:

- Receives a letter within seven to ten days explaining the waiting time for an assessment appointment (12-20 weeks), with contact details in case the patient has questions or symptoms deteriorate, and a leaflet giving links to the *Next Steps* website, with SP guidance to match the patient's interests for self-referral to local activities, including Artlift.
- Receives a phone call from the memory nurse to:
  - Establish their favoured assessment method by email, telephone, face to face at home, or in the clinic.
  - o Hear how the assessment will be carried out and take advice.
- Receives an appointment letter, with leaflet explaining the process.

#### Assessment appointment:

- The memory assessment nurse will carry out the assessment and take results, with brain scan to the MDT.
- A diagnosis may be decided now or after a further assessment.
- The patient will be invited to the clinic for diagnosis, medication and information sheet.

The post-diagnostic appointment with the nurse takes place four weeks later. SP referral to A.R.T.S. at the outset fits Managing Memory Together's desire to bridge the waiting time through SP to activities of interest.

# A4D regional case studies

At our first meeting, for south-east England, we heard of GPs referring patients to their SPLW at the point of referral to memory assessment. This makes sense. When inviting the patient to the next diagnostic stage, this would be an encouraging moment to offer an SPLW appointment to choose empowering A.R.T.S. to preserve brain health and would do much to ease the symptoms, anxiety, fears and strain on the individual and their partner at home, and their worry about impending diagnosis and their increasing loneliness as friends and colleagues drift away.

However, consulting those who had lived the diagnostic experience, it has become clear that years may pass even before referral to memory assessment. Symptoms on first presentation in the surgery may be due to a range of causes. The patient often passes initial screening tests. Early referral to the SPLW – whatever the cause – could ease stress at home caused by symptoms and help preserve the health and wellbeing of the individual and their partner, maintaining social links to their community – and protect against cognitive decline.

Here are case studies of regional diagnostic practice, together with developments arising from cross sector meetings A4D held for every NHSE region, and for Scotland, Wales and Northern Ireland:

# 2.4.3. SOUTH-WEST: DEVON

Dr Michael Dixon, Co-Founder of the International Social Prescribing Network (SPN), established the <u>Community LIFE Hub</u> with a healing garden inspired by the Russian writer and humanitarian Anton Chekhov's healing work as a doctor (see page 85), at his general practice, the College Surgery at Collumpton that makes one long to live there: If ill health strikes, their thoughtful approach hits the spot:

# Dr Daisy Robinson GP, College Surgery Partnership, Culm Valley Integrated Care Centre, Senior Fellow, Cullompton Social Prescribing Testbed, (A4D Devon July 2020)

Mr B, in his late 70s, could not run as far as he used to. We found a simple medical diagnosis. He returned, worried about his memory and feeling lonely. We went through the GPCOG and a slightly more detailed test. There was no objective evidence of memory loss at that point, so we explored what else could be going on. What Mr B really wanted was greater social connection now that his physical ability has decreased. I referred him to the local SP service. He wasn't interested in the coffee group, Knit and Knatter, or a memory group he wanted to use his brain and to meet people. So he was connected with nature walks and a puzzle group, to enable him to use his brain in company. He felt better connected and delighted to be using his brain. That is a classic story of how I would experience SP as a GP.

Twelve months later, Mr B came back feeling unwell again. He did now have a life changing diagnosis. As he said, his memory had deteriorated, and his wife confirmed this. We then formally referred him to the memory service. It struck me that this was someone who had twice come with something physical and psychological; and each time there had been an opportunity to connect to a non-traditional dementia service. He really found that helpful. Everyone's journey is personal.

The SPLW is the one that can find that purpose and meaning that stays even when the mind may go:

College Surgery Partnership SPLW in 2008 employed Ruth Tucker as activity facilitator as part of a co-operation between the surgery and Natural England. Ruth, now SPLW Community Builder, is a tour de force at the Culm Valley Integrated Care Centre (See page 86).

# Dr Chitra Srinivasan, Consultant Psychiatrist, Associate Clinical Director, Devon Memory Service.

Devon Memory Service. Runs the clinic across three locations, Exeter, Barnstable and Torbay. I want to think about the challenges one faces between the GP referral to how the person presents in the clinic. At a 'one stop shop' everything happens in one day and this can be exhausting for the patient, and quite traumatic, when they come with fears of the diagnosis, reduced confidence and not wanting to be there. But actually we want them to get a diagnosis early, as it's helpful for both the patient and the family members.

I feel better connected, happier, and I have a reason to get out the house when my family are busy and I'm on me own. I'm using my brain, and I am feeling more myself

Whatever the journey is in the future, he is still connected to these previous groups that gave him that social connection.

# 2.4.3. Dr Chitra Srinivasan, Devon Memory Service

Although the aim is to diagnose dementia early, a large proportion of those we see do not end up with a diagnosis of dementia - it could instead be MCI, or depression is seen for the first time and managed appropriately, working closely with primary care. The heart of all of that is recovery focused, the whole service. I'm involved in a research study to see how we can improve quality of life for people with dementia, what are the markers in their journey, even before the diagnosis? Something like perceived quality of life, activity levels, socio-economic background, social interactions, family support. They all play a huge role, even before diagnosis, to influence what is it exactly that could help this particular person on their onward journey after diagnosis.

As a service we understand that it can be traumatic, with concerns about stigma before they come to the clinic. It would be really useful to start SP early on. The post-diagnosis appointment is a good time for us to get involved in trying to get things moving, but having thought about identifying people early on, even in primary care, when someone is being referred to our service, it would be really useful when people come with fears about the diagnosis, when people may be struggle to express themselves. These things when started early on will help them go through the diagnostic process better, and for us to carry on with the journey afterwards to help them successfully. We can even start thinking about this before they come to the clinic, to make their journey to the clinic a bit better.

I have seen how the arts and how music can help people. Whether it is to lift their mood, improve their confidence, their ability to express better, it is a different way and you can see it works very well when it is regular activity. I can see that as a starting point before they come to clinic with fears and communication difficulties. We also know that social isolation and inactivity are dangerous factors, so however early we can, we need to link people, so guide them along the journey, and help them live well, even with the diagnosis. The diagnosis is there to help, but they should live a good quality of life with or without a diagnosis.

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# 2.4.4. NORTH-EAST: TYNE & WEAR

<u>Dr Karen Nielson</u>, GP Lead, Newcastle, for Later Life Mental Health & Dementia (A4D September 2020)

I've been a GP in Newcastle for nearly 28 years. Part of my week is also spent working in commissioning services for the CCG. I started off as Dementia Lead. This has morphed into older people's health, frailty, falls, all the links, which shows how holistic we have to be. Everybody is an individual, and individuals have lots of different issues.

From the GP point of view, it is about getting awareness raised and trying to get SP as part of the pathway, something you think about as part of the offer. We are trying to be more preventative in our involvement with referring into SP. Hopefully, the arts can come as part of that awareness. We are tending to refer to our SPLW in relation to fall prevention, for example. I like the idea of having 'brain health' rather than 'dementia' in the title. Rebranding can help reduce the stigma, particularly pre-diagnosis, when people often don't want the 'dementia' word mentioned. There is a new opportunity with PCNs and the more localised links with navigators and SPLW. I really look forward to getting more involved as a commissioner. The structure is developing for SP, and the more holistic approach is being taken on board.

There are lots of opportunity pre-diagnosis - it takes several years from the start of symptoms to get a diagnosis. It depends on the individual. Some people take longer to present, but it is generally family or friends who express their concerns to the GP or the practice nurse. We try and do a bit of case finding. One of the issues at the moment is getting people back into normal services. As memory service waiting times have increased due to COVID19, that might be an opportunity to get in SP sooner. But it is also accessing it, how do we get new people into these services, and arts for brain health? With COVID restrictions, it is getting those links made, and thinking how do people start engaging in something that may be a virtual engagement? It is difficult for lots of people to be online and often very difficult for people with dementia, then there are the issues about relying on a third party or carer, and how you get the patient's actual voice in that situation? But I the love human rights approach to services and dementia.

Professor Lynne Corner, Chair: Karen, you raised some important points there about raising awareness and that focus on brain health as opposed to dementia, which can be very stigmatising. We will pick up some of the points you've raised about how SP can be part of the pathway in subsequent talks.

# 2.4.4. NORTH-EAST: TYNE & WEAR

Dr Lisa Newton GP, Dementia & Care of Older People, Saville Medical Group. Alzheimer's Society Clinical Training Fellow, Newcastle University

Saville Medical Group is a large practice in Newcastle, with 35,000 patients. SP is pretty embedded. Our four or five SPLW are a valued part of our team.

#### First Consultation:

We will be getting a bit of depth about what is going on, looking at:

- Capabilities how well they function in day-to-day life.
- Carers or a family members perspective a collateral history of what's going on.
- Cognition that can be a memory score or a tool that we use to try
  objectively measure that, there are lots of these tools.

We then talk to the person, look for reversible causes to their issues. I screen them for things like depression, send them to the nurse to get bloods. If biochemical arrangements indicate that their thyroid is not right, or they have low folic levels, that can present like a memory problem, as can infections, repetitive episodes or delirium, we want to trace these, because it might get better. Also, if they're on certain types of medication, and we stop or reduce them, it can improve their memory.

# Second and third consultations, and referral to memory clinic:

I bring the patient back in front of me - sometimes virtually or by phone with a carer. If we have found a reversible cause, we address it, say, by giving folic acid if their foliates are low. We reassess after three months. Meanwhile, if there is a functional problem, that could be dementia - the score might not necessarily be bad in terms of the questionnaire, but if they're not functioning and we find nothing reversible, then referral to the memory service is appropriate, depending on the person. If they're not ready, they might have more than one appointment If they consent, we refer to the memory clinic.

#### SP referral:

In terms of SP, from the start of the journey to the end, I am always thinking 'What does this patient need as an individual?' If they had come up with something at the outset and were really struggling, or needing help with care, I would refer to social services at that point so the need is addressed. If there are wider, financial, relational worries, I would refer to the SPLW team. But if it is obvious they have dementia, we have support services, particularly the carers I would refer to the Dementia UK service in Newcastle.

The SPLW are very good in our practice, we have a great relationship. We have the electronic note system, EMIS into which we embed a form for the SPLW, with an option to tick certain boxes. We've got a box to write our concerns - that is the most important bit. I can write these are the issues for the family and the person, and this is what I would like you to look at. It gets sent internally through a system to our admin team, and then through to the

#### 2.4.4. TYNE & WEAR: Dr Lisa Newton GP

SPLW who triage it themselves; look at how urgent it is, look at the opportunities. Before COVID it was either face-to-face or telephone calls, but now they might do video calls. I do think they may be able to occasionally see people face to face. But that is embedded in the system there, and if I'm worried or something is more complicated, I can just pick up the phone and speak to a SPLW who are all within our big PCN. Paul is our fantastic prescriber within Saville, (see page 91). He is a valued member of our team - we really appreciate him.

# Raising awareness

In terms of how arts could be better for us, it is knowing what is there, so that SPLW can say 'There is something they might enjoy here.' We have got no problem about helping them access it, it is just if they don't know it's there it is hard to do that. We also have an educational session at Saville every week, we do it virtually now, but we often have guest speakers, charities comes in, we have consultants from the hospital, but if it is something that is interesting we can actually have people come and talk to us and tell us what they're doing, so that is an opportunity we could use to get the arts promoted to our patients, and also we can disseminate the information to all the GPs within the practice.

Professor Lynne Corner, Chair Lisa, you have raised a really important point there about knowing what's out there: I remember working with the Alzheimer's Society on their road map for dementia for GPs with Dr Louise Robinson to look at how we navigate it - they were incredulous at how complicated it was for GPs to understand what is out there. So that is something we can certainly look at collectively as a group. It is brilliant to hear you say words like *embedded*. What a step forward that it is - embedded in practice. It is a lovely segue from your perspective on the patient journey as a GP into that navigation, so welcome to Paul Ellison who is the lead Care Navigator for SP in Saville Medical Group (see page 88).

# Dr Karen Franks, Northern England Clinical Network Lead for Dementia and OPMH. Consultant Old Age Psychiatrist, Gateshead.

I shall outline the journey people usually have coming through us, thinking about a potential diagnosis, then think about how we could fit the arts and culture into that, and how we could better do that in the future.

#### Referrals

Generally, referrals come from primary care through to us around someone where there are concerns for their memory, and we will arrange an initial assessment three to four weeks later.

#### The assessment:

Our service in Gateshead is quite flexible as to whether assessment is carried out at home (usual) with the person, if that is what they are comfortable with,

# 2.4.4. TYNE & WEAR: Dr Karen Franks GP

or it can be in their GP practice. We take as much as that information and history as we can to help us devise what is going on. A lot of it is around what people are able and not able to do more importantly than the tick box memory tests. We will do a more in-depth assessment than the GP has done, with quite a bit of detail about where their strengths and weaknesses are, and a more detailed memory test, and we explore any other difficulties they may be experiencing.

# Neuroimaging and diagnosis

Next, we usually arrange for neuroimaging and will see them the patient with the results a couple of weeks later at home. At that follow up assessment diagnosis may be delivered if we have enough evidence, or it would be an explanation that this is what we know, and this is what else we need to know, and we might have to monitor them for a further three to six months. Somewhere along that process, a diagnosis will be made, it may be a diagnosis of dementia, it may be an alternative diagnosis - we make a diagnosis of depression, or MCI, which is memory or functional difficulties that don't reach the threshold of a dementia.

# Post-diagnostic support:

Within our services we would then support people and follow them up and look at other levels of support that they might need in terms of care, or medication, or other groups, and that would be an ongoing relationship as best we can. At the moment, that would be the point where people would think about arts interventions. In Newcastle they' have been doing some work post diagnostically with people through the memory clinic - (see Equal Arts page 187).

#### Potential culture shift:

What is interesting is how we could change that narrative, and how we could have that cultural shift, in terms of that being part of our conversation right from early doors, before we've even met somebody. An expectation between us and primary care that this should be something that we're thinking about at the same time as checking bloods and all these sorts of things.

It is about normalising that into our conversations, trying to bridge that gap between what's medical and what is seen as 'fluffy' arts stuff, which really annoys me. It is trying to normalise SP, putting practical activities and creative activities into those conversations at points throughout the pathway. The other thing about shifting the narrative is that it helps about being able to talk about positives, rather than conversations being about deficits and things people can't do. It is that shift to that growth mindset and looking at the sort of things people can do. It is about revisiting it all the way through, I think it would be beneficial for people even if they don't have a dementia diagnosis, and if they do. A lot of it boils down to a culture change, a change in relationships. For example, the memory clinics could have links with the SP leads in areas. It is that changing focus from these sorts of activities just being nice to do, to actually being seeming that is core and essential, and as important as people getting their medicine and their fall assessment.

# 2.4.5. SOUTH-EAST: OXFORD

# Dr David Chapman GP, Mental Health Clinical Lead, Oxford CCG, Oxford City Council (A4D May 2020)

We are familiar with SP, in particular with dementia. We have had the post-diagnostic dementia support service run by Age UK, Young Dementia and Guideposts for at least four years. I was part of the commissioning group that put that together at Oxford City Council.

General practice is a biopsychosocial model. Firstly, it is physical medicine. Then psychological medicine came on the scene. Now we realise that the social bit is probably most important of all, or at least another strand of looking after patients. If you want to look after patients and give them what they need then you have to address all three of those and not just one.

Medicine demands evidence where we can - but we don't always have evidence. For example, we pile tons of drugs on people where the trials demonstrate the evidence. They were very clean trials with one drug, and yet we extrapolate that immediately and put people on lots of drugs and then spend half our time fighting side effects and taking people off drugs. Evidence is important, but we shouldn't get totally hung up on that being the only driver we should use. We have lots of SP in Oxford City in particularly, we have the Dementia Support Service, we have Citizen Advice, Oxford Federation, initially SPLW were for frail elderly people, but is now a much broader group. NHSE has now allowed us to employ SPLW as part of our PCNs (see page 72). We also have Mind Workers which is an initiative I bought in Oxfordshire, they are not across the county but are in the city in the south-west, they are SPLWs from Mind.

We have to work out the components of SP: there are the SPLW who explore in detail with the person what social deficits we might be able to fill; and that links them up with something which may fill that social hole - for example arts for people at the onset of dementia may be one of their social deficits.

The NHS currently recognises SPLW bit, but it does not recognise you have to link to something. That raises the issue of funding: the funding now is for the SPLW, not for the end point. I don't think the NHS has grasped that nettle yet, that is a big issue that we need to get our minds round. We haven't answered how we fund the A.R.T.S. prescription.

But there are a huge number of people: those with dementia or loneliness — that is a huge burden on the carers. From a primary care point of view and commissioning view, we are all up for the sorts of things that the arts would bring in, not just for dementia, but for other mental health issues. I will support a push for that.

# Dr Rupert McShane, Consultant Psychiatrist, Head of Oxfordshire Memory Clinic, Warneford Hospital and Associate Professor, Dept of Psychiatry, The University of Oxford.

I am going to take you on a journey of my relationship with music and dementia. It started about 35 years ago, I lived as a medical student with music therapists and used to have heated arguments about why we should fund music therapy instead of renal transplants. I may have been a bit naïve but the distinction between arts, entertainment, therapy and education I think lies at this issue about getting the evidence. I very much liked what David Chapman had to say about this, and the inadequacy of evidence. As I have got older, I have appreciated that more and more. I worked briefly for Live Music Now and the Wigmore Hall to fund my medical education and they emphasised the importance of professionals providing music in a variety of different contexts.

# Mozart on Prescription

Fast forward to now, I am in the world of looking after people with dementia, and I just wanted to share this prescription with you (left). We've heard a lot about arts and SP but there is a question about how you try and encourage patients - how you encourage a horse to water, so to speak. With good quality content you can get them to drink, but it is getting them there in the first place. I had a patient who was a holocaust survivor. The daughter called me to see her 83-year-old mother. I wrote this prescription for her. It amused her enormously and lightened things a little for her in the dark times. It is the only prescription I have ever written for the arts. I think this speaks to the issues about how you engage patients.



# SP - How the consultant's recommendation encourages the patient

In our clinic, I have about 75 mins to gather the story from the patient, get an idea of who they are, talk to the carer, get cognitive tests, review their CT scan, explain the diagnosis, make a treatment plan, tell them about Lasting Powers of Attorney, other benefits and legal matters, then talk about SP. Actually, we spend a lot of time on SP in the memory clinic. The reason that we do that, as well as referring to Dementia Advisors, who are the key pin of this for us, is that when a doctor says something, the patient tends to listen. You have influence at that point.

# Post-diagnostic support - belt and braces approach needed

Patients often lack confidence to think that they could do something different. Of course, it is part of dementia that you draw you horns in as things become more frightening. We try to help people overcome that by engaging and reassuring them, but there is only so much one can do. As well as referring to the Dementia Advisor, I send the carer a post-consultation letter by email, introducing the advisor, with links to available information There is an important issue here. We need to have a belt and braces approach, so that they hear the same approach from different areas.

# 2.4.6. NORTH-WEST: GREATER MANCHESTER

# Dr Jonathan Kaye GP, Dementia Clinical Lead, Manchester Health and Care Commissioning, speaking at A4DConf21.

Currently, we start to offer treatment for brain diseases, such as dementias, when symptoms affect daily life, when the damage has already occurred. What we could do is to intervene earlier, to delay or prevent brain disease getting to this stage. Cognitive stimulation and improvements to lifestyle can reduce the risk of dementia developing.

#### What do we do now?

We identify those at risk of dementia, for example, those with heart disease or diabetes, and in Manchester we ask them about memory at chronic disease annual reviews. If they do have a memory complaint, we may offer blood testing, memory tests and referral to memory assessment services for a diagnosis. We do this, but it may take time.

#### What can we do better?

We could refer patients at the outset to a brain health SPLW who can support the patient to make prompt lifestyle improvements, those which stimulate the brain, such as arts, crafts, music and dance. Any mentally stimulating arts-based activity should be dementia friendly, not dementia specific. MCI and dementia are not the same, and people may feel different about attending activities. Brain health in a personal, culturally sensitive way is offered, and the risk of dementia is reduced.

# How do we refer people?

There's a pathway developing: a patient presents with concern about their memory, professional curiosity means that these concerns are identified and taken seriously, the patient is investigated appropriately whilst being referred to a SPLW by a recognised referral form, with a specific indication. In our practice, our SP referral form, has a box to tick, to refer people for brain health.

#### How do we advertise this service?

We need to notify clinicians of the change to the referral form, that there is a box that they can use to tick for this purpose. It is about having local champions to help drive things forward.

#### 2 How do we reach out to SPLW?

These are a disparate group. I've contacted the SP peer support group, so that education and training can be offered.

# 2.4.6. GREATER MANCHESTER Dr Jonathan Kaye

We need to instil passion in our workers - the brain is fascinating - explain a little and light the spark of interest. This is vital. As we know there is no adverse effect from mentally stimulating activity, in fact building brain resilience can be advantageous for everyone in the long term. There are opportunities. If one speaks to a GP, they will say they are too busy, but general practices are working together in their PCNs. There is money for additional roles, new members of staff who can provide new models of care - this could be a SPLW. This is extra help. Somebody else may say, 'But I have a Quality Outcomes Framework (QOF) to worry about!'. This role could include being trained to facilitate annual dementia wellbeing plan reviews. This would satisfy the QOF work and free up staff. As for social distancing, many of us have embraced Zoom, and we can think of new ways of working, such as interactive webinars.

Now we come to solutions. What about training? Dementia United has training for dementia wellbeing plan reviews and is interested in MCI. A4D could help with training. I have spoken to SPLW colleagues - there is great interest in this work. It is important to have champions, to help drive things forward and make sure they happen. The outcomes will be that our patients have the opportunity to live longer, healthier, happier lives. They and their loves ones will feel better supported. Those working in this area will also feel more professional satisfaction and feel proud that they are helping. So, what are we waiting for?

At A4D's SP meeting for Greater Manchester in September 2020, Dr Kaye explained that until researching for the meeting, he had been unaware that SPLW could help with cognitive impairment issues. Immediately after the meeting, he had 'brain health' added to the practice SP referral form.

There must be a straightforward way of referring, the SP form could have a cognitive element added to it. It would be very easy to promote A4D in primary care from an early stage bearing all of this in mind. It is important to me that those with cognitive problems such as dementia, or pre-dementia, are not treated differently from normal society. Courses and programmes should be general, but dementia friendly to encourage inclusion and welcome without stigma.

The value to commissioners will not only be to provide a better experience, but also promote independence which will hopefully result in less or delayed dependence on care in the community.

# 2.4.6. GREATER MANCHESTER

# Memory Service

# Phil Jennings, Senior Specialist Nurse, Later Life South Community Mental Health Team, Greater Manchester Mental Health NHS Foundation Trust.

We receive a referral in the memory service and talk briefly about the patient journey in terms of memory assessment to diagnosis.

#### Pre-assessment conversation, at home:

Our starting point is to go out and see people in their own home, with someone who knows them well. This is important for someone to feel comfortable and relaxed, and to have the sights, sounds and smells that are familiar to them, and for you to be a guest in their home, so they continue to have some control and sense of mastery over what is happening.

Before we start the formal assessment process, it is important to have a pre assessment conversation, this is to talk about what is involved in the assessment so they are prepared, and to remind them why the assessment has come about as it may be some time since they've seen the GP before we get to see them.

Crucially, at this point, very early on in the process, we start to touch upon the possible outcomes of the assessment. This is important to prepare people for the possible outcome of a dementia diagnosis. I think the sooner this is talked about honestly and openly the better the outcome is in the long-term when you go back and talk about a diagnosis.

At this point, crucially, arts for dementia and SP could be a valuable intervention. This conversation about the possibility of a diagnosis may elicit a number of cognitive and emotional responses, and themes from acceptance and hope in terms of understanding what the issues may bring, to the possibility of fear and despair. These are very powerful emotions and thinking about how they could be expressed is certainly something I have reflected on in preparation for this meeting.

#### The assessment focuses on the person's story:

Their life history as the starting point gives us a picture of who they are, what is important to them, where they are from, their key life events, their interests.

For us as clinicians, the clinical history is important to get a picture of the development of the symptoms, how they affected the person and the order in which they appeared. This is the starting point to put together a diagnostic picture.

We carry out cognitive testing as part of the assessment, this means looking at a number of different areas, not just memory, but language, visual spatial function, orientation in time and place, problem solving. This is another key point where certain emotion may be elicited, particularly people that have struggled with the assessment, and that sense of failure when they cannot answer these questions. Frustration, possibly anger too, this may then key

# 2.4.6. GREATER MANCHESTER Phil Jennings, Senior Specialist Nurse

into previous memories from their younger days at school or college, and again the opportunity to express this beyond words may be helpful here. After we have completed the assessment,

# MDT meeting

We present our report in our multi-disciplinary team meeting. We discuss it with consultant psychiatrists, the psychology colleagues and other nurse colleagues, and often at this point we come to a provisional diagnosis, or a final diagnosis - often they may have had a brain scan at this point.

# Diagnosis

I would then share the diagnosis with the person and their family, and again at this point, various emotions, thoughts and feelings are often elicited. After that point, our Admiral nurses and dementia support advisers signpost people into community services and the arts.

#### SP to A.R.T.S. for brain health:

Key points at least where SP to A.R.T.S. could be important are the pre diagnostic talk, the preparation for thinking about a diagnosis, and in the early post diagnostic period, when things are just starting to sink in, and there may be lots of other emotions starting to come to the surface.

# Dr Mehran Javeed, Consultant Old Age Psychiatrist, Clinical Lead for Salford Memory Service, Woodland Hospital.

I have been clinical lead for Salford Memory Service for four years. Ours is predominantly a one stop shop model. Around 80% of our initial assessments are seen by the nurse, and the same day we have a discussion with the consultant, myself or one of my colleagues, and a plan is made in terms of what needs to happen next. We make sure not to overindulge the patient with too much information, but to provide them with the right level of information so that they can make the right choices. It is all about the right diagnosis at the right time. With Covid, face-to-face appointments have been limited, but we made the decision to resume face to face contact with the correct PPE and environmental changes, and this has certainly been positive and well received.

# MCI Pathway

We also have the MCI pathway, whereby once someone has had their diagnosis for a MCI, they are followed by our service for two years. During that period ,we will focus on that personalised care approach, what are the things we can potentially reverse, whether that is around medication or

# 2.4.6 Dr Mehran Javeed, Consultant Old Age Psychiatrist, Salford Memory Service

isolation, even functional mental health problems about low mood, or it may be sensory impairment. There may be other things that we can quickly signpost them to. We also have dementia advisors, as well as carer support, and occupational therapists and a psychologist who work very closely with the community assets offered in Salford so that they can make the right steps and the right conversations. We do know that it is not just the person, but for the family it can be a very difficult time. It is all about quality of life and thinking how do we optimise that? Even when we have functional problems or organic problems, the key conversation is how can we help you age well.

# Pre-diagnostic counselling

We also have a pre-diagnostic counselling element to our service, for if people are hesitant or very unsure of what to expect, and what that means for their journey, because dementia can mean a lot to a lot of people. Again, it is trying to understand their concerns and worries, and the right steps forward. The key message is on person centred care and digitalisation, and the need for this as well, the need around Greater Manchester is very important. There have been numerous times where we haven't been able to do consultations because there is no Wi-Fi available, or no technical material that could support us. So that needs to be supported, but at the same time we also need to understand our ethnically diverse community. Our support needs to be tailored to all the ethnic groups.

For Salford SP, see page 92.

# 2.4.7. WEST MIDLANDS: Birmingham

# Dr Sonia Asraf, Governing Body Member, Birmingham & Solihull CCG, GP Partner Dementia Lead at Hall Green Health Stratford Road

Dementia is one of those conditions associated with a lot of stigma; and as a GP, we are usually the first contact for patient or family when they have memory problems. We often will see a family member with the patient who first comes to the GP. It is quite the spectrum. You may see someone with very early memory impairment, or quite severe end-stage memory impairment.

#### **Initial Assessment**

We use the 6CIT assessment tool to help decide if it is normal, mild or severely impaired and more importantly whether a referral to the memory clinic is needed. Once the patient has had this initial assessment, we will then discuss whether they would like to just be monitored, especially if it is just very mild, they can decide that they don't want to be referred, and they are happy to just see the GP again in six months, or the family decide they do want to be referred to the memory clinic.

After that referral, the other thing families often ask us is, 'What can we do in the interim?' Being seen by the memory clinic can take six to twelve weeks, and now with COVID, we don't know how long the wait is. This interim period, pre-diagnosis, is really important. One thing we do have is our own PCN, groups of practices that have come together, and we have our own SPLW (see page 95), Jenny will discuss this process, but during this interim period, there is a lot you can do to enhance brain skills and brain activity whilst they're waiting to be seen formally by the memory clinic. The final point is that being a GP, with that first contact, it is vital to make it count.

At the moment referral to SP is through GP surgeries. At Hall Green Health, a patient can ring in, explain their symptoms, and our receptionist can bypass the GP for an SP appointment. That has worked well for certain areas, but if it is for a dementia diagnosis, it is important also to see a GP who can exclude other causes of memory impairment and decide with the patient/family if a referral to the memory clinic is warranted.

Dr Nikki Belsham, Clinical Psychologist/Clinical Lead at Birmingham & Solihull Memory Assessment Service. explained at our West Midlands meeting in November 2020 that their waiting list had gone through the roof, that at the moment they don't do SP, but would be really interested in making those more direct links.

# 2.4.8. EAST MIDLANDS: Nottingham

# Dr Jeremy Griffiths GP, Joint Clinical Lead, NHS Nottinghamshire and Nottingham CCG, GP Partner, Partners Health (A4D E. Midlands November 2020)

I've been a GP 25 years and I sit on the Health and Wellbeing Board for Nottingham as well. I have been involved with the SP vanguard project in Rushcliff for two years, and I am now the SP lead for South Nottingham. From a GP perspective, the prevention aspect is important, we know that there are preventable risk factors, healthy heart equals healthy minds, so that is an important role to state. We are often involved to persuade the patient to engage with the services that we wish them to engage with.

I'm excited to learn about the possibility for SPLW at the point of referral to memory assessment - a really interesting point that we could introduce a different pathway for patients. After the diagnosis we are there for support and navigation into services, we also take a role in medication monitoring, we may well have shared care protocols manged with our psychiatric colleagues. GPs also act as clinical leads and commissioners trying to improve the diagnostic rate and making sure we can get timely access and diagnostic support services. GPs are in an optimal position to support patients and families through this journey in terms of assessment, coordination and monitoring.

Six months later, Dr Griffiths, now Vice Chairman of Nottinghamshire County Council wrote to say that the Health and Wellbeing Board had agreed that patients with early cognitive impairment can be referred to SPLW to link with the local arts world; and that as GP Partner, he had advised colleagues to refer patients with early onset cognitive impairment to SPLW, using the SP referral form to indicate need to access resources for brain stimulation using arts and library services, referencing the <u>A4D web directory</u>.

# Emily Kirkham, Clinical Nurse Specialist, Team Leader, Memory Assessment Service, Nottinghamshire Healthcare NHS Foundation Trust.

Referral to Nottinghamshire Healthcare's Memory Assessment Service requires patients to have evidence of sustained cognitive changes over a period of at least six months as well as a recent physical health screening by primary care, to exclude physical or reversible changes for cognitive changes.

All our memory assessment nurses have access to 'Recap' Nottinghamshire Healthcare's online SP service, which allows us to provide relevant information to patients and carers via email.

I've gained valuable insight about what's available for our patients, and I'll certainly disseminate information from today to my team.

See page **97** for Nottingham City GP Alliance and South Nottinghamshire's Community Development Co-Ordinator.

# 2.4.9. EAST OF ENGLAND: Suffolk

# Dr Dean Dorsett GP SP Lead, NHS Ipswich & East Suffolk CCG

Dean Dorsett sits on the Governing Body of NHS Ipswich and East Suffolk CCG. He practices at Burlington Primary Care in Ipswich, the first GP practice to offer SP through the Connect for Health programme. Dr Dorsett supports integrated care, medicine management, mental health and the inequalities workstream and is the RCGP East of England Regional Clinical Lead for Person Centred Care.

I was given the brief to describe the patient journey from presentation to my surgery, right through to diagnosis, 17 weeks:

- 1. Patient and family present to the GP: ten-minute chat (one week = first delay because it is not seen as an emergency appointment)
- 2. Dementia trained health care assistant: 30-45-minute assessment and blood test (two weeks = second delay because these longer appointments don't come up frequently at the surgery).
- 3. GP assessment with results: (two weeks = third delay GDPR/Consent causes issues with delay).
- 4. Referral: (Waiting list six to eight weeks = fourth delay, referral process is quite good usually because of Covid 19. Most of the other patients' appointments have been cancelled or reduced, around a two-month wait).
- 5. Memory Clinic: (two weeks = fifth delay, multi-disciplinary team tests, assessment, reports and letters).
- 6. Diagnosis: (two weeks = sixth delay, GP appointment).
- 7. Planning: (seventh delay = This can be unlimited legal, financial, social, medicinal implications)

What is important to the person is their spouse, friends, children or parents around him. Those people are much more impacted, and families and community account for 80% of an individual's health and wellbeing, which is where the arts come in.

#### Why does it work?

Because every sense we have is connected to a part of the brain, and although we estimate there are only five senses, most officials say there are probably 21 senses, and the arts in all its forms impacts all of them! We probably suggest that the earlier you get a diagnosis the better, but the diagnosis can be a little bit of a red herring because going through all that process and ending up in hospital delays things, so there are lots of guilt and family pressure that come, but referring somebody when they have MCI, when they are just starting to forget things, is the best time to refer. We are very lucky that in Ipswich and East we have had a SP offer for the last three years, so anybody can refer straight in.



# 2.4.9. EAST OF ENGLAND

# Dr Anna Seiffer, Clinical Psychologist, Memory Assessment Service, East Suffolk, Norfolk & Suffolk NHS Foundation Trust.

Speaking after Rachel Nightingale, East Suffolk's Community Connector SPLW (page 99):

Rachel, some of what you were talking about was music to my ears, coproduction, psychological readiness for referrals, especially when we're thinking about referring to SP earlier in the dementia journey. It might be helpful to think about the assessment and diagnostic process from a psychological local perspective. When someone is referred to a memory assessment service, that pre-diagnosis counselling really starts in the first appointment when we're trying to find out how aware someone is of their issues, what they think is causing them, and naming dementia as a possible diagnostic outcome of the assessment. Identifying those people who might be psychological vulnerable for whatever reason and need psychological support throughout the assessment and diagnostic process.

#### Post-diagnostic support

Usually, it is here we think about SP, and for things like arts for dementia, historically it is post diagnosis.

#### Use of language

I think what would help earlier in the process is being mindful of language, if they're not ready to hear about dementia, then maybe make it more inclusive for people with MCI and those who are worried about memory issues and their ageing, and perhaps more of focus on health promotion and wellbeing, and less of a focus on dementia

Teresa Longhurst, Specialist Mental Health Practitioner at Peterborough Memory Clinic, pointed out at this A4D East of England meeting that

'In Peterborough we don't actually have, to my knowledge, any SP, but what we do have is a very active U3A. Most people come through for assessment, you ask them what they do, what their interests are and what they're maintaining, and most of them are involved in the U3A, as I am They've got arts, needle craft, men's sheds, they've got lots of visits to museums, so for over 55s in Peterborough there is more going on than there is for those under 55 if you tap into it! Just to say, I would look forward to seeing more SP in Peterborough, because I think it would be well used. It has been challenging with the video assessments, the waiting lists are horrific, but we are working through it!

When people don't get a diagnosis of dementia and get a diagnosis of MCI I feel would most definitely benefit from contact from a SPLW

I will email Sian [Brand, East of England SP Learning Co-Ordinator] for info in the Peterborough area. I have learnt a lot from today's meeting and I will follow up some of the contacts that I now know from joining.

# Dr Jen Dooley GP, Port Glasgow Medical Centre, NHS Greater Glasgow & Clyde

Port Glasgow, in the West of Scotland, is a particularly deprived area, I've 24 years of experience working here. My job here today is to give you an idea of patient journey, about who we see in general practice and how patients with potential dementia present. Every patient has a different journey, presentation varies across the ages. It can be the patient who presents, family members who phone up with concerns or the pharmacist phoning to say that someone hasn't picked up a prescription and they think they might be becoming unwell.

Some people present with of loss memory of recent events, loss of language skills, loss of orientation skills. There may or may not be insight. There may be a sort of change of behaviour. We have a lot of very late presentations.

Many families tell us that they don't want the family member to have a label of dementia. We get patients presenting in an incredibly undifferentiated format, because there are many presentations who might have these symptoms who might not even go on to have a dementia-type illness.

It is quite interesting when you then talk about engaging people in this type of therapy, because you've got to get acceptance and understanding of what is there to offer. Many say they think their family member has got a dementia, and they would prefer us not to be engaged at all in case it upsets them.

The role of the GP is to listen to what is happening, and to start tests and investigations into what might be the cause. In general, we then might decide to refer to a memory clinic

#### Timeframe to Memory Clinic (seven months wait with COVID19).

There is usually about a three-month wait for the memory clinic, possibly even longer with COVID19. I would imagine many people waiting six to seven months. At that point, it is not until a patient might attend memory clinic, see a consultant psychologist, and the day after possibly get a diagnosis

#### Post diagnosis - arts prescription?

Then the support (SP) starts. People are still frightened of a diagnosis, and whether we need to allow people to use these kinds of things as 'keep your brain healthy' rather than a prescription. Get it away from health and get it as part of our society. We look after our physical health, why don't we look after our brain health, rather than have it linked to a diagnosis. Our patients might not find it very easy to engage in the arts. It is one of the things I don't want a deprived population to yet again miss out on a valuable resource.

#### Community Link Workers (CLW = SPLW)

A little insight into Community Link Workers (CLW = SPLW): A few years ago ,we had lovely Brenda start with us as a CLW, and after a couple of years we've now got half of Brenda. It's just not enough, for the resource of CLWs, we could keep Brenda, we could even keep about four or five Brendas going full time with all the resources we need. That is a big stumbling block in terms of CLWs. (See page 101.)

# 2.4.10. SCOTLAND

# Dr Elizabeth Lightbody, Consultant Old Age Psychiatrist, NHS Greater Glasgow & Clyde.

When a referral is made to our team, we discuss all referrals at weekly allocation meetings, we will discuss urgency of referrals to we can prioritise the workload, and perhaps identify what disciplines it might be important to involve sooner rather than later with individual cases, based on the information we have available to us with the referral.

#### Initial assessment - and SP

Most patients will be allocated to a Community Psychiatric Nurse (CPN) to undertake an initial assessment, that would help us get a better understanding of the persons needs and difficulties at the time. We would look at background information, highlight any particular risk issues, and the CPN may be able to signpost on referral to support services – (including SP) – at that point.

#### Outpatient clinical assessment - 12 weeks

The person would then be offered an Outpatient Clinical Assessment. We work to a guide time of 12 weeks, but it can be a much longer wait in some areas. At the Outpatient Clinic, the person would have an in-depth psychiatric assessment, examination of their mental state, and perhaps consideration of any other physical health issues.

#### Brain scan and further assessment

We would then refer them onto brain scanning, and perhaps other assessments like an occupation therapy assessment, or perhaps more in-depth cognitive assessment by a psychologist. When we have got all of that information, we would bring the person back to the outpatient clinic.

#### Outpatient clinic and post diagnostic support - SP

We would discuss the diagnosis and plan treatment. Not all clients would necessarily require ongoing follow up from the Community Mental Health Team but anyone who is given a diagnosis of dementia is referred for post diagnostic support. In our team that is provided by CLW - that is where at the moment the vast majority of SP referrals from our service would come from.

#### Could SP be offered earlier?

I was asked to consider whether in our service I think referrals could be earlier. Yes, I certainly think they could. The obvious time would be at point of initial assessment, usually by a CPN. For us to make these referrals, first and foremost we need to know what's out there, who it's for, how you can access it, and how we can refer clients to it. With that information I would be confident that we could make SP referrals more frequently, and at an earlier stage.

Craig Ritchie, Chair, asks: 'Do you think SP should fall under the same General Medical Council guidelines as medication prescribing?'

EL: It comes back to that medical model, I'm sure I would not be alone in saying the medics are perhaps the least likely members of the team to be making those referrals, but there is no reason that we shouldn't be doing so.

# 2.4.11. WALES: North-West Flintshire

# Dr Karen Pardy GP, Meddygfa Lansdowne Surgery, Community Director for SW Cardiff Cluster & SP Lead for Cardiff & Vale University Health Board.

Cardiff SW Cluster is a group of ten GP surgeries, but also all the other community and social care organisations within that area. I became the lead about eight or nine years ago, and when I first joined, the GP that I took over from said the best thing about Cardiff SW Cluster is that they have fantastic third sectors organisations working within in that area. So, I decided that would be one of the first things I did as Cluster Lead, link up with third-sector organisations; and I've got to say I was just bowled over by all the wonderful activity. It is great to see we've got Hazel here who will tell you more about what they do. (See page 102).

When patients are coming to us with needs which are not purely medical, we've got all this fantastic resource to build on and link up with within our community. When we are thinking about people with MCI, not yet diagnosed, there are actually a lot of the patients like that whom we do support. Thinking about the work we have done during COVID19, a lot of people are coming to us saying they're isolated and are really struggling. If someone then comes to us, thinking they are worried they might have dementia, then we would organise an initial memory assessment.

# Initial memory assessment and investigations – and SP:

It is important that we're not just focusing on purely medical side of it, but we are looking at how it affects them in their daily lives. We would then organise series of investigations, blood tests for specific underlying causes, and we would probably then refer them onto the memory clinic. Looking at how this is impacting on their lives, this is where we would look at SP in order to support those patients and link them up with the organisations within the community that can help support them with the needs that they have. They can be referred to SP at any point - certainly at the point of referral to the memory clinic.

# Referral to the memory clinic – waiting time 8-12 weeks.

That could be on the first visit. It doesn't need a number of visits to be referred. It may not be at the first visit as people are reluctant to be referred. Relatives may have noticed it before the patients themselves, but in a normal circumstance they would be referred at the point of presentation. Prior to COVID19, referrals were quicker. We have a certain number of memory clinics in primary care (currently closed) with a lot of GPs trained to make that diagnosis.

#### Referral to SP

People can be referred to SP at any point along the journey. They can certainly before referred at the point of referral to memory clinic - hopefully even before.

# Dr Cherry Shute, Locum Consultant Geriatrician, Memory Team, Cardiff and Vale University Health Board.

I am a consultant in both geriatric and internal medicine, but with a specialist interest in cognitive disorders. As a lead for Cardiff and Vale UHB Memory Team, taking over from Professor Tony Bayer, who set up the memory team in 1984 as one of the first MDT for memory across the UK. Our MDT includes medical doctors, clinical nurse specialists, research nurses, clinical psychologists, speech and language therapists, administrative staff and memory SPLW, who are integral to way of working and have close links to community services and Allied Health Professionals. We work alongside GPs with a specialist interest in memory, who run clinics in the community, trying to deliver diagnosis and outcomes as close to home as possible.

# Referral for memory assessment

Waiting time is 12-14 weeks due to COVID19. We receive 100-150 new referrals each month.

# Referral to SP – post diagnosis.

Our focus is as a team to provide support from the point of diagnosis throughout an individual's journey living with dementia, and also to their families and carers. We try to ensure we provide individualised person-centred care, delivering outcomes that really matter to those individuals and their family, ensuring the right person is involved in their care at the right time and at the right place.

The memory SPLW role has proven to be so beneficial in helping to deliver that style of care. It has been really enlightening to see so many creative communities and projects that are already in place and are doing fantastic work, and from our perspective we are very keen to reach out to additional services and to meet the need of patients. I would be very keen to be in contact with all of you so we can link in with our patients as well.

For Hazel Cryer, Health and Wellbeing Co-Ordinator at Action for Caurae & Ely in South-West Cardiff, see page 102.

# 2.4.12. NORTHERN IRELAND: Western

# Dr Laura McDonnell GP Irvinestown, Regional Clinical Lead Western Integrated Care Partnership.

After our own GP investigations, I explain to the patient that referral to the memory service can be a lengthy process, that it involves a series of assessments, MDT meetings, imaging and scans. Sometimes that process can take a year or 18 months before they get the label of dementia. Often, I would say when I am referring them that it's about brain health, that what I have done in the surgery indicates there may be concerns about brain health and that we need to do further tests. In that interim period, I would focus on what we can do in a preventative role, in the same way as any other failure in the body. This is a chronic brain condition, and there are things the patient can do. It is about optimising medically cardiovascular health, blood pressure, cholesterol, addressing lifestyle, smoking, obesity. That is where the role for SP comes in. That is your avenue to get them to engage. You're identifying there are issues and giving them another outlet to improve brain health while you're waiting for assessment.

I am lucky I have a Healthy Living Centre (HLC) on my doorstep here, which pre-COVID19 I would have utilised. For example, there are strength and balance, physical activity and painting programmes - a lot have gone virtual via Zoom. But it is finding out what matter to them, what gives them joy?

Not forgetting the carer perspective, sometimes carer needs that SP to manage the stress and the appointments and the complex journey until they get that label. The other thing that came to mind is that often a common concern in terms of an impending diagnosis of dementia is a worry about loss of capacity. A lot of patients to bring up concerns about the future. It is a very opportune time for advanced care planning. I know in Northern Ireland Arts Care has partnered with the Healthy Living and Dying programme. I think that this is something that should be done early in the diagnostic process, it is important we give them the opportunity, when they have the capacity, the opportunity to have those important discussions about what matters to them in their living, not just end of life.

# Dr Katherine McCracken, GP Registrar, Toome Surgery, Northern Trust; Queen's University Belfast.

I am in my last year of training to become a GP and currently work in Toome Surgery. I am really interested in SP and as part of my training with Queens University, am researching alongside SPRING SP service.

# 14-week wait for memory assessment

The current wait on routine referral to memory assessment is 14 weeks - we are seeing impact of COVID on this as well; and it can be much longer before a person reaches their diagnosis. This is certainly a period of significant waiting, and it can be a time of fear, uncertainty and isolation. Awaiting memory assessment can affect confidence as well.

I quite often see a patient or a family who know that there is a deterioration, but it hasn't shown up in the tests yet. SP is the perfect approach to engage patients either before any decline is noticed as a means of maintaining function, or in those early stages, because it is an opportunity to slow progress. Or if someone is awaiting assessment, it is an opportunity to engage and find support.

Prof Louise Dubras GP. Dean of the School of Medicine, Ulster University.

# 2.4.12. NORTHERN IRELAND: Northern.

# Dr Katherine McCracken, GP registrar

Caring for or living with the individual can be overwhelming. This time before diagnosis can also be difficult in terms of accessing services and support. Many GPs know there are specific services for people affected by dementia, but it can be less clear about what is available at this time when the diagnosis is awaited. For individuals with early-stage symptoms, SP arts activities are a brilliant option. More rarely, patients can present later with more complex needs, perhaps with significant difficulties with communication or perhaps not coping with everyday tasks; at this stage, referral to appropriate community activity is challenging and it may be that these individuals are referred more urgently for assessment. Social work support can be vital during this period.

SP really fits in with the holistic person-centred approach which we aim for in practice, where the mental and social needs are prioritised, not just the physical. With more focus on what matters to them, not just what is the matter with them. In general practice addressing need holistically can be challenging, especially due to limited time with patients and it being difficult to keep up with available services within the community. This initiative by A4D promoting weekly arts activities in this peri-diagnostic period is fantastic, and the directory of activities which was sent through as well will be extremely useful. Overall, this discussion today shows how this period can be reframed as an opportunity, with more emphasis on support. Through arts for brain health, the benefits can be enjoyment and social interaction. Even if the diagnosis doesn't turn out to be dementia, we still know the great benefits of SP for people with a wide range of conditions.

# Dr Frances Duffy, Consultant Lead Clinical Psychologist, Memory Service, Northern Health & Social Care Trust

We have a single referral pathway to the Memory Assessment Service in the Northern Trust, so all the referrals from GPs come into our Community Mental Health Team for Older People. If the referral mentions a change in cognition or problems with memory or behaviour, then that will be referred to the memory service. We do a comprehensive assessment including a collateral history. Depending on the outcome of the assessment, the person will then be seen by either a psychiatrist or a geriatrician. If the person has a complex physical health presentation, tit may be more appropriate to be seen by geriatrician rather than a psychiatrist, that decision is made based on what the person's history is.

# Pre-Covid nine-week target waiting time

The assessment usually takes about an hour and a half appointment, then all the information is discussed with the psychiatrist and geriatrician. The psychiatrist and/or geriatrician reviews all the information including medical history from the GP and the Memory Service Assessment. At that point they may or may not be able to make a diagnosis. There are some people where it is

# 2.4.12. NORTHERN IRELAND: Northern.

# Dr Frances Duffy, Memory Assessment Service

very clear cut that it is a dementia, but others, particularly with early onset or the younger or more complex presentations, may need additional neuropsychological assessment and brain imaging. The length of time of diagnosis really depends on complexity. For some more complex presentations it may take multiple appointments to make that diagnosis.

#### 35% will not have a dementia

What is also important to highlight is that there is a range of different outcomes of an assessment. Around 35% of people who present to the Memory Service do not have dementia. There will be about 65% with a specific type of dementia, another percentage who have a physical or mental health condition which changes their cognitive function but is treatable, and there will be a percentage of people who have a MCI. Some people with a MCI will go onto develop dementia at some point in the future, but some will just retain that MCI and it won't get any worse. Then there will be another subset of people where there is no evidence of any change in cognitive function, or a physical or mental health condition. These are people who are worried about their cognitive function, but there is actually no evidence that there is anything wrong. Those are the potential outcomes of the assessment.

The CLEAR Dementia Care app highlights the importance of activity in dementia. It provides information about dementia, and why a person with dementia may engage in specific behaviours and how best to respond to these behaviours. The app highlights the importance of purposeful, meaningful activity.

# SP – at what stage?

What I am keen to think about as well is at what stage in the whole referral process do the arts or SP come into it? Is it at the point where the GP makes a referral? Is it the point where the person comes into the Community Mental Health Team while they are waiting for the assessment?

What we also need to be very mindful of is that the SP will be very much related to the person's level of ability. When you see the outcomes of the assessment people may be further down their journey than others. There will be people with MCI, or who don't have dementia or MCI. It is important that activities offered meet the needs of that person, taking into account their ability.

We have Memory Link Workers and dementia navigators who could also potentially signpost.

For SPLW, see page 104-5).

# Supporting Well



# 3 Supporting Well - Social Prescription

#### Culture shift

Social prescribing (SP), the enabling, holistic movement that seeks to fulfil people's health and wellbeing needs in a personalised, way, providing non-medical solutions such as A.R.T.S., had a terrific spurt in November 2018, when the then Secretary of State for Health and Social Care, Matt Hancock, announced the introduction of NHS SPLW to become available to every UK GP through their primary care network (PCN). SP had been practised for decades in deprived pockets of the UK to reduce social inclusion and uphold the wider social determinants of health and at the time there were 330 SPLW. Now there are over 1,500 around NHSE (aiming for 4,500 by 2024) and growing too around Britain, Ireland, Portugal Canada, Australia and beyond.

#### What is SP?

SP, a human mechanism linking patients with non-clinical sources of support within the community, enables GPs and other primary care professionals to refer patients to local services including A.R.T.S. to support their wellbeing and empower them to take greater control of their own health.

GPs have just ten minutes per appointment. Where patients' needs extend beyond the biomedical, for psychosocial support, the GP can refer them to their SPLW who has more time to listen to what matters most, their wellbeing needs, interests and empower them to choose and participate in local activities, to nurture their resilience in the community. <sup>46</sup> (See page 86 ff). Of mutual benefit to GP and patient, SP decreases GP workload and enables patients to find solutions to social problems protect against potential health crises and transform the diagnostic experience at impending dementia, from despair, to opportunity and desire, through A.R.T.S. (See page 107 ff).

#### What comprises a social prescribing scheme?

A healthcare professional or allied health professional who makes an initial referral;

'Making sense of Social Prescribing' (Polley et al, 2017, p.14)

# Bridging the gap for dementia

Through the medium of the SPLW, who creates the referral pathway between the GP, patient and local A.R.T.S., people need no longer suffer loneliness, traumatic fears of stigma in the months/years awaiting dementia diagnosis. Now at the onset of symptoms, SP guides them and their companions to A.R.T.S. opportunities to override the strain, to preserve their brain health and stay connected as valued members of the community.

<sup>&</sup>lt;sup>46</sup> Buck D. (2017), 'What is Social Prescribing' 2 Feb 2017, The King's Fund.

# 3.1 Social revolution – health and wellbeing partnerships for A.R.T.S. on prescription

The idea of health and wellbeing being driven by social rather than medical factors sprang from early beginnings in 1984, when the social reforming minister Andrew Mawson set about transforming church buildings to regenerate the deprived multi-ethnic community of Bromley by Bow in the London borough of Tower Hamlets, creating a nursery, dance school, art workshops and café. Involvement with Bromley by Bow must have been exhilarating as Mawson galvanised residents to create their innovative artistic community centre, catapulting them from despair into collaborative endeavour, using superb quality materials in architectural design, hand-carved chairs, mosaics, stained glass, to inspire camaraderie and wellbeing.

With their burgeoning reputation for community regeneration and entrepreneurship, the acquisition - for one pound - of the surrounding derelict three-acre parkland and governmental support from both sides of the political divide, paved the way in 1997 for the Bromley By Bow Centre, its open-plan reception doubling as an art gallery.<sup>47</sup> The model for the UK's Healthy Living Centres, it was formally opened the following year by Tessa Jowell, Minister of State for Public Health, after whom the new Dulwich Healthy Living Centre is named. Aware of Sam Everington's interest in complimentary therapies, Mawson invited him, Julia Davis and Angela Burnett as their GPs, prescribing not just drugs, but 100 activities each week. The entire centre acted as social prescribers, taking patients round to artists and their groups, which continue today, now with trained SPLW guiding patients to A.R.T.S. ideal to preserve brain health. The atmosphere remains strongly artistic, with handmade tables, stained glass, mosaics, sculpture, pottery, art and beautiful gardens.

1997 saw the first evaluation on the impact of an Arts on Prescription programme (Stockport). The increasing body of evidence and role of Arts, Exercise, Learning and Reading Well programmes for the health and wellbeing of the community has flourished over the millennium. Engaging in A.R.T.S. was seen to boost self-esteem, confidence, self-worth and identity – the latter especially vital for people worried about their deteriorating brain – as indeed reducing symptoms of anxiety, depression and feelings of hopelessness and valued as a resource for promoting social inclusion and strengthening communities.

# Visionary GPs

GPs set up partnerships to refer their patients to A.R.T.S. onsite. Dr Simon Opher engaged an artist in residence at his Gloucestershire practice in 2001 to ease patients' anxiety, stress or social need and noting improvements in their mental health and fewer revisits to the surgery, leading to the foundation in 2007 of Artlift (see page 40). Dr Michael Dixon, then chair of the NHS Alliance, engaged an activity facilitator in 2008 as part of a cooperation between his Devon surgery and Natural England, an SP partnership highly rated in 2013, and where patients now enjoy a physic garden and Anton Chekhov garden in which to read, cultivate, relax and create. (see page 86).

<sup>&</sup>lt;sup>47</sup> Green Paper, Our Healthier Nation: A Contract for Health, February 1998.

# 3.1 Supporting Well - Social Prescription

SP highlighted in the White Paper, Our health our care our say, (2006) aimed to

- Provide better prevention services with early interventions.
- Give people more choice and a greater voice.
- Tackle inequalities and improve access to community care services.
- Provide more support for people with long-term conditions.

In 2007, the Department of Health together with ACE published *A prospectus* for arts and health 'to celebrate and promote the benefits of the arts in improving everyone's wellbeing, health and healthcare.

The arts are, and should be clearly recognised as, integral to health and health services, A proposal for arts and health (2007).

# Championing SP & the Social Prescribing Network (SPN)

SP burgeoned throughout the 2010s, with third sector partners setting up A.R.T.S. workshops for people with health needs and a plethora of SP evaluations endorsing SP for A.R.T.S. to alleviate pressure on GPs and address patients' unmet needs. The key to successful SP programmes is the quality of partnership, joint working, research and cooperation between primary care and the SP provider – voluntary and community sector organisations and local authorities.<sup>48</sup>

In 2016, SP became a national movement when Dr Michael Dixon, chair of the College of Medicine, and Dr Marie Polley, then Senior Lecturer in Life Sciences at the University of Westminster, as founders, got together with a group of ten colleagues, They included Professor Chris Drinkwater, chair of Ways to Wellness at Newcastle (see page 24), Dr Sam Everington (see page 39), Dr James Fleming of the Green Dreams Project and other SP pioneers launched the SPN at the House of Commons, in collaboration with the College of Medicine. In January, 96 health professionals, researchers, academics, SP practitioners, representatives from VCSE, local authorities, funders, patients and citizens vowed at the inaugural Social Prescribing Network (SPN) Conference to empower the patient to seek solutions to social problems before a crisis occurs that might affect their physical or mental health, the 'link worker' (health advisor, health trainer, community navigator - SPLW) had come of age.<sup>49</sup> A primary care navigator role had been established in Gateshead to help improve dementia care (post-diagnosis) through SP. Dr Michael Dixon was appointed National Clinical Champion for SP.

While the NHS General Practice Forward View (2016) highlighted SP as a high-impact action, the SPN reviewed 94 SP projects;<sup>50</sup> and Aesop's first National Arts in Health Conference, attended by the Secretary of State for Health, the Chairs of ACE and NHSE, confirmed that the arts deliver cost effective, robust health outcomes.

Awesome, Inspiring,
Brilliant, Game Changing –
We need more of this!'
NHSE National Clinical
Director for Innovation
on 1st National Arts in
Health Conference

NHS should prescribe tango dancing and book clubs, not 'a pill for every ill' Laura Donnelly, Daily Telegraph, 27 December 2017

<sup>&</sup>lt;sup>48</sup> Kimberlee, R.H. (2013).

<sup>&</sup>lt;sup>49</sup> Report of the Annual SPN Conference, 20 January 2016.

<sup>&</sup>lt;sup>50</sup> Polley, M. et al (2017). A review of the evidence assessing impact of SP on healthcare demand and cost implications, (June 2017, University of Westminster).

# 3.1 Supporting Well - Social Prescription

In January 2017, Bogdan Chiva Giurca, an Exeter University medical student, founded the National SP Student Champion Scheme in collaboration between the College of Medicine, the SPN and from 2019 NHSE (see page 233) to inform future doctors in every medical school in the country.

Northern-Ireland-based Elemental Software<sup>51</sup> introduced a measuring tool on its innovative SP digital platform to enable health and social care professionals to track patient referrals to health and wellbeing activities and monitor their uptake and progress. Their award-winning technology enables health teams to evaluate the impact of prescribing non-clinical activity to improve their patients' health and wellbeing. Elemental Software, now widely used around the UK in association with clinical systems, EMIS Web, SystmOne and Vision, enables GPs to make and manage referrals to SPLWs within three clicks. (see Appendix 3 page 219).

Marie Polley explained in 'Making sense of Social Prescribing (2017), the first of a series of valuable SP resources, how SP supports the individual, families, local and national government, and VCSEs to work in collaboration.

Physical and emotional health & wellbeing	Cost effectiveness & sustainability	Builds up local community	Behaviour Change	Capacity to build	Social determinants of ill-health
Improves resilience	Prevention	Increases awareness of what is available	Lifestyle	More volunteering	Better employability
Self-confidence	Reduction in frequent primary care use	Stronger links between VCSE & HCP bodies	Sustained change	Volunteer graduates running schemes	Reduced isolation
Self-esteem	Savings across the care pathway	Community resilience	Ability to self-care	Addressing unmet needs of patients	Social welfare law advice
Improves modifiable lifestyle factors	Reduced prescribing of medicines	Nurture community assets	Autonomy	Enhance social	Reach marginalised groups
Improves mental health			Activation		Increase skills
Improves quality of life			Motivation		
			Learning new skills		

Outcomes described by 2016 SPN Conference stakeholders. 52

SPN steering group member Dr Richard Kimberlee's Bristol SP evaluation recorded a mean return on investment (RoI) of £2.3 for every £1 spent.<sup>53</sup> The Mayor of London's 2018 SP Strategy Conference highlighted the need to ensure financial support for the VCSE, notably, A.R.T.S.

In April 2018, 'Making Risk Reduction a Reality', Dr Charles Alessi, Senior Advisor for Dementia at Public Health England (PHE), proposed working with partners to develop a more positive narrative on 'productive healthy ageing', to engage in social activity and raise awareness of dementia risk factors. PHE planned to work with the VCSE Alliance, bringing together partners, securing funding.

<sup>&</sup>lt;sup>51</sup> Elemental Software. is one of a range of digital SP platforms.

<sup>&</sup>lt;sup>52</sup> Polley et al. (2017), 'Making sense of Social Prescribing' (Aug 2017, University of Westminster).

<sup>&</sup>lt;sup>53</sup> Kimberlee, R.H. (2013).

# 3.1 Supporting Well – SP comes of age

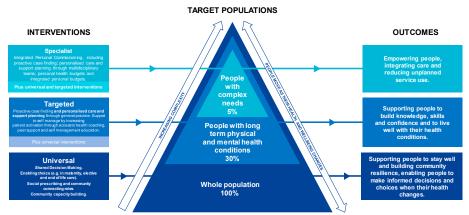
#### SP comes of age

In May, the Royal College of General Practitioners called on government to fund a dedicated SPLW for every GP surgery. June 2018 saw the first International SPN Research Conference held at the University of Salford, with keynote speaker Dr William Bird demonstrating how telomeres through physical activity, reduce stress and reverse ageing. That month, Professor Helen Chatterjee of UCL's systematised review of 86 schemes concluded that SP addresses most of the modifiable risk factors for dementia: increases self-esteem, confidence, sociability, sense of control and empowerment, improves mental and physical wellbeing, mood, motivation and lifestyle; encourages new learning and reduces anxiety, depression, loneliness and feelings of social exclusion and GP visits.<sup>54</sup>

The SPN conference 'Social Prescribing: coming of age' in partnership with the King's Fund, College of Medicine and NHSE, brought the A.R.T.S. together with health and social care as never before, in November 2018. James Sanderson, Director of Personalised Care at NHSE/I spoke of transforming the service, of SP as 'a truly collaborative process' of shared decision-making, an evolutionary approach, of partnerships to link people from primary care into communities, of finding innovative ways to connect patients with their experiences.

#### Comprehensive Personalised Care Model

All age, whole population approach to Personalised Care





There were 330 SPLW in place across the country and there would 1,000 by 2020/21, rising further by 2023/24, as part of the NHS Long Term Plan.<sup>55</sup>

Explaining how SP enables professionals to refer patients to a SPLW to connect them into community-based support, he presented NHSE's Long-Term Plan for a Comprehensive Model for Personalised Care and the model for SPLW. Matt Hancock's speech on the power of the arts

 $<sup>^{54}</sup>$  Chatterjee, H et al (2018), Non-clinical community interventions: a systematised review of social prescribing schemes', Arts & Health (2018), vol 18, 1, 2, 97-103.

<sup>&</sup>lt;sup>55</sup> There are 1,500 SPLW as at May 2021.

# 3.1 Supporting Well – Paradigm shift

'scientifically proven' to improve the nation's health, was the first a Secretary of State for Health had spoken about creativity and culture in relation to health and wellbeing for over a decade. His impassioned commitment hit home. 'The NHS is life-saving, the arts life-enhancing'. Hancock challenged the perception of arts as elitist. 'They are for everyone. The common thread is personal creativity, dusting off old skills, learning new ones', citing as an example, A4D's poetry workshop programme for people with early-stage dementia and carers, at the National Poetry Library at Southbank. Prevention being fundamental to health, he spoke of SP as an 'indispensable tool' for doctors, he planned to create a National Academy for SP (NASP, see page 73) 'The arts and health in action together – life saving, life enhancing.'

In December 2018, the Healthy London Partnership, (HLP) supported by the Mayor of London, issued a comprehensive strategy: 'Social prescribing: our vision for London 2018-2028, aiming for every Londoner to have easy access to SP, with a focus on developing healthy and thriving communities, calling for local innovation and coproduction between commissioners, VCSE and service users. Local authorities and VCSEs across the capital were developing SP opportunities. HLP sought to build on existing assets and strengthen the infrastructure that supports high-quality provision. The strategy set out the core building blocks for partnership development.

#### Paradigm shift

In January 2019 the British Medical Association GPs and NHSE agreed plans to fund SPLW for PCN as part of the English GP contract agreement. The NHS Long Term Plan Personalised Care Policy was issued with a commitment to roll out SP across England, recruitment starting in July. GPs and their ideally surgery-based SPLWs – known variously as social prescribers, navigators, community connectors –would have a central role to play to ensure the success of SP schemes, SPLWs to build up relationships with providers of local A.R.T.S, and a range of services to help patients address the wider determinants of health. Here was a real opportunity to bridge the support gap for people at the onset of dementia.

To enable individuals with early symptoms of a potential dementia to access A.R.T.S. prescriptions, on National SP Day 14 March, A4D launched ArtsPAL, a network of cultural and creative befrienders around the country, co-ordinated by UK region. (see page 180)

A4D held a conference (The Wellcome Collection, May 2019) to open the debate for SP to A.R.T.S. at the onset of dementia (see page **196**) and would address cross-sector concerns arising over the ensuing two years.

In November 2019, Dr Michael Dixon launched a new Institute of Social Prescribing, hosted by the South-West Academic Health Science Network to

- Demonstrate how SP practice in south-west England increases quality of care and helps decrease GP workload
- Innovate, test and spread innovation and keep the communal energy that really changes the face of the health service in the UK.

# 3.1 Supporting Well – National Academy

In July, the SPN's steering committee member Craig Lister, chair of The Conservation Volunteers Green Gym, published a quality assurance guide for SP. At SPN's 2nd International Conference in July, Dr Michael Dixon announced that universal SP available to every doctor and patient in England had been achieved and that SP reduces GP costs by 20%. Professor Dean Ornish, President of the Preventative Medicine Research Institute at the University of California, emphasised the importance of SP to stimulate lifestyle activity to reverse ageing level, modify dementia risk factors, ease loneliness that more than trebles the risk of depression. Kate Milligan, Director of Policy and Communications at the Alliance for Healthier Communities in Canada quoted a GP referral 'Take in two museums and call me in the morning.' Alyson McGregor, National Director of Altogether Better, called for communities to work alongside GPs, collaborative practice being essential for the future – SP to transform lives, improve morale.

#### National Academy for Social Prescribing

The National Academy for Social Prescribing (NASP) was launched London's Southbank Centre in October 2019 in partnership across government, with ACE, Sport England, and other VCSEs, so as. to standardize the quality and range of SP, build an evidence base, develop and share best practice, nurture partnerships. James Sanderson, its CEO, spoke of the power SP brings, linking people to A.R.T.S. Their first partnership event, chaired by Professor Helen Stokes Lampard, chair of the Royal College of GPs and now of NASP was endorsed by Matt Hancock, who swept in from a COBRA meeting at the onset of the pandemic, promising funding, calling for behaviour change, and NASP to coordinate academic research. Time needs to be invested to build up the partnerships, coordinate and collaborate SP schemes. The chief challenge was funding - while NHSE was funding SPLWs, they were not offering to fund the A.R.T.S. prescription programmes for which the NHS was already experiencing financial savings.<sup>56</sup>

To address this, on 10 November NASP launched their, in my view, brilliant Thriving Communities Fund, (see page 184). Being place-based, the A.R.T.S. provider is the catalyst around which the prescription funding is centred. The Fund itself guides the A.R.T.S. provider to bring in partners for natural and inclusive local referral to SP programmes. Arts and health collaboration ensures that modifiable risk factors for dementia are catered for, diverse ethnicities and faiths welcomed. Local authorities, who are proud of such services and whose directories spread awareness to potential participants, encourage working in partnership with referrers, local PCNs, their GPs and SPLW. This in turn triggers financial support from NHS Charities Together and other NASP partners<sup>57</sup> So constructive is the partnership structure that

The Conservation Volunteers Aug 2020, 'Enabling the potential of Social Prescribing'; National Voices, Sep 2020'Rolling out Social Prescribing'.
 ACE administer the fund on behalf of NASP, Natural England and Historic England, with support from NHSE/I, Sport England, the Office for Civil Society, the Money & Pensions Service and NHS Charities Together.

#### Illness Wellness

If you don't hear what I'm thinking, how can you know what I want?
Ronald Amanze

Take in two museums and call me in the morning,
Kate Mulligan, 'Social
Prescribing in Ontario,
Canada.

Inspire, Empower Enable! (NASP)

It's about all of us in health, arts, culture, sport, communities coming together around one simple principle - that prevention is better than cure. Rt. Hon. Matt Hancock, NASP (2019).

# 3.1 Supporting Well – SP advances

If SP can increase nature's capital . . . social capital and social connectedness, then I believe it will make a major contribution to some of the most important issues of our time.

HRH The Prince of Wales, International SP Conference 2021

'You have got to make social interventions the first offer to the public, not an afterthought. You need a structure for SP. You need to fund it and create sustainable voluntary organisations as equal trusted partners.' Rt Hon Andy Burnham, International SP Conference 2021.

consortia who failed to achieve funding in the first distribution found it useful to collaborate nevertheless, strengthening their arts and health partnerships, widening creative opportunities, networks. NASP provides regional and national training, an Ideas Hub to share best practice and an Academic Partners Collaborative to produce evidence and identify research needs.

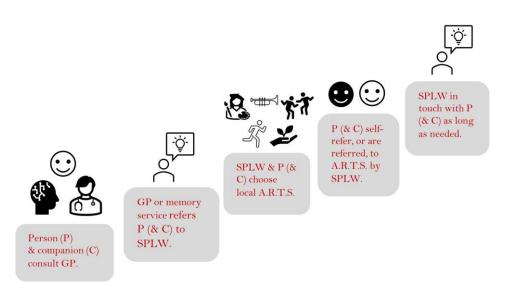
The March 2021 International SPN conference, established that there was now a SPLW in every group of GP practices, as well as in the VCSE sector and local authorities. HRH The Prince of Wales filmed impassioned support for SP 'I always find it immensely encouraging to hear of the transformation that SP can bring to people's lives ... I have seen first-hand the importance of people being connected to nature, and all the benefits this brings to body mind and soul.'

James Sanderson announced that NASP's Global SP Alliance was now working with the World Health Organisation (WHO) to spread SP. Andy Burnham, Mayor of Greater Manchester encouraging SP to physical activity and green prescribing to lift people's mood, spoke of SP referrals rising, but called for funded SP to be integrated into the infrastructure rooted in VCSEs, for the funding of [A.R.T.S.] prescription programmes to move away from project or even annual funding, towards core funding – to take the place-based perspective. 'We have got to move this system now decisively in a 21st Century direction. Prioritise mental health much than we ever have before, and prioritise social interventions, because they in the end build health and prevent the need for costly spending on ill health.'

The cross-departmental extent of SP was revealed by James Sanderson who pointed out that the Departments of Digital, Culture Media and Sport, the Environment, Food and Rural Affairs as well as Health and Social Care are collaborating on SP, which the Government's 25-year environmental plan as a component to support climate change. NASP was now developing a Global SP Alliance, working with the World Health Innovation Summit, WHO and the UN Global Sustainability Index Institute, to innovate through SP. Led by ACE, SP to A.R.T.S., widely discussed, is flourishing nationally and internationally, encouraged by the SPN and WHO's Healthy Ageing Unit's highlighting the role of primary care in preventive, integrated service throughout life and the important role communities play. For all parties nationally and internationally, it was clear that SP reduces costs, increases capacity and improves outcomes.

Funding remained a challenge, but in our view, increased Thriving Communities funding would resolve this, as was demonstrated at the A4D Conf21 in May, when leaders in dementia prevention, the SP movement, culture health and wellbeing, GP and memory service practice and A.R.T.S. participants shared evidence and experience and debated the value of engaging in A.R.T.S. at the onset of symptoms.

# 3.2 Supporting Well – SP models



The Patient Journey, SP from GP to A.R.T.S. (A4D 2021)

SPLW, along with GPs, have a central role to play to ensure the success of SP schemes and help patients address health and wellbeing needs. Having built up relationships with local A.R.T.S. and other providers, SPLW's primary role is to help GPs, their patients and family carers to navigate the VCSE environment through signposting and enable them to access services of interest.<sup>58</sup> For arts organisations, raising awareness of their offer to participants whose wellbeing is positively transformed through engaging A.R.T.S. for health programmes, has long been a challenge. Natural referral through SPLW will enable more to benefit at this vulnerable time.

Anyone can self-refer for an appointment with an SPLW for themselves, their partner, friend or client, for guidance — whatever their non-medical need, lifelong. However, the aim of this report is for GP referral for people at the onset of a potential dementia, to relieve the strain for them and their family partner during the isolating fear-filled wait for and trials of memory assessment and diagnosis — to empower them to take up A.R.T.S. to preserve brain health and involvement in the community.

#### 3.2 GP contract reform

British Medical Association GPs (England) and NHSE agreed plans in January 2019 to fund SPLW for every PCN as part of the GP contract agreement. Under the NHS Long Term Plan's five-year framework or GP contract reform –the Comprehensive Model of Personalised Care – an SPLW was to be provided for every network of over 30,000 patients during the introductory year 1 July 2019 – 31 March 2020, two SPLW for over 100,000.<sup>59</sup> We shall discuss the various models for SP, for arts prescription programmes below, but the model most accessible to people at the onset of a potential dementia is that provided by the surgery-based SPLW.

<sup>&</sup>lt;sup>58</sup> British Medical Association, 2019, Social Prescribing: Making it work for GPs and patients.

<sup>&</sup>lt;sup>59</sup> NHS England, Investment and evolution: A five-year framework for GP contract reform to implement *The NHS Long Term Plan*, 31 January 2019, pp 32, 35 & 45.

# 3.2 Supporting Well – The GP as referrer

#### The GP as referrer

Quite simply, at the onset of symptoms or a potential dementia, whether or not the eventual diagnosis is actually a dementia, the GP can, with the patient's consent, refer the patient to their SPLW, who having discovered their interest, strengths, passions in life, can refer explore local A.R.T.S. options to preserve their brain health. The A4D web directory also signposts opportunities at heritage and arts venues, historic and natural environment, healthy living centres, community arts hubs, by postcode, artform, brain health or dementia need (see page 253) – and the individual and their partner or companion choose their favoured activities.

The GP – or their practice staff – can refer their patient at any time. If they do so at the onset of symptoms or at the point of referral to memory assessment, the individual can preserve connectivity, sense of identity, of belonging in the community and protect against the otherwise lonely, fear-filled months worrying about the diagnosis, trauma of stigma etc. If they are engaged in weekly cultural or creative activity during the period of assessment and diagnosis, that sense of purpose, despite dementia, will help preserve their brain health and wellbeing.

#### Referral process

The GP, having sought the patient's interest and consent in the surgery, and entered the referral into the patient's data on the practice medical information system (EMIS Web, Systm1) into which Elemental SP software connects and refers the patient to an appointment with their often surgery-based SPLW. Through this system, both the GP and SPLW keep track of the patient's SP activity. GP referral to the SPLW can also be by letter or telephone. Individuals can self-refer, or their family partner or friend can do so.

#### Memory service referral and DCAN Next Steps:

Memory services, in their first contact letter, inspired by the Dementia Change Action Network (DCAN) Next Steps guidance, are directing patients to take up activities while awaiting their memory assessment appointment.

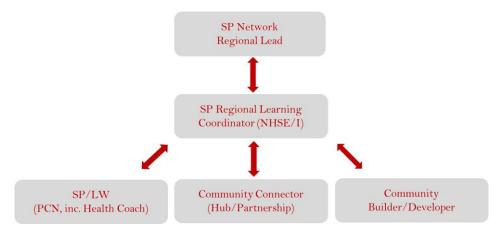
#### Healthy Living Centres (HLC):

GPs based in integrated community and primary care HLF, such as at Culm Valley Integrated Care Centre in Devon, the Bromley-by-Bow Centre in East London, or the Robin Lane Health and Wellbeing Centre in Leeds and many others, can refer patients to their SPLW and with ease choose regular uplifting activities.

#### A.R.T.S. on Prescription consortia programmes:

These carefully planned place-based programmes involving arts organisations, primary care referrers, ethnic groups and local authorities, now supported or guided by NASP's Thriving Communities initiative, work well together, raise the awareness and have the enthusiastic innovative edge to sustain and encourage interest ongoing.

#### 3.3.1 SPN NHSE Regional Leads



SPN has leads operating in every NHSE region - health professionals, researchers, academics, SP practitioners - who chair regional steering groups with access to a range of skills to provide cross-sector support at a local level. Each builds up links with A.R.T.S. organisations, to spread awareness to PCNs of the health and wellbeing benefits of their offer, to embed SP practice.

**Jo Robins,** SPN Midlands lead explained at A4D's West Midlands SP Zoom in November 2020:

We need assets in the community that are easy for people to access, with staff who have got good engagement and connection. We know that the arts and culture community have that and we need to embed this in the PCNs and showcase local work.; and when people challenge me and say we haven't got the evidence base, I say, 'Here is the opportunity to build it!' This is about creating a stronger evidence base to demonstrate impact. 'Regional SPNs run conferences and promote A.R.T.S. offers through their Learning Coordinators.

Sian Brand, co-chair of the East of England SPN said (A4D SP Dec 2020):

It is important that the strategic space has places for key people to expand their knowledge of SP, to share good practice, for us to feed to SPN teams across the country. Equally, we can share stories from other regions for our learning.

I became a Dementia Friend Champion to understand how best to support a person living with dementia diagnosis. We need to work centrally to make sure understanding on the regional SPN of the needs of people awaiting diagnosis and that SPLW appreciate the arts as a valid tool to offer patients; and to understand what local A.R.T.S. are available. Organisations such as Health Education England are looking at the training needs analysis for SPLW that I'm supporting on. if there is a need for us to do any specific training that enhances that understanding, then I would be very willing to work with the ICS and the region to make sure that happens. We encourage in SP to look at asset-based community development approach and make sure all parties know about each other's opportunities.

# 3.3.1 SPN NHSE Regional Leads

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# **Jo Ward,** Chair, North-west SPN (A4D Greater Manchester SP Sep 2020):

From an NHS England perspective, we can see where SP can contribute in those frightening stages pre diagnosis, but also through the life course for individuals living with dementia and the impact on their care partners. It is also about a conversation with clinicians, because not all get the agenda of understanding how people live their lives. In terms of SP, there is something of an offer around prevention and protection of people living with dementia, that support is essential to slow decline, which the biomedical sciences alone can't bring to the table. SP is about harnessing an array of non-clinical interventions and understanding how we can harness these additional tools to do good. From an NHS England perspective it is about the growing army of SPLW, who can be allies in this journey to support people the onset of dementia. It is also around the Long-Term Plan (see page 71) and personalised care agenda, which is a huge lever to argue the case for personalised care journeys.

This new relationship with patients and our communities focusses on a wellness, not an illness agenda. Alongside that, SP is predicated on working with others, on collaboration and understanding that when we work with people, we understand the context in which they live their lives, and what matters to them – that is the nub of SP. It is not about their diagnosis. It is also about challenging the current paradigm of Western medicine, which is highly focused on the biomedical model and negativity surrounding dementia.

The wellness agenda enables creating an optimistic narrative about how you can live well with dementia, the breakthrough in communication which the arts provides when other mechanisms do not. From doing joint work with colleagues in Warrington, it has been interesting how SP offers the opportunity to reduce and ameliorate the risk for dementia, including carers whose likelihood of developing dementia is increased due to the stress and strain of the care responsibilities. SP provides more bang for your buck, because it actually provides support mechanisms for both individuals who are living with dementia, and carers - this helps supports the system.

Those issues are important in terms of SP. We need to work together to influence our SPLW, to understand about the opportunities out there, but also, we need a call out to NASP's regional coordinators, to support the voluntary sector to develop more wellbeing journeys, to make this positivity happen.

# 3.3.1 Northern Ireland: Tony Doherty, Co-Chair, All Ireland SPN (A4D March 2021).

My role is the Co-Chair of the All-Ireland SPN. My day job is in the community sector, I am the Regional Coordinator for the Healthy Living Centres in the North of Ireland. We are a network of locally based bottom-up health improvement projects. My role is mostly as an influencer, not necessarily a decision maker, although I'm not divorced from decisions either. The remit of the network is to champion SP so it is valued, understood and fully sustained across Ireland. The potential for creative linkage between arts and SP is huge at this moment in time.

As a network, our principles have become clear. We are member driven; the membership is fairly widespread. We are collaborative network across sectors, which I think is vital in terms of the various sectors in touch and the creative conversations with one another. We are an all-Ireland to approach to lifelong learning. We are focused on inequality and the wider social determinants of health. We are open to new ideas, models, and approaches. Peri-diagnostic in terms of dementia would be one of them. I would imagine that will come up in the near future.

In terms of the steering group of the network itself, it's quite well contributed to on an all-Ireland basis. There are hospitals involved, collages involved, the Health Service Executive in the South is involved. We were set up in 2018, we are currently setting the focus on longer term foundations for the network. As I said the membership is quite widespread, there is over 100 organisations currently involved. Many of them resonate with arts and culture in terms of their everyday work and make creative linkages between SP to tackle loneliness and social isolation. SP could well be described as in its infancy in Ireland, but we are keen to innovate the community sector, public sector and the academic sector in peri diagnostic dementia and the arts linkages.

Personally, I am very much involved in SPRING SP and in a peer support framework in the North of Ireland. It has been a great pleasure to recently be involved in the Old Library Trust's Carers Collective, which you may hear from later on as well. I'm just delighted to be here, and I'm all ears and all eyes

# 3.3.2 NHSE Regional Learning Co-Ordinators

### Support for SPLW across each NHSE Region

Learning Coordinators are responsible to and work closely with SPN Leads in every NHSE region, engaging regularly with and providing support for SPLW across each extensive area. Super mindful that NHSE investment must make SP work, relieve the GP workload and connect SPLW with local community A.R.T.S. and other groups to address the wider determinants of health, the connectors and ensure they have the communication skillsets necessary to provide support:

They provide training and facilitate peer support for SPLW in their region on a monthly or fortnightly basis, upskill them through workshops, special interest webinars – for example, on asset-based approaches and hold annual conferences. Coordinators explore knotty issues, share positive stories, try to help SPLW as much as possible and ensure they are kept up to date with of community opportunities for their patients and to find out what else could be provided. (See **Community Developers** on page 80). They then feedback to the central team for infrastructure support. While SPLW are part of the PCN team, they also seek to be part of a wider network, to act as a link between A.R..T.S. organisations and their PCN, with digital support to connect them. (See page 181).

# A.R.T.S. organisations invited to join their networks

Learning Coordinators welcome A.R.T.S. organisations to contact them as a conduit to SPLW, to attend peer support sessions, join their networks and signpost their events and contact details electronically for SPLW keen to locate programmes of interest to their patients. With regard to learning about people awaiting memory assessment, Sue Bloomer, the West Midlands Regional Learning Coordinator, pointed out that she will now be working closely with dementia SPLW to share knowledge, particularly about A4D, because they will be dealing with people with MCI. '

# 3.3.2 Community Builders / Developers

Community Builders, also known as Community Development Workers, and who may themselves be SPLW, or specifically employed by NHSE or VCSE agencies, work as a conduit between SPLW, the community and the A.R.T.S. organisation to provide for unmet needs. Community Builders work with local organisations, local councillors and volunteers to map community opportunities – asset map – provide resources to fund new activities or resources for groups, enabling them to build resilience and sustainability and to establish A.R.T.S. opportunities for SPLW to engage and reconnect patients with community, culture and creativity. If SPLW finds that what the person really wants to do is unavailable in the area, Community Builders work to turn their aspirations into action.

'It is really important that we support people, pre-onset of dementia and their partners, particularly to art' Maria Willis, Learning Coordinator (A4D East Midlands Zoom, 26 November 2020).

This is exactly the cohort of people we're trying to reach at this time.' Sue Bloomer, Learning Coordinator (A4D West Midlands Zoom, 4 November 2020) SPLW – known variously as social prescribers, link workers, community connectors, community navigators, social navigators, care navigators, health advisors – are funded by NHSE through PCNs. They are not clinically trained, but work holistically alongside GPs, embedded in their practices and/or are electronically accessible subcontracted agencies or VCSE organisations.

Their role, as outlined on page 67, is to understand what matters to the patient and to link them to appropriate support to rebuild their resilience in the community. VCSE-based Community Connectors may provide a straightforward signposting service, whereas SPLWs give considerable time with patients to help understand their needs and co-produce a plan to connect them to A.R.T.S. and other services. SPLW describe themselves as the glue bringing medical services and the community together. Like Community Builders, SPLW may also seek to set up a support group around a new A.R.T.S. project and achieve a grant to support this.

SPLW coming from various working backgrounds, value being able to call on the expertise of other SPLW – for example, with regard to brain health - in their regional network to resolve specific issues.

### SPLW Asset-mapping

To provide informed choices open to patients, SPLW keep up to date with A.R.T.S. and other services through their Learning Coordinators and regional culture, health and wellbeing leads (see page 77). They use social media, subscribe to local A.R.T.S., ethnic or religious group mailing lists, and search the A4D SP web directory and Google Maps to connect A.R.T.S. hubs and community centres on bus routes local to patients.

# 3.4 SP Referral process: From GP to SPLW

In the surgery, the GP explains to the patient, who may be accompanied by a companion,\* both having concerns about symptoms of a potential dementia, how taking up A.R.T.S. can preserve their brain health and if they like an appointment with the SPLW to discuss local A.R.T.S. opportunities. With their consent, the GP will refer them either by phone, electronic referral form or letter, or invite them to make an appointment to self-refer. The GP's SP referral form or electronic platform allows them to indicate the reason for referral, which may be added freehand, indicated by category - since our Greater Manchester SP meeting, Dr Jonathan Kaye has added 'cognitive stimulation' as a category.

\*The companion may be a family partner and in due course take on the role of carer, or a friend. Here 'P&C' refers to person/patient and companion/carer.

Referrals may come from anyone in the practice or from administrative staff contacted by the family, a district nurse or other external organisation, community hub or local council.

GPs can make and track electronic SP referrals through the software that links to their clinical system and also enables SPLW to see services their patients are receiving and to document the support they themselves are giving to patients and update GPs about outcomes. (See page 219).

# 3.4.1 Referral process: SPLW - Triage, allocation, health coaches and first contact

Usually within a few days or a week, SPLW will give P&C a welcome call, have a preliminary chat, check how urgent their need is, and arrange their first appointment, either at home, in the surgery, in the open air, or virtual and whether future appointments will be the person alone or P&C. For brain health or dementia, the SPLW lead may allocate a specialist health coach as SPLW.

#### 3.4.2 Time to listen

SPLW visit P&C at home if possible - (otherwise remotely or outside in fine weather) - in a relaxed, unrushed manner, giving time to listen to their concerns and understand what matters most to them.

In strength-based conversations, they discuss lifelong hobbies, career, nationality, religious and cultural background, strengths, weaknesses, activities they enjoy or used to enjoy, their aspirations and what would motivate, inspire and empower them if they had the chance. Looking together at what the person can do for themselves gives a sense of ownership that can increase personal motivation, affirm their strength and resilience. Other aspects, financial, housing, legal etc. are also discussed.

# 3.4.3 Opening the door to A.R.T.S. opportunity

SPLW prioritises immediate concerns and together, with consent, they explore local A.R.T.S. possibilities that appeal to them most, are easily accessible for P&C and excite their interest and co-produce a plan. They discuss steps they may need to rebuild confidence to leave the house and attend



Swirling mosaic greets patients at entrance to Bromley by Bow Health Centre.

# 3.4.4 SPLW Referral process

a group. Do they need help to get there? If desired, SPLW can accompany or introduce individuals to their chosen activity. (For Cultural and Creative Befrienders, see ArtsPAL page 180)

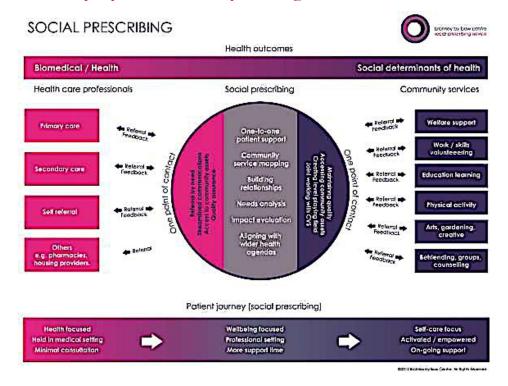
#### 3.4.4 Time frame

Generally, SPLW will work with P&C for as long and as often as needed, starting with weekly or fortnightly appointments or calls, checking whether the A.R.T.S. programme, for example, is going well or whether to choose another. After the initial introduction to activities, this may be enough, or P&C may value phone calls.

There are no limits to the number of times a beneficiary is seen on a SP project. Time parameters may be set but the number of sessions offered can be more or less depending on need. After a period, the SPLW may close their case and inform the GP.

#### 3.5 SPLW Case studies.

# Bromley by Bow Healthy Living Centre



Bromley by Bow: Annual Report April 2015 - March 2016

GPs in each of Bromley by Bow's three Health Centres and the Healthy Living Centre itself, may refer patients to their SPLW at any time during their consultations for referral to A.R.T.S. Their SPLW, trained and acquainted with the 100 or so A.R.T.S. opportunities that address the social determinants of health and already aware of the individual's concerns, will explore their desires and interests, encourage them to choose from the range on offer – and if not yet, assume it is possible to set up a new venture.

#### Khadeja Chowdhury explains:

When the referrals come through, we have one-to-one consultation with each individual client, figuring out what their needs are, how we can best support them to access all the services we have at the centre, including all the Space to Connect projects (see page 142). We see some clients who are at the early onset of dementia, and we work with them and their support workers and their family, to make sure that they get the best service from us. Making a plan, setting some goals for them, meeting once a week attending a session online, as much as they can.

On a regular basis we do wellbeing check in with our clients who are accessing things online. Also on site, we have talks about how we are feeling, how are moods are that week. We use the 'Mood tree' and it just opens up discussions for everyone to try and find out where they are this week on this mood tree and have a conversation with the rest of the group if they wish to. '.

# 3.5 Case studies from A4D regional SP meetings 2020

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A key feature of the 15 regional cross sector meetings that A4D held for every NHSE region and one each for Scotland, Wales and Northern Ireland (see page 207) was the patient journey for which GPs, memory service description of the tests and time frame to memory assessment and diagnosis, was followed by SPLW, both surgery-based and agencies and community developers outlined their approach:



Entrance to Culm Valley Integrated Care Centre



Anton Chekhov Garden at the Community Life Hub.



Culm Valley Physic Garden's humanshaped parterre surrounding medicinal plants, at College Surgery.

#### 3.5.1 **DEVON**

Ruth Tucker, SPLW and Community Builder at College Surgery, Culm Valley Integrated Care Centre, Cullompton (A4D July 2020)

I started as a SPLW ten years ago. My position was always about being in a non-medical role and supporting people in different ways. Initially it started with just activities, then progressed to a full-time roll.

#### Community Building

I am also a Community Builder, where I look at what is there in the community, if there are any unmet needs, and if so, is find a way to put something in there. A few years ago, one of the unmet needs was memory cafes, so I linked with local volunteers and to help set these up.

#### Memory issues and CST training

Over time, we got more referrals direct from GPs with people who were having memory problems, who wanted to see if there anything we could do for them. I was then also approached by a local charity looking to hold training in Cognitive Stimulation Therapy. They wanted to find a venue to trial a 14-week course. They approached me and I put the two together, spoke to all the partners and we made it work.

### Community Life Hub

We are fortunate, at the Culm Valley Integrated Centre for Health, that we have a large area which we could use for groups — we now call that our Community Life Hub (Listening, Inclusion, Friendship, Education). The idea was to make this very much about the community and groups that were not available anywhere else. We set up this up initially for twelve people, but slowly we were getting more, but we were also conscious that at the end of 14 weeks we may not have another group.

For me, sustainability is hugely important; a lot of things may work well, but then they disappear and that doesn't help the group of people who attend. I approached a couple of volunteers, they then actually trained to be able to continue that group. However, with COVID19 it has been interesting, as I have spoken to carers who are really struggling when people are shielding, so I am forever grateful for our volunteers who have taken on this group to help these people. They now have a weekly phone call at the same time as they would normally have the group, but now recently they have started doing activity packs, maybe colouring or something which they could interact with on their next meeting. That has made a lot of difference, some of these people are feeding back and saying that they we would not be doing anything without this interaction, they still see themselves as in the group, so it is important to see those things.

#### 3.5.1a DEVON

# Ella Sadler, Wellbeing Exeter Coordinator, CoLab Exeter (A4D July 2020)

We have 16 Community Connectors (CC) or SPLW and offer SP alongside asset-based community development. We work with 17 GP practices in Exeter and we are still expanding. Right from the start we were able to work with Community Builders, which largely works with what is already in the community. Our 13 Community Builders cover a neighbourhood ward, and they are there to support the residents and turn their ideas into action. If there is a gap, we will link them to local organisations or local councillors who could perhaps help fund a group, so they are really there to listen to the residents.

#### Referral in

Our pathway is quite standard for SP. It goes through from a single point of referral and we do a welcome call so that the person knows that the referral was made and to check is there was any immediate or urgent needs. The person will then be linked to one of our organisations in a specialist field.

#### Time to listen

The initial step is really about the active listening. Our CC have to give that time, to explore possibilities, see what motivates the person and think what they would like to see their life to look like. We use the Devon Partnership Trust's Five Ways to Wellbeing model. We're very much hands on and face to face.

#### Connecting to A.R.T.S.

Our CC can accompany them to the group, make sure they feel comfortable, and might even travel with them, anything to break down those barriers which are stopping them from connecting to their local community. Whenever we refer someone to a group or organisation, we log what theme is comes under – such as social activities (20%), advice services (12%) and physical activity (11%). These are all crucial to increased connectivity to local community.

#### Time frame

We generally work with people for eight weeks, but we have no time limit, a CC may see someone quite a lot in that time, or it may just be a few phone calls. We then do a 'Close Case' to the GP so they are aware of what happened.

#### Dementia

With dementia we will also work closely with the carer and the next of kin. Our approach is personalised, to the individual's priorities. We then connect them with a local group, service or organisation. We have had around 81 referrals – with 2.8% dementia is involved, whether it is the individual with dementia, or someone who cares for them.

We are grateful to Gail Mistin, Wellbeing Exeter's Coordinator, who updated the figures and explained at our conference that four Community Physical Activity Organisers act as a point of contact for individuals after they have finished working with the CC; and can continue to accompany people experiencing early signs of dementia on walks and introduce them into more local activities.

# 3.5.2 NORTH-EAST: TYNE & WEAR Paul Ellison, Lead SPLW, Savile Medical Group, Newcastle (A4D September 2020).

#### Referral in

I am one of four SPLW receiving referrals can be from anyone in the practice, mostly likely a GP or nurse, but admin staff might ask us to have a chat with a patient or their family, or from a district nurse or other external organisation.

#### Time to listen

We have that precious opportunity of time to sit, talk and listen to the individual and their family in a relaxed way, where they're not feeling uncomfortable or rushed; and we can elicit what the issues are, have ideas of what might be going on, of where it will be useful to refer them to.

#### Prioritising the patient's needs

It is really important to have time with the person, and with their consent, their family, to get a full picture of their wants and needs. We look at priority concerns - safety, food, finance - and holistically what is important to them. With their involvement, mindful that as navigators we're not taking their independence away, we're working with them, and with their families.

#### Their aspirations, culture and nationality

We look at their aspirations, likes and dislikes. Everyone is in an individual, with different ideas, backgrounds, cultures and nationalities. We bear in mind what's important to them, and together incorporate it all into our plan.

#### Working alongside healthcare colleagues

We work alongside our health care colleagues and communicate with each other where we think that there might be an issue. Being embedded within a practice is a really useful resource, because we can talk to each other.

#### SPLW – different working backgrounds, expertise.

Having a big SPLW network is really useful. We come from various working backgrounds and have different areas of expertise, so to be able to tie into SPLW across the network and across the region is a really useful resource. We can then email 'How do we address this issue?' As we work independently a lot of the time, it is fantastic to know that we've got that resource and we've got those systems in place, where we can actually call on each other to assist.

#### Ongoing support.

We work with our patients for as long as necessary. There is no time limit. It may take take just one or two calls, or we may be working for over a year, or call them every couple of weeks. What we tend to find is that things may go quiet for a time, and then there will be a crisis, or something happens and we have to re-engage with them more frequently. We're there to be supportive, and a lot of the time when we are supporting them, their knowing that we're available actually helps them alleviate a lot of the problem.

# 3.5.2a Jackie Jamieson, North-East Regional Learning Coordinator and Community Linking Project Development Manager, Edberts House, Gateshead (A4D September 2020).

In addition to my role as North-East Regional Learning Coordinator, I manage a team of 21 Community Link Workers (SPLW) working in GP surgeries across Gateshead. At Edberts House we employ our SPLW who are seconded into surgeries to become part of the practice team, picking up referrals made by the GP, a nurse, or any member of the practice team.

We worked closely with PCNs as they developed in 2019, building on our existing SP model. This put us in a really good position to understand issues at an operational level, and some of the challenges of integrating SPLW into a health environment to allow us to support other SPLW on a regional basis. We are building up knowledge and understanding of how SP schemes work on the ground, but also identifying some of the issues moving forward.

There is a huge expectation on SPLW. We are not experts in everything. The clue is in the title, we link people to the appropriate support for whatever issues they are experiencing. We try to embed a very community- and personalised service into quite a robust health environment, which is great, but has its challenges. It can be a clash of cultures in terms of how our provision works: Clinical environments are very structured and time limited, whereas a SPLW – and this is the strength of SP - has the time to spend with somebody. The key is building that relationship and trust with a patient, to fully understand what issues they are experiencing, which can often include early onset dementia or the pre-diagnosis of various conditions.

The added value of that is that under normal circumstances we do home visits and we see patients in community settings to take them away from that clinical environment. That really opens up somebody to be able to share and understand how their life is, how they're coping or not coping, and you understand the impact of something like dementia on the whole family in that sense as well. You are not just supporting that person; you understand some of the challenges that the whole family are facing. Then we can identify the local support services available, and we will accompany patients to their appointments for those who are anxious or concerned about things, and we can advocate on their behalf too.

This is our model, and we try and roll out and share our learning at a regional level, but also the breadth and depth of other schemes so that we can continuously develop and learn from each other, so that SP becomes much more embedded in communities.

To date we have been very reactive in terms of referrals we receive, but as PCNs develop more, and the expectation in addressing wider population health management, I would like see more resources and SPLW becoming more proactive, so that the prevention agenda becomes more significant, and we can link people to support at an earlier stage – to collectively better address the health inequalities our communities are facing.

# 3.5.3 GREATER MANCHESTER: Heather Etheridge, Director, Be Well SP, The Big Life Group, (A4D September 2020)

#### Dementia - You don't need a diagnosis

Be Well is the SP service for Manchester. We are passionate about helping anyone who has got anything going on in their lives, including those prediagnosis, during diagnosis or post diagnosis of a dementia. What I would really encourage is that please do not wait until someone has been diagnosed – You don't need a diagnosis to work with a SPLW. We can work with SP at any point on that journey, any time in their life, with or without dementia. Get people to us as soon as possible. We all know the more people that engage in activities, the more connections they've got and the more relationships they build, the more positive effect that will have in delaying the onset of dementia.

#### Referral in

We receive referral forms from any organisation in Manchester, a GP or memory service. — 'I would like to pick that conversation up with you, Jonathan, around having an indication of cognitive support on the form so people are aware they can refer to us for that.' — (Dr Jonathan Kaye, see page 50) has since added a 'cognitive stimulation' category to the referral form.)

#### First conversation - SP'/LW allocation

Once someone is referred in, we have an initial conversation to find out what is happening in their life, what is important to them. We're not working with a diagnosis We're working with the person, who they are, their strengths, and pulling those into every area of their life. We allocate them to the worker best placed to meet those needs and help them to connect to services or activities that will help them to achieve what they want.

#### Health coach

For someone pre-diagnosis or who has just been diagnosed, they will tend to work with a PCN coach or a coach, who will pick up people with more complex issues. We know about lots of services across the city, we can get them to the right place as well as them doing one-to-one coaching sessions along the way. If they are waiting for a diagnosis, or going through a lengthy process, that one-to-one support is important; and when they are diagnosed with a dementia and go through all sorts of different emotions, we are there to listen, to have conversations, and to connect them to the services that they need.

#### Care partner

We also work with the person who cares for them, on a package of support. The beauty of SP is that we are super flexible with what we can do, and we adapt to an individual's needs. We build relationships with other organisations, so that they can also meet the needs of people.

That person supports them for as long as they need, we work with them to do everything that they want to do in their life, help them connect, get in with activities

# 3.5.3 GREATER MANCHESTER <u>Heather Etheridge</u> Be Well SP, The Big Life Group

#### Asset mapping

We work with numerous different organisations across the city, Manchester Museum, for example. We know what they provide, how they provide it and can connect people in.

#### Community Development/Building

If there is a block in terms of what someone wants, and there isn't a service to provide it, we'll work together with different organisations to come up with a solution to meet that person's needs. We think about what they want, and how we can best deliver it at all points.

#### Student Placement

Another exciting development is our placement programme with students from The University of Salford, as well as other universities, and we're ensuring that they get that community delivery aspect and connect with different services along their education journey

# 3.5.3a Rebecca Kershaw, Manager, Oldham SP Service, Action Together.

#### Referral in

We have four SPLW in each of the five areas of Oldham. Referrals from GPs and wellbeing agencies come to us through our Elemental electronic case management system. People can self-refer to us by telephone or through our website into our Elemental system.

### Conversation and connecting to A.R.T.S.

Within a week, the SPLW will contact the person face to face, virtually or by phone. There is no time scale, no right or wrong way. It is very much that strength-based conversation of asking what they are interested in, seeing what is available, and we will then support them to access this - whether that is the arts or a community singing group.

We look at the steps before attending a group, if they can afford to get there, are they happy to make that first step over the doorstep, or whether there are caring issues.

# Development Workers (Community Builders) and funding support

If anyone has an interest that isn't happening in Oldham or isn't accessible, our Development Workers will support a new activity. We then support the group to look at funding, places to meet. Also, if we know that people are accessing a group, or if an existing group is struggling to provide resources, then we will also support people in groups to develop that.

# 3.5.3b Bruce Poole, Strategic Lead for Wellbeing, Health and Social Care, Wellbeing\_Matters, Salford Community and Voluntary Services (CVS)

Wellbeing Matters is our person-centred and community approaches programme. It has two workstreams – SP and Community Approaches - both well interlinked.

Commissioned by Salford City Council and CCG to provide a SP service across Salford, we manage that on a five-neighbourhood footprint - five neighbourhood community anchor institutions who host five Community Connectors (SPLW). Our referrals are chiefly from primary care providers.

#### Person-centred conversation with P&C

The Community Connector (SPLW) will then have a person-centred conversation with P&C. If the person has a cognitive impairment or dementia, they may talk more with the carer, if necessary.

#### Connecting to A.R.T.S.

Connecting people into activities that they love, or used to love, or that they find inspiring is really important to us – the outcome for the person is about them. None of this would exist without our equally important workstream two, the support we offer for community organisations in support of SP:

#### Volunteer Community Development Workers

Our five volunteer Community Development Workers (Community Builders), work in the five neighbourhoods, alongside their Connectors (SPLW), to ensure that there is that voluntary and community infrastructure to support SP. Our Community Development Workers connect people into all types of community groups, from gardening, to Knit and Natter, the Tech and Tea programme, Start Art and Singing for Dementia. At the last count we had over 150 organisations they were referring people into.

### **Funding Support**

Over the last 18 months we have invested over £130,000 worth of grant funding into those organisations to support and continue their activities, and to shape them so that people who are referred through Wellbeing Matters can access them. That includes an element of quality assurance, so we know that they aren't being referred into activities that are going to fall apart or disappear, or that they haven't thought about their safeguarding or their insurance or how they'll manage, and their sustainability as an organisation.

# 3.5.4 OXFORD Emma Fuller – Lead SPLW, Oxford City PCNs (A4D May 2020).

Oxfordshire CCG has commissioned Oxford City six PCNs' team of five practice SPLW to help connect patients to non-medical sources of help and support in the community. Our initial focus was on the frail and elderly, but as the service has evolved, referrals are now broadened to all adult patients.

Sometimes GPs describe catching a glimpse of one or two social determinants of the patients' health, like seeing the tip of an iceberg, whilst the SPLW spends time and expertise to explore with the patient the rest of the iceberg, bit by bit. Meanwhile, SPLW regularly attend the primary care health meetings or huddles to work collaboratively with the GPs, practice nurses and admin team.

#### Referral in – and out

Our SPLW take referrals from GPs – now for patients at the onset of dementia symptoms – and from other local agencies through the GPs' electronic patient record which allows them to have a fuller picture of the patient and the services they are currently receiving and enables them to better support patients and to document, track and signpost to GP about the outcomes of the services into which the SPLW is connecting them.

#### Conversation and connecting P&C to A.R.T.S.

SPLW are able to see patients at home, or at clinics and GP surgeries. Our conversation focuses on what matters most to them We support them to build resilience and take control of their health and wellbeing. SPLW provide clear information about community groups and activities, the choices the person has so that everything is understood, they help the person understand what support they want to be connected to. We introduce them to the groups and help build their confidence to engage in them. SPLW support people to make their own decisions.

We assist them to think through the practical issues facing them getting involved in this support, such as how they will get to an activity or group, or how they will deal with new introductions and what their fears are. We give them time to co-produce a plan that will meet their wellbeing needs and give lots of opportunities for the person to ask questions and create clear goals with the person about what they want to achieve, to ensure the support is owned by the person and of use to them.

Where possible SPLW use the Patient Activation Measure (PAM) to identify what level of support people need, and how activated they are to manage their health and wellbeing.

Helping explore what the person can do for themselves gives a sense of ownership, can increase personal motivation, affirms a person's own strength and resilience - which is essential to personalised care - and prevents dependence on services and activities.

#### 3.5.5 WEST MIDLANDS

Bavinder Kaur, Service Manager, SPLW Gateway Family Services, Birmingham (A4D November 2020).

Gateway Family Services currently manages 62 GP surgeries within nine Birmingham PCNs. I manage the SPLW. We offer the full range of SP support, including issues of isolation during the pandemic. The impact of that has been quite tremendous, the need for holistic wellbeing, the need for emotion support, and the need to empower someone.

#### Referrals in

We are referred through the GP, we have surgery-based SPLW and outreach SPLW

#### Conversational walks

During the pandemic, we started walking sessions, meeting someone on a walk - the impact is immeasurable. The one-to-one session that would help plan that very individualised journey to the point where the person felt comfortable to see it through. The service is very much about what matters to them, so the support plan and the focal point is around the individual, very catered to the person in that situation.

#### Befriending and empowering community connections

It is critical that the role of the SPLW meets that through asset mapping. It has been very difficult to access services that we would normally just walk down the road to or signpost them to. It is very much around befriending and empowering, community connections are essential to this role, the ability build that relationship and have a seamless approach to the service, to see someone from start to finish, and be with them through that journey.

# 3.5.5.1 Jennifer Luisada, SPLW, Hall Green Health, Northbrook Group Practice, Community Care PCN, Birmingham & Solihull.

SP support is working with clinicians, not instead of them, which is really important during this diagnosis process. It helps put the patient at ease and ensures we are all singing off the same hymn sheet and reading the same notes, things like that.

#### Referral in

Referrals come from the GP and other practice staff - receptionists are really good at picking up on social things that patients are mentioning when they are contacting to get an appointment. Our referral form addresses whether patient needs to be contacted within 7 days or 27 days.

#### 3.5.5.1 WEST MIDLANDS

# Jennifer Luisada, SPLW, Birmingham

REFERRAL TO SOCIAL PRESCRIBING Community Care PCN Numbercole Group Processes.	
<ul> <li>From clinician or other practice staff</li> </ul>	Reason for referral *
	Employment, Education, Training
<ul> <li>Contact as an urgent within the</li> </ul>	Welfare and Benefits
week or within 4 weeks	Support round disability
	Cognitive Stimulation
<ul> <li>Initially contact to arrange best time</li> </ul>	Healthy Lifestyles  Physical Activities
to speak	Housing / Homelessness
	Social Network
<ul> <li>Does carer need to be present</li> </ul>	Families & Parenting
<ul> <li>Based on needs and social</li> </ul>	Carers Support
environment is there a best time of	Domestic Abuse
	Emotional Wellbeing
day	☐ Volunteering
	COVID-19 after affects

#### Personal support

In a first contact call to a person, we enquire whether they need a family member or carer present, and ascertain whether they look after grandkids during the day, so is it best to call of an evening, to meet face to face, home visit, phone or video. The support is ongoing for however long is necessary. It often starts off with weekly or fortnightly appointments, checking the support being put in place is appropriate and working for them. This might change to a check-in call every month or so, to see how they are doing.

#### Understanding the patient's aspirations

From there, the initial appointment is about trying to get to know the patient, building a rapport with someone, understanding their assets, we have an asset approach looking at skills, their knowledge, what matters to them, rather than focusing on their problems. What did you used to do that you may not do anymore? Is there an accessible version of it now?

#### Connecting with dance

For example, a patient who loves ballet; used to dance when she was younger, but because of her mobility now, she worried about her coordination. We found a seated ballet class along her bus route, so she was able to go independently, instead of relying on when her son would come. Over lockdown, it has continued over Zoom, so she has been able to carry that on.

#### Supporting an action plan

We co-produce an action plan so the patient, carer and family know where to go from there. They can try activities and if they need support accessing the service, I can meet them there, help take them there, and introduce them. Access is really important, if they rely of public transport, I will look for services along the bus route, because often, if they're not able to walk there, then they will rely on something on their bus route.

# 3.5.5.1 Jennifer Luisada, SPLW, Birmingham

#### Asset Mapping

I asset map once a month and ask to be put on mailing lists so as to keep up to date with service changes. There are resources, such as route2wellbeing and The Waiting Room health and wellbeing services in Birmingham, but to be sure about updates. I like to do my own mapping. This can be on social media, through social groups, seeing what people are talking about, what their needs are. I go on Google Maps and look at all the bus routes in the local area that our patient is in, go along the bus route and see what community centres are there, talk to local churches or worship groups. I message local councillors about funding pots, and from there I message these community centres and ask if they can keep me informed about what going on.

#### Filling the gaps – Community Development

Community centres often then ask if they can do more to provide for patients' needs? From there we work with groups to fill in those gaps. One example of this is, since COVID19, people missed face-to-face contact. People need human interaction, so it has been about helping them organise socially distanced coffee morning in parks, looking at what they can do around that, can they provide activity packs? So that when they have a diagnosis waiting to happen, this can fill in the gaps, fill in the time, and keep their mind active and away from the diagnosis and the negative connotations that go with that.

# 3.5.5.2 Michaela Griffiths, Supervisor, SP, Health Exchange, Birmingham

Health Exchange support PCNs SP service taking referrals from GPs, as well as self-referrals and contact the person within 48 hours. We offer six one-hour sessions or twelve hour-hour sessions and if necessary, we go back to the GP for further discussion. Looking at our pathway, we provide face to face assessment to see how we can help support the needs of the patient. We look at empowerment and allow patients to make the decision on what they want, not at what we think they want.

#### Early onset dementia

We are piloting a research project with Sandwell and West Birmingham, looking at how patients with early onset dementia can use technology to enhance their skills, or look at things in the wider environment, using iPads.

# Peri-diagnosis

Post diagnosis, we look at Dementia Connect and the Carers Hub, but we have a challenge on our hands for people who are being diagnosed with early onset, who are very afraid of the diagnosis, or for those who are a bit further on. We find that challenging ourselves, but coming on this team brief, we can see what is available for us to help us refer into the dementia services.

Are there any gaps, is there something more we could be doing, is there an opportunity to build on what patients are mentioning?

# 3.5.6 EAST MIDLANDS Carol Burrell, SP Service Manager, Nottingham City GP Alliance (A4D November 2020).

Nottingham City GP Alliance has 16 SPLW working across eight PCNs across the city. SPLW were out connecting with community services, seeing people within GP practices, or we would see them in their homes or at a community venue. Since COVID19, we called people and did the health and wellbeing checks and have spoken to many people in the early stages of dementia and carers.

#### Connecting to A.R.T.S.

The arts are really important. Nottingham Contemporary have reached out, I've had discussions with Nottingham Playhouse and the New Art Exchange. SPLW come with different skills and look for gaps; and if there's something they are passionate about, they will try and set up a support group around that. I've got a SPLW doing a Grow Together project.

#### Community Development

Another SPLW has been awarded a grant to purchase tablets so that people who are digitally excluded can be involved. I also deliver sessions, I've secured some funding for chair-based activities, for a small group or over Zoom, as well as physical activity sessions. We've done 'Walks and Talks' and recently all been trained to be walk leaders, so we'll be putting on additional walks.

#### SPLW Training

If you have some training that you could share with my SPLW, because that would be really useful, we are just seeing the demand of more carers calling, we're not experts in that but we're willing to take things on board. (Nottingham SPLW attended A4D training – see page **216**).

#### 3.5.6.1 EAST MIDLANDS

Ebele Omo-Bamawo, Community Development Coordinator, Gedling Borough Council, South Nottinghamshire ICP.

My role is a conduit between SPLW, the community and the voluntary organisation. There is a need for collaboration. Without voluntary organisations, it can be difficult for community groups to stay connected, build resilience and sustainability.

I've seen, even during lockdown, so many good outcomes from community development initiatives and I have been able to map out so many assets to make sure that SPLW have enough resources to engage with their patients.

#### Connecting to A.R.T.S. to tackle loneliness

Music and arts are so important, and I know that some of my groups in South Nottinghamshire offer art support online. We also have the CVS tackling loneliness and isolation. I would like to share some figures with you around what has gone on in supporting SPLW to tackle loneliness and isolation in South Nottinghamshire.

On 8 June 2020 we launched in South Nottinghamshire a phone befriending service, through this service we reached 187 patients and community members in less than a month; we delivered 283 calls in July, 253 in August and over 300 in September. We find that most of the referrals we get through SPLW are for mental health, loneliness and isolation.

#### Community Development Funding for A.R.T.S.

These groups also need funding to support initiatives in the community. My role is also to respond to grass root funding demands, and I happy that recently I supported 15 groups to access more funding to provide COVID safe health and wellbeing activities to support people in the community; and I've been able to initiate and land a very good deal with Inspire Libraries to support patients in adult learning, family learning, art and music.

#### 3.5.7 EAST OF ENGLAND

Rachel Nightingale, Community Connector, Access Community Trust, Connect for Health, East Suffolk (A4D December 2020).

Our SP service covers Ipswich and East Suffolk, and is delivered by four voluntary sector organisations, including Access Community Trust. I cover tiny patch of Leiston and the surrounding villages.

#### Referral

People are referred for a range of reasons, but often key is low mood, social isolation, and low activity levels, factors that can all be connected to people who may be at risk of dementia.

We were set up to be based in GP surgeries, but anyone can refer. We are moving more into integrated neighbourhood teams and hope to be picking up more referrals through social care. I also work closely with the Citizen Advice Bureau who refer in. My favourite referrals are self-referrals, because when people self-refer they feel ready to make some change in their life. I think that is so crucial, because that is a big block, because if people aren't ready to make even the smallest change, then it might not be the right time for them to be referred to us. The client needs to give permission to the refer, or go fill out a form themselves, or contact the GP and say they would like to take up the SP survey, or they can contact us directly.

#### Time frame

We offer up to six sessions, more if it will be valuable to them, either face to face or phone call.

#### Time to make that change

We have time to hear about the client, what's going well for them and what really matters to them in life. Then we make a plan for how to make some change, however small, and that change might start with making that list of what matters to them or doing even five-minute walks each week. But breaking through and doing something different in life is really crucial and finding what their passion is.

#### Connection to A.R.T.S.

That is where something like the arts may come in, I've just met someone who loved making silver jewellery, but hasn't done it for ages, so we've connected him with an artist mentor, and he feels able to get out of bed again. That's really crucial - making the change and finding the passion.

At Connect for Health we really believe in co-delivery as well as co-production. We have a voluntary run café in Leiston called the Worry Tree. A lot of our patients run it, so instead of it just being done to them, they take control, as volunteer facilitators. Finally, COVID19 has been interesting for local empowerment, villagers have set up a sea swimming group, a family rounders group, a community garden.

#### 3.5.7 EAST OF ENGLAND

Kelly Austin, Social Navigator LW, Granta Medical Practices, Cambridgeshire & East of England NALW Champion, NHSE SP Ambassador.

Our work is based on the what-matters-to-you model, not 'what is the matter with you?'. So, it really fits in with the A4D's ethos of activities before diagnosis, not because of diagnosis. We can work with the patient with or without a diagnosis, to identify what matters to them, and what is of benefit to them.

#### Referral in

Initially, our patients had to be referred through a clinician. We extended our service so that patients can now be referred from any member of the primary care team. We also have great links with our locality teams, so patients could be referred through our reablement team, health visitors, or occupational therapists, anyone in the wider community health team, and we now have self-referrals in the community. Key to this is having our own service email and telephone number, bypassing the medical reception clinical system, so that patients can directly access the service. That means that if anyone has concerns, for example, about elderly relatives or neighbours, they can access our service without having to go through the GP.

#### **Timeframe**

We try to contact the patient within a couple of weeks. Contact could be anything from ten minutes just to signpost a patient, or if they need support, we work with them for up to an hour, for six to twelve sessions, depending on their need. This might be telephone call, or by video as it has been during COVID19. Or we can see them in surgeries, in any one of our five practices, or in their own homes if that is more appropriate. We help them access all the groups and services that they want to. It is a real valuable service.

#### Asset mapping

How we map services in the community is by getting out into the community and finding out about A.R.T.S. groups and other services. We try to make as many community and organisational contacts as we can within our network, so we can really see what is going on locally. Also, we can figure out things through patients and keep them on the database that we can all access, and this can be updated as and when it needs to be. We are also looking at other technologies.

### Community Developing

We can also help with the community – building assets and resilience. If we're in the community then we can help get initiatives up and running to fill that need. A local church café said they wanted a restaurant for dementia and came to us to get that started. This job is about communication. People know we are here, so we can talk and break down the barriers and pathway referral lines, I'll talk to anyone about anything to get the best outcome for our patients.

#### 3.5.8 SCOTLAND

Brenda Tinney, Community Link Worker, Dubbs Road Medical Centre and Mount Pleasant Practice, CVS Inverclyde. (A4D February 2021).

We went into practices three years ago. Each Inverciyde practice has a Community Link Worker (SPLW) to link medical, statutory & community services. We are a team of seven, with a full-time lead.

#### GP referral in

GP staff identify changes in people's behaviours – through missed appointments, the way they're dressed or present, or if they don't follow up appointments etc. They and GPs can refer patients directly to us.

#### Timeframe:

Within four to six weeks we initiate contact with the person. Normally we see them at home for an hour, communicate with families, and then look at the issues that are actually facing them, their priority needs, which can be anything outside the medical model. Then we follow up, working side by side with that person and their family, source their skills, their interests, and what is important to them, and we can look at what is available within our local community.

#### Connection to A.R.T.S.

We are very blessed in Inverclyde as we have a full range, from the arts stuff, to community arts projects, to lots of community centres that we can tap into. We look at how are we going to get them there? Do they need support? Is it accessible? Can we take them or refer them onto a Community Connector organisation in Inverclyde who can actually get people on the bus and can be there to build up confidence.

#### Pre-diagnosis

What has been proven is that if we improve people mentally, physically and socially, they will have long-term benefits. It means that in that gap between changes in behaviours and getting to diagnosis, or possibly not, they can have enriched and enhanced life, and have the opportunity to do that.

We take direct referrals within practices and we also accept self-referrals. We work with all community organisations within Inverclyde and anyone who provides services.

Within our funding we get supervision monthly from a counselling project in Inverclyde, which provides that one-to-one support, because we are dealing with patients who have high end needs a lot of the time.

We have a couple of really good community groups in Inverciyde. Rig Arts is just ordinary people using skills that they've had for years. There are knitting groups, crochet groups, all these smaller groups getting together, under the art and craft label. The other is the Beacon Art Centre, who run dance and music classes which the deprived population may struggle to afford.

#### 3.5.9 WALES

# Hazel Cryer, Health & Wellbeing Co-ordinator, Action for Caurae and Ely (A4D March 2021).

Action for Caurae and Ely is a charity based in South-West Cardiff. We work with our local community to co-produce solutions to local issues. Something we've been trying to work on with our community and our local GPs for the last eight or nine years, since Dr Karen Pardy (see page 61) came in post, as it's something we've been trying to work out together, is how GPs can help their patients to get to some of the things we offer. These are a range of community activities which people can get involved in.

#### Referral in

GPs and anyone can refer to us through the Elemental platform. GPs enter in the details of the individual, the platform works out who they need to go for support, SPLW, organisations and projects, such as A.R.T.S. they can refer or be referred directly into. Our team of SPLW pick up the referral through the platform. Within two to seven days, the SPLW calls the person, talks through what we can offer, and see what they would like to do next, whether they would like to receive our service; and arrange a meeting within a week of meeting, either by phone, face to face, outdoors, in the home or GP practice. Four or five people have recently been referred in while awaiting assessment for a potential dementia.

#### Conversation and action plan

We put together an action plan with that person, based on what is important to them. Then we discuss and recommend particular things in the community that they might like to do, and t give whatever support is needed to get them to that activity. It's not as simple as just knowing what is out there. Sometimes they may need us to come and introduce them and really get to grips with what is on offer there. We carry that support on until that person is satisfied, and they are in with something which is helpful to them.

### Community Development Workers

We also have a team of Community Development workers who work with our local community and with people who are referred to Develop New. Many people have been referred through that project, saying that there is nothing in the community that I want to do, or that help with the things that are important to me. We would work with those people to develop what is needed, bringing other services in, or just helping people to do that thing themselves. It is really important to us that people don't just come and receive support. Every single person has things they can offer, skills or attributes, and everyone can offer something to what we're doing. That is the really key thing for us.

#### **Asset Mapping**

We map what is available in our community, and we update that and share it with other partners. We bring in the GP and other services to support that as needed, it is an ongoing process. We're constantly talking to anyone that will talk to us to see if we're doing the right things, if we should be doing something different, and if people want to be part of that.

#### 3.5.9 NORTHERN IRELAND

# Leanne McBrearty, Regional Manager, SPRING SP. (A4D March 2021).

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SPRING IS a SP project working right across Northern Ireland, with ten sites in Scotland, supported by the National Lottery Community Fund, by the Department of Agriculture, Environment and Rural Affairs in Northern Ireland. Tony Doherty is the Coordinator for Health Living Alliance. Our SPLW, based in Healthy Living Centres (HLC), are community led, neighbourhood based, health improvement projects. 16 sites, over 20 SPLW there.

#### Referrals

GPs, primarily, and other health professionals and pharmacists refer directly over to our SPLW at the HLC. Some GPs use the Elemental system to make a digital referral right to the HLC, others will use the old-fashioned way with email or send it in the post.

#### First contact

We make contact with the person at home, or over the phone and carry out a holistic Needs Assessment. The Outcome Star tool enables us to have an explorative conversation with the person around what they feel their support needs are. SP for us is all about individual's choice, so it is about us facilitating a conversation around what they would like to get involved with and their need. We then take it from there. We see ourselves as being based in community, this is a big advantage to our work, as that gives us ongoing knowledge of what is available in terms of arts programmes for clients. We then offer it to them and help them to link in from there!

#### Connecting to A.R.T.S.

One of our HLC and SP projects had developed a local partnership with an arts project for older adults. Those who were referred through SP, worked with that organisation and developed a Tree of Resilience that was displayed in the library - an absolutely beautiful piece of work. Another group referred to our partnership with another creative arts organisation wrote their own play and they performed locally. With COVID19 we don't have those opportunities to go into different settings, so we help our clients connect through Zoom and online. Within the HLC we have been able to provide some of our clients with iPads and support in order to connect online with WiFi. We have been able to offer a whole plethora of programmes such as craft classes, photography and the Big Sing. Just a whole variety of programmes online. So that is the journey from the GP right into the community!

# 3.5.9 NORTHERN IRELAND: Jenny Dougan, Community Navigator, Mid & East Antrim Agewell Partnership (MEEAP)

I'm one of four Community Navigators (SPLW) based in the Northern Trust area. I cover the areas of Ballymena, Carrickfergus and Larne. MEEAP is funded by Northern Health and Social Care Trust, and our job is to signpost older people onto services and support within their local area. We are like the Yellow Pages for older people.

We would work with the person from the beginning of their journey with dementia, their carers and family members. I suppose this topic was really of interest to me because my background is in the arts as well. I tread the boards quite often and would normally be involved in local panto. One of our aims over the next couple years, whenever COVID19 finally disappears, is to do a panto with a cast of older people and delivered to a target audience of older people. If you have any volunteers, or if you know of anyone who would like the tread the boards then get them in touch with me!

I suppose in regard to my role of signposting to older people, targeting those lonely and isolated, we would very much be trying to promote and signpost people towards the arts. There are lots of different organisations available in the local area. We would be signposting onto lots of different groups including Knit and Natter groups, circus skill groups, photography, painting. We are very much trying to positively express the benefits of arts by signposting people onto those. Part of my role is to try and support these groups as well, to enable them to keep going and be there after COVID19 as well.

Update: We are most definitely seeing an increase in the uptake of activities with restrictions being relaxed here in Northern Ireland.

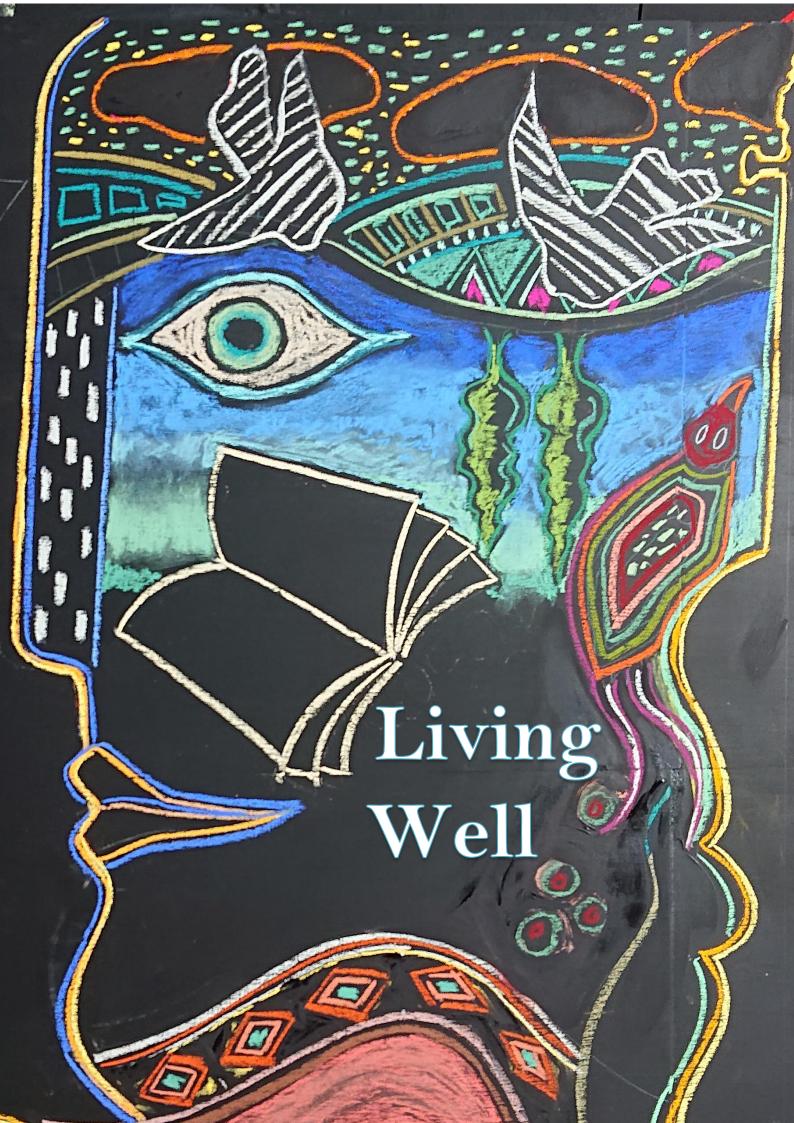
#### 3.5.9 NORTHERN IRELAND

# Nicola Arbuckle, Arts and Wellbeing Manager, Northern Health and Social Care Trust.

I have the remit for the development of arts and wellbeing across the trust. One of the key programmes which I want to talk to your today about is the Singing for Health programme. Within the Northern Health and Social Care Trust we recently developed an arts and wellbeing strategy which was released, just before we went into lockdown. A few years previous to that we had established three community-based Singing for Health programmes in County Antrim: One in Newtownabbey, Ballymoney and Larne. The programmes were open to all people within local community. We met on a weekly basis face-to-face. The groups attract around 20 people per week. Participants are a mixed group of adults with a wide range of medical conditions including dementia.

Singing for Health has been funded through the arts strategy within the trust. Two groups are facilitated by Karin Diamond, who is trained through the British Lung Foundation. It is a very open and inclusive group. Since COVID19 we have adapted virtually, continuing to meet on a weekly basis and grow in numbers. Because the group is no longer facility based, it means we have been able to open up the group to the whole of the Northern Trust. Within the Trust we have four Loneliness Networks attached to the four local councils, and have been able to advertise and promote it so we can reach a wider audience. Some people have found participating through Zoom more beneficial because it has reduced some the barriers to getting to a facility, but some would obviously prefer face to face. Longer term we will be looking at blended approach where we offer both in one weekly session.

We have also linked in with Arts Care as well, we've linked in with the regional arts programmes for older people. As part of that, a few of the groups have been able to participate in a number of events, they have performed at the Opera House in Belfast, the parliament buildings in Stormont, and one group in particular has been going out to nursing homes to perform, pre-COVID19. The group in Larne, it is called the This is Me choir, they recently won the Alzheimer's Association DF Communities award. The great thing about group is that it has great sustainable attendance, so it has high numbers of people participating on a weekly basis. The outcomes and the feedback have been extremely positive, especially in relation to improving health and wellbeing, in particular mental wellbeing and also the physical benefits, especially in terms of lung health. It has been a great support network for the carers who attend. It has offered some respite and opportunities to mix with other carers. A lot of new friendships have been formed, a few of the group have set up a WhatsApp group so people can be supported as well through that. It has had a major impact on reducing loneliness and social isolation, particularly over the last year because a number of people in the group were in the shielding category, and because of age and medical conditions, they had restricted opportunities to socialise.



# 4 Living Well A.R.T.S. to preserve brain health

# From Despair to Desire – The healing power of participating in A.R.T.S. – Activities to Revitalise The Soul

Everyone has the right freely to participate in the cultural life of the community. 60 For referral to arts support for dementia you need a diagnosis. Yet, for people in the lonely, fear-filled months awaiting memory assessment, the right to arts participation has been hard to access – until now.

Thanks to SPLW available to every GP, arts can be offered at the onset of symptoms, and in so doing transform the diagnostic experience, reduce anxiety and preserve resilience for the individual and their partner, together in the community for years longer. If they are engaged in a social A.R.T.S. group, overriding isolating challenges, building new friendships, creating and feeling valued in an inspirational milieu when diagnosis comes, their sense of identity, purpose and joy can continue, whether or not the diagnosis is dementia. All side effects are positive. If the thought of A.R.T.S. seems daunting at first, breaking down barriers, the challenge of learning new creative skills, activities in nature co-producing projects, with guidance from trained professionals, brings health-giving excitement, restoring personal motivation and wellbeing and can even improve cognitive function. SP revives the opportunity to aspire, the thrill of achieving the unexpected.

Involvement in imaginative, healthy endeavour demonstrates to the community that older people, even those with mild cognitive impairment, have skills to share and inspire others. An A4D SP drama pilot participant, awaiting memory assessment, was new to drama. Nervous at first, his confidence sprang back over the weeks, months: Negotiating Zoom by phone, Ron's crooning Elvis Presley-style repartee in an improvised COVID scenario spurred a medical student's brilliant responses – the effect remained with her – see page 240. Both Ron and Sue (see page 31) whose memory and reading ability have been much improved by art and drama participation – her vascular dementia diagnosis now seen as stroke damage – continue to enjoy the challenge of creating scenarios with others whose diagnosis is dementia, all keen to preserve brain health through their chosen A.R.T.S.

The vital role of the arts in preserving health and wellbeing and protecting against cognitive decline is globally acknowledged. Evidence is widely disseminated at International Culture Health and Wellbeing and SPN conferences, WHO reports and the All-Party Parliamentary Group on Arts Health and Wellbeing Inquiry *Creative Health: The Arts for Health and Wellbeing* (2017) has led to opening of the UK's National Centre for Creative Health. Weekly participatory arts for creative ageing, given a terrific boost in the UK by the Baring Foundation's grant programme (2010-19),<sup>61</sup> offered by larger arts organisations as community learning programmes, and increasingly at arts hubs and healthy living and community centres.

'It gets your brain working – you get into the character. You think something quick. You don't usually think like that. It's amazing!' Ron, participant in A4D SP pilot with Southwark Playhouse, 2020-21.

<sup>&#</sup>x27;We feel reawakened,
exclaimed 'You learn more
about life in art than
anywhere else.' 'It's
inspirational, gets you
focussed.'. 'Each time you
come there is something new
to discover.' participants
in The London Arts
Challenge, 2012.
Franklin Gould (2013)
Reawakening the Mind,
pages 48-49.

<sup>&</sup>lt;sup>60</sup> Universal Declaration of Human Rights (1948) Article 27.

<sup>61</sup> Gordon-Nesbitt, R. (2019).

# 4.1 Growth of participatory A.R.T.S. for older people

While participatory arts also take place in healthcare settings, because our cohort – people at the onset of a potential dementia who are keen to preserve normal life, this report focusses on A.R.T.S. venues in the community; and the position I encountered in 2009 when the musician who had reawakened my mother's communication skills seven years after her diagnosis of Alzheimer's disease, when to my astonishment, after his exquisite playing of Bach's cello suite, she began to interview him with such fluency about his life as a Russian music student in London, that I began to research the use of arts for people with dementia.

Far from Gateshead, Manchester and Canterbury, London's museum and theatre learning departments were focussed on youth and activities were for more advanced dementia activities and chiefly involving care settings. So it was to New York Museum of Modern Art, MeetMe at MOMA programme for participants in the early stages of dementia and their care partners (2007) that would guide A4D's partnership programmes with arts venues – weekly workshops across art forms to re-energise and inspire people above symptoms of early-stage dementia and carers. Informed by early-stage dementia awareness training into the challenges people face as symptoms of the various dementia subtypes arise, their existing skills and how best to access them – see Appendix 1 page 216), these weekly workshops engage the intellect and imaginative instincts of participants and override any sense of dementia. It is this approach that we propose for people at the onset of symptoms, whether or not the diagnosis is a dementia.

#### Early beginnings: Performing arts in California, USA

There is now much more on offer, but participatory A.R.T.S. had begun decades earlier. In 1978, Dr Stuart Kandell founded the performing arts company <u>Stagebridge</u>, at Oakland in California, providing weekly classes in drama, dance, storytelling, music with ideas for practice between sessions, to keep up the stimulation, and performance opportunities at the end of every quarterly session.

#### Drama, Dance and Creative writing in London, 1980s:

Throughout the 1980s pioneering participatory arts organisations sprang up in London: Pam Schweitzer founded Age Exchange, the intergenerational theatre company at Blackheath specialising in reminiscence. Fergus Early founded Green Candle Dance to improve the physical and psychological health of young people and older adults in Tower Hamlets. David Slater founded Entelechy Arts in Lewisham, originally for people with learning difficulties and using music, participatory theatre and dance as a means of communication and exchange, introducing an elders' performance company Seven Ages in 2006, involving theatre, dance, new writing and video to explore the themes of identity, diversity, memory, risk and change and in 2013 a weekly arts club for isolated elders, Meet Me at the Albany which still today offers a range of participatory arts and outings. Sadler's Wells' Company of Elders, founded in 1989 as an arts club – now the Lilian Baylis Arts Club – while in 1991 the

Company of Elders. became a performance company for amateur dancers aged over 60 working every week with professional dance artists.

#### Creative ageing around the UK, 1990-2000

In 1990, the new West Yorkshire Playhouse – now Leeds Playhouse – invited people aged over 55 in 1990 to join their Heydays, now the UK's largest and longest-running arts programme for older people, offering weekly creative activities – drama, dance, creative writing, and visual art. (Leeds Playhouse case study page 130). Alice Thwaite, the award-winning founder of Equal Arts at Gateshead, set up the now internationally renowned charity in 1993 to specialise in working creatively with older people. (See case study page 191).

In 1997, the first known Arts on Prescription evaluation is published of the programme run by Stockport Arts and Health referring people with anxiety or depression to art workshops as an alternative to medication. <sup>62</sup> As the Bromley by Bow Healthy Living Centre, with GPs onsite introducing patients to 100 arts activities, is opened by Tessa Jowell, in Devon 'Time to Dance' at Attik Dance offers, weekly classes of fun creative dance for active vulnerable older adults in a range of styles. In 2000, the Community Arts Forum of Northern Ireland set up an Arts and Older People Network.

#### International events

Arts and Health hosted a World Symposium on Culture, Health and the Arts at Manchester Metropolitan University, attracting considerable interest. In 2001, Dr Gene Cohen of George Washington University conducted a study of weekly participatory arts – poetry, jewellery, choral singing and performance – for people aged 65 and over in three community settings in Brooklyn, Washington and San Francisco in the USA. Participants included 30% racial and ethnic minorities, and showed improved health, fewer doctor visits. The oldest participant was aged 103.<sup>63</sup>

#### Museums reach out to older people

In 1998, Manchester Museum and The Whitworth Gallery appointed as Head of Learning and Engagement, Esme Ward, who as Strategic Lead for Culture oversaw the development of the Greater Manchester Ageing Hub and of Age-Friendly Manchester. Esme is now chair of the Culture Health and Wellbeing Alliance and Director of the Museum. With her Arts for Health Programme Manager, Wendy Gallacher, as Head of Learning and Engagement, Manchester offers outstanding A.R.T.S. opportunities for brain health – see case study page 119).

Pallant House Gallery in Chichester, opened a Learning and Community Programme in 2002, with inclusion at its heart. Treating everyone as equal, providing nearly 200 people whatever their support need, with meaningful long-term opportunities to learn new techniques, discuss art, work on personal creative projects and volunteer in the galleries. Birmingham Science Museum

<sup>63</sup> Cohen, G.D. (2006). The Creativity and Aging Study: The Impact of Professionally Conducted Cultural Programs on Older Adults.

<sup>62</sup> Arts on Prescription (1995-2005), Wellcome Collection, ART/AH/1.

invited older people to co-curate its 2002 exhibition, *Changing Times: Our messages from the past to the present*, working with a local college and special school to choose the exhibition theme – communication and music – select objects and help guide the interpretation and display, here working with the designer. The museum subsequently published *We Chose It: Connecting collections and communities*, as a toolkit as a guide to sustainable partnerships.

Dulwich Picture Gallery's Good Times: Art for Older People<sup>64</sup> began in 2005 in response to deep concerns felt by the Gallery education team about the way older people are treated, to enrich life for people deserving respect for their age, experience and life-long contribution to society. Some had dementia and all were included.

Tate Modern set up a Seniors Programme of four workshops a year, each preceded by outreach at local community centres to help combat social isolation in the London boroughs of Southwark and Lambeth, with gallery sessions led by an artist education and organised collaboratively with Age Concern. Tate St Ives offered 'Tea and Tate' in the café for people over 60 to discuss each exhibition and draw sociably together, with an extra event at the nearby Barbara Hepworth Museum.

Meanwhile, in New York, Meet Me at MOMA launched its weekly participatory gallery discussion programme for people with early-stage dementia and carers in 2007.

#### Arts and Health stride forward in partnership

The Sidney De Haan Research Centre for Arts and Health was founded at Canterbury Christ Church University in 2005 to explore the benefits of participation in creative arts activities, particularly singing and dance, for wellbeing and good health, coinciding with the establishment of monthly Silver Song Clubs for people aged over 60, singing at Age Concern community centres, in the south east, with an experienced facilitator and accompanist with volunteer support from local choral societies Their cross-national study would involve choirs in England, Australia and Germany..

The Department of Health together with Arts Council England (ACE) published A prospectus for arts and health 'to celebrate and promote the benefits of the arts in improving everyone's wellbeing, health and healthcare:

- The arts are, and should be clearly recognised as, integral to health and health services' Participating in arts projects has a positive impact on the mental health of participants by raising self-esteem and reducing social isolation, as shown in projects at Bromley by Bow Healthy Living Centre
- One aim of the Department for Culture Media and Sport is to improve the quality of life for all through cultural activities, not only for their intrinsic value but also for the instrumental benefits they can bring in areas such as health, education and building sustainable communities. Arts and health projects not only promote positive mental health and wellbeing for all but also widen access to arts and cultural opportunities.

<sup>&</sup>lt;sup>64</sup> Harper, S & Hamblin, K, (2010) This is living' Good Times: Art for Older People at Dulwich Picture Gallery, Oxford Institute of Ageing Report.

To complement the prospectus and promote a role for the arts in healthcare provision across the country, ACE published a framework Strategy for the Arts Health and Wellbeing for partnerships to integrate arts into mainstream health strategy and policy making, with a wider healthy living remit. This advance, directed to arts in healthcare settings, excluded arts venues. However, in 2010, the Museums Association's Healing Places: Therapeutics Museum conference attracted education representatives from over 60 museums, the Wallace Collection, talking of the 'immense value' of thinking about artworks and their story for people with dementia and their carers, the opportunity to discuss visual culture socialise and socialise in a serene, relaxing atmosphere. National Museums Liverpool were already linked in with GPs and SP. That year, the Royal Academy of Art hosted an international conference Access for All: Making Art Accessible to People with Dementia, including a presentation from MoMA as the RA was about to launch In Mind at the RA.

Arts and culture can create a sense of wellbeing and transform the quality of life. Arts Council

ACE's ten-year strategy literary review of *Achieving Great Art for Everyone* (2010) found that older audiences more likely to attend arts events, theatre, exhibitions and opera, and that they were well served by social activities to develop creativity and skills and instead devoted their focus to young people. Yet its south-east branch funded a Growing an Old Audience initiative to engage people aged over 70 at risk of social detachment, with cutting-edge contemporary visual art. Fabrica, commissioning contemporary visual art installations specific to its Regency church building in Brighton, set up a series of events, 'See Culture Together', 'Conversation Piece' and 'Experimental Life drawing, and partnerships with Men in Sheds, Textile Flow and Draw for Life.

However, the focus of major arts venues' educational programmes when setting up A4D was children and young people. A4D piloted a new arts venue learning and participation stream to provide inspirational visual arts, dance, drama, poetry, music, photography at 17 venues around London, to re-energise and inspire individuals and carers to override the strains of early dementia, with new training for arts workshop leaders and post-graduate arts students, Coinciding with the London Olympic, A4D's scriptwriting and drama programme at the Tricycle Theatre represented our London Arts Challenge in 2012 at the Inspire Day Exhibition. Funding, provided by trusts and foundations, and an initial £10,000 Award for All Big Lottery, was boosted by The Baring Foundation, whose decade of specific funding (2010–19) enabled strides forward participatory arts for older people, and the Rayne Foundation.

A4D participants continued to derive benefit and enjoy the challenge of this model some three years post diagnosis. Developments in the intervening decade are included in case studies to recommend for SP to brain health – the term indicates dementia, without the branding that offends those newly diagnosed. In India, where the term is avoided, people refer to 'a brain condition', as one might refer to a heart condition. Indeed, on a Global Brain Health Institute podcast, a woman said the same, that she would rather think of her dementia as a brain disease. Whereas arts for dementia are provided for.

<sup>65</sup> Franklin Gould (2013).

<sup>66</sup> Cutler, D. (2009); Gordon-Nesbitt, R. (2019).

you, the idea of discussing interests with a SPLW and choosing arts to preserve brain health is positive and empowering.

The idea of volunteering, the legacy of the Olympics, inspired arts and now medical students to join A4D workshop programmes. Their youthful spring and expertise stimulate participants, inform their own careers and help spread A.R.T.S. practice.

A4D training has informed similar workshops around the UK and beyond; and it is this programme, that preserves identity, cultural interests, encourages new learning and movement – as well as heritage and the natural programmes – we propose as A.R.T.S. to preserve brain health. (see pages 166 ff).

#### 4.1.1 Age Friendly Museums Network

The British Museum, together with Glasgow Museums, Manchester Museum and National Museums Northern Ireland set up the Age Collective in 2012, to explore how museums could extend their offer to older audiences; they were joined by National Museums Wales, National Museums Liverpool, health and social care researchers, professionals and volunteers to become The Age-Friendly Museums Network. Wendy Gallacher, concerned that few older men in Age-Friendly Greater Manchester joined gallery activities published *A Handbook for Cultural Engagement for Older Men* (2015) with case studies from around the UK.

#### 4.1.2 National Alliance for Museums, Health and Wellbeing

The National Alliance for Museums, Health and Wellbeing was set up in 2015 under the leadership of by UCL Public and Cultural Engagement. The Alliance included National Museums Liverpool, the British Museum, Thackray Medical Museum, Tyne & Wear Archives & Museums, Manchester Museums and Galleries Partnership, the Research Centre for Museums and Galleries (RCMG) at the University of Leicester's School of Museum Studies, the Museums Association and the National Alliance for Arts, Health & Wellbeing. New strategic partners -: Public Health England (PHE), Happy Museum Project; Age Friendly Museums Network; Age of Creativity; Group for Education in Museums; Sport in Museums Network; Cultural Commissioning Project and The Wellcome Trust - joined in 2016.

#### 4.1.3 Aesop

Aesop – the arts enterprise with a social purpose – established an arts and health framework for evaluation (2016), in association with PHE, for health commissioners, third sector organisations, trainers, funders, practitioners, managers, arts organisations, researchers and others with an interest in the development and evaluation of arts for health and wellbeing programmes. Aesop's 2018 'National Arts in Health Conference and Showcase', in partnership with the College of Medicine, and Guildhall School of Music, coprogrammed by Dr Michael Dixon, celebrated SP, prevention, health as a social movement and building community and personal resilience through A.R.T.S.

#### 4.1.4 Museums on Prescription (2014-17)

The outcome of Helen Chatterjee and Paul Camic's pioneering project (2014-17, discussed on page 32) was the resource *Museums on Prescription: A Guide to* Director of Arts and Health South West, and of the National Alliance for Arts Health and Wellbeing was led the Secretariat for the Inquiry and Dr Rebecca Gordon-Nesbitt of King's College London carrying out the research. The resulting report, *Creative Health: The Working with Older People*.

#### 4.1.5 Dementia and Imagination (2014-17)

Clive Parkinson, Director of Arts for Health, led a multi-site three-year participatory visual arts project Dementia and Imagination. Extending the creative ageing principles of Cohen's 2006 study (see page 110) to older adults with dementia at Nottingham Contemporary, Newcastle upon Tyne and Denbighshire in North Wales. Artists offered a dynamic, high quality art experiences. Requiring no prior knowledge, experience or artistic skills, the artists encouraged creativity, interest, challenge and learning and adjusted practice activities week by week. Their focus was on connecting people, wellbeing, self-expression and pleasure and the quality of life as we age – with or without a diagnosis of dementia.<sup>67</sup> In 2017 Clive Parkinson founded the Manchester Institute for Arts, Health and Social Change.

The arts embody human expression – physical evidence of the impulse to create – influencing culture, changing culture and sharing stories with a wider world. (Dementia & Imagination, 2017)

#### 4.1.6 Created Out of Mind (2016-18)

Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology, headed an interdisciplinary team of scientists, visual artists, musicians, broadcasters, clinicians and people living with dementia to explore, challenge and shape perceptions and understanding of dementias through science and the creative arts.

Do you see what I see?

# 4.1.7 The AHRC Cultural Value Project: Understanding the value of Arts & Culture

The Arts and Humanities Research Council three-year investigation had involved the commissioning of 70 pieces of research. With an emphasis on the role of culture in the health of individuals and communities. Cutting across the polarisation of the elite versus the popular, amateur versus professional, , *Understanding the value of Arts and Culture* opened up a fresh approach, looking at the contribution of arts and culture to improving health and wellbeing, to community arts interventions to improve social inclusion, mental health and the benefits of engagement for older people and those experiencing dementia; and how Nordic studies showed an association between long-term arts engagement and positive health outcomes.<sup>68</sup>

The potential for the arts to maintain health and quality of life for older age groups in general, and to address problems associated with dementia in particular, has emerged as a major policy issue.

<sup>&</sup>lt;sup>67</sup> Parkinson C. & Windle G. (2017). Dementia & Imagination: Research Informed Approaches to Visual Arts Programmes).

<sup>&</sup>lt;sup>68</sup> Crossick G. & Kaszynska P. (2016), *Understanding the value of arts & culture*. Swindon: Arts & Humanities Research Council.

Arts engagement can diminish anxiety, depression and stress while also increasing self-esteem.

Arts-based groups offer a popular social activity in rural areas ... museums and galleries in urban areas are reaching out to ... particularly isolated older adults

Arts engagement can boost brain function and improve the recall of personal memories ... have a part to play in many aspects of dementia, from delaying its onset and diminishing its severity to improving quality of life for people with dementia and their carers

The creative impulse is fundamental to the experience of being human.

# 4.1.8 All-Party Parliamentary Group on Arts Health and Wellbeing (2014) and *Creative Health* Inquiry (2017)

The All-Party Parliamentary Group on Arts, Health and Wellbeing) was formed in 2014 to improve awareness of the benefits that the arts can bring to health and wellbeing, conducted a major Inquiry into practice and research in the arts in health and social care, with a view to making recommendations to improve policy and practice. Alexandra Coulter, *Arts for Health and Wellbeing* demonstrated the powerful positive impact engagement with the arts and culture – notably, participatory A.R.T.S. – on health and wellbeing and argued, 'it is essential to improve access and engagement where they are lacking, so as to create and sustain healthier lives.' demonstrated arts-based approaches that help people to stay well, meet aging and health challenges and overcome loneliness.

Their recommendations, now bearing fruit, included

- Secretaries of State for Culture, Media and Sport, Health, Education and Communities and Local Government develop and lead a crossgovernmental strategy to support the delivery of health and wellbeing through the arts and culture
- NHSE and SPN support CCGs, NHS provider trusts and local authorities to incorporate arts on prescription into their commissioning plans
- Healthwatch, and Patients groups, A.R.T.S. providers work with patients and service users to advocate health and wellbeing benefits of A.R.T.S. engagement to health and social care professionals to the wider public.
- Research Councils consider an interdisciplinary, cross council research funding initiative in participatory A.R.T.S. and wellbeing and that other research funding bodies contribute resources to advance the arts, health and wellbeing evidence base.
- NICE to regularly examine evidence as to the efficacy of arts in benefiting health and, where the evidence justifies it, include in its guidance the use of the arts in healthcare. (See page 193)

# 4.1.9 Culture Health and Wellbeing Alliance (2018)

The National Alliance for Arts, Health and Wellbeing merged with the National Alliance for Museums, Health and Wellbeing in March 2018 to form the Culture Health and Wellbeing Alliance (CHWA)

Creative Health and the work of CHWA in terms of policy and practice, have had a major impact around the globe with regional CHWA champions helping

# 4.1.9 Culture Health & Wellbeing Alliance

to spread participatory A.R.T.S. practice around England and has led to the creation of the National Centre for Creative Health (NCCH). With the Right Honourable Alan Howarth, co-chair of the APPGAHW as Chair and Alexandra Coulter as Director, NCCH will play a pivotal role in enabling creative health approaches to become integral to health and social care and wider systems.

#### 4.1.10 Creative Ageing

According to Age UK's Index of Wellbeing in Later Life (2017), older people rated 'Creative and Cultural participation' the highest indicator of wellbeing, followed by physical activities, thinking skills and mental wellbeing.

The Baring Foundation's decade of support for professional participatory arts for older people led to a series of publications, notably David Cutler's Ageing Artfully: Older People and Professional Participatory Arts in the UK (2004), Kate Organ's After You are Two: Exemplary Practice in Participatory Arts with Older People. (2013) and Rebecca Gordon-Nesbitt's, Older and wiser? Creative ageing in the UK 2010-19. Barings' campaign has encouraged the spread and academic study of creative ageing and led to the foundation of the Creative Arts Development Agency, based at Manchester Museum.

#### 4.1.11 Creative Ageing Festivals

Bealtaine, the world's first creative ageing festival, founded in Ireland in 1995 invites hundreds of organisations in towns and villages throughout Ireland to take part for the month of May. Embedded in local communities, the festival encourages older people to participate. Over 3,000 events take place in arts centres, libraries, theatres, galleries, involving artists, orchestras and community groups. Bealtaine inspired the development the UKs creative ageing festivals, offering events throughout the four nations of the UK,

- Gwanwyn (f.2007), led by Age Cymru offers events around Wales each May
- Age of Creativity, hosted by AgeUK Oxford, programmes activities throughout England each May.
- Luminate, Scotland's creative ageing organisation, extended its May festival to offer year-round creative opportunities and training for older people.
- Here and Now Older People's Health and Wellbeing Arts Festival, led by Arts Care (see next page), offers activities around Northern Ireland from October to January, even March each year.

There are specialist art form festivals, such as Sadler's Wells Elixir dance festival, (f.2014) and local festivals, such as the Brighton and Hove Ageing Well Festival, the 2018 (Bold) Festival at Southbank for older artists, the Festival of Creative Ageing 2019 (formerly The Capital Age Festival) hosted by Entelechy Arts in the London Borough of Lewisham, curtailed since to the pandemic. Festival events can be useful to SPLW, individuals and families as taster experiences, to guide them towards the A.R.T.S. that most inspire them.

# 4.1.11 Creative ageing festivals

# NORTHERN IRELAND - Here and Now Older People's Arts and Wellbeing Festival,

Dr Jenny Elliott, Chief Executive, Arts Care (A4D Conf21)

Arts Care, a leading arts-in-health organisation (f.1991), delivers a wide range of regional arts programmes in healthcare and community across Northern Ireland. We deliver services to older people; and there have been increasing requests during COVID19 for us to support older people out in the community living with ageing conditions, including those in that early stage, pre-dementia diagnosis.

Our annual Here and Now Older People's Arts and Wellbeing Festival, spans the period from around November into January. This year the huge challenge to us was to deliver this very vibrant and dynamic festival right across the region, within a pandemic context. Our artists rose to the challenges. One of the most exciting outcomes of this festival has been that 72% of the older people, mainly living in communities, engaged with digital services via Zoom or through Arts Care online digital workshops facilitated by our artists, musicians, poets and dancers

We have found over the years and, increasingly, working in this field of arts and dementia and arts pre-dementia, the many benefits that the arts can bring in terms of quality of life. Self-value, self-confidence, and the management of a health life as we progress through the different stages. It is exciting to work with many partnerships and community partners. Over the last year, working with COVID, we have connected with older people's services, around 55-60 organisations, that we depended on out in the community to assist us to deliver the arts programme.

Many older people we work with have accessed the arts at some stage in their life; but they say that as they move into older age, it is more inaccessible. Some have never really participated in the arts, because of the quality issues or lack of access. The wonderful thing about our Arts Care programmes is that we work with the most vulnerable, try to increase our outreach and reduce the inequality that can sometimes prevent people and act as a barrier to people participating in the arts.

One of the most exciting things really has been this key benefit of older people using Zoom in terms on their connection, their sense of reaching out and being with others, because many of them have been extremely isolated. We have been looking at this model and developing something that we are hoping we can move forward with post-COVID and using digital services in a very new and exciting way for older people to articulate exactly what they want to say.

# 4.2 Participatory A.R.T.S. case studies

Participatory A.R.T.S. for creative ageing and for early-stage dementia, both ideal to preserve brain health before and for the first few years post diagnosis have burgeoned throughout the last decade, arts leaders and participants adapting imaginatively to Zoom or to outside activities during the pandemic. For people experiencing cognitive challenges face to face activities, with the exercise of travel together, are ideal – for befriending support for individuals, see ArtsPAL page 180) but the Zoom camera's eye offers encouraging personal eye contact and with guidance imaginative ways to use screens for dance, drama and visual arts.

Access issues are discussed on page 167.

Most of the following, listed by region, are taken from organisations represented at A4D conferences and meetings.

#### 4.2.1 NORTH WEST: Greater Manchester

Manchester Museums: Andrea Winn, Curator of Community Exhibitions, Age-Friendly and Volunteer programme lead (Host, A4D Sep 2020)

#### Made to Measure: Inclusive programmes for Older Adults.

All our programmes are age-friendly, accessible to everyone, including those pre-diagnosis of dementia or living with dementia. We try and develop them for and with older people, so their input, time and support are valued, and it gives our participants a sense of purpose.

The museum is developing a specific age-friendly volunteer programme which will build on IF: Volunteering for Wellbeing. It was a three-year programme with a longitudinal study attached to it, an evaluation, bringing in lots of the conversations we have been having. This programme evaluation followed a social return on investment model - we found that for every pound invested, there was £3.50 worth of return on social benefit to society. The final report recommended for the next steps looking at integrating the SP model into volunteering, and the opportunities that would bring, not just for participants and their wellbeing, but to society as a whole.

What we are considering actively is an age-friendly volunteer programme which has the opportunity to include specific training on museum's documentation, conservation and support and care of the museum collections, and then at a later stage, working with collections and with the public, based on models we've worked on before. All the staff who would deliver the training would have been trained as Dementia Friends, but we would also look to work with support providers. Once the volunteers have completed their training, they would be offered a regular volunteer time to suit their chosen role and their availability, ensuring appropriate support is in place, working with a service provider for this. We found that regular structure supports all our volunteers, not just those living with dementia or with a pre-dementia – it is that contact and social activity, it is bringing people together.

A lot of our volunteers do tell us it is not just the volunteering, getting to know the collections and sharing their knowledge, but they feel valued by the museum. They have that sense of purpose, but there is also a very social aspect to our volunteering. It is not done in isolation, we have over 120 active volunteers that are very much looking forward to getting back when we reopen. We all know that volunteering has been well documented in the benefits it can bring in supporting wellbeing and sense of purpose. It fits with our core values as museum, which are to be inclusive, imaginative, and caring. So, we want to talk with service providers and connect with LW to see how we can make this work. We have got the experience on the volunteer side that we would like to really develop, so we would love to follow up these discussions after the event.

#### 4.2.2 NORTH-WEST: Greater Manchester

# <u>The Whitworth</u>: Claire Cowell, Artist and Age-Friendly Coordinator (A4D Sep 2020)

We have a programme of activities, but I want to talk to you today about our Handmade programme. We wanted to develop a programme where to only criteria is being over the age of 50. The Whitworth having covered very aptly the specific dementia work, through *Beyond Dementia* (see Partnerships, page 185), so the Handmade model was developed, available to anyone despite your health condition, so we set up weekly craft-based sessions, as other people have mentioned, crafting, making and socialising is really important to people's wellbeing generally. We wanted to make them accessible to as many people as possible, so we made them free. It runs every week, during term time, all materials are provided, and each session is facilitated and led by an artist, that was the model we developed, and it has worked really well. We don't ask people what their health conditions are, but through the natural weekly process of making and socialising, we do know that a number of people who have accessed the workshops have got various health issues, including dementia.

We were able, through the Live Well Make Art Programme a couple of years ago, to take that Handmade model on tour. We set up and ran an eight-week series of sessions where the participants were referred by local GPs, we spent time developing relationships with GPs in the area, which was Whalley Range and Chorlton. We worked closely with local community groups to support the project, and we also employed a local artist to facilitate the workshops for the project, again we made this free. The development of the relation with GPs, to refer people onto the programme, worked really well, so that model is something that we would like to do again and build up in other areas. Within the weekly sessions, and the evaluation that came with that, one of the participants said,' This course has been invaluable to me as a newcomer to Manchester; it has enabled me to meet a lovely group of like-minded people, it has been lovely to do the craft sessions which have been so varied.' Although it was a couple of years ago, the project has actually carried on with a lot of the participants learning new skills and passing those on to other people as well. I wanted to finish by saying how important it has been to have the Handmade sessions continue over Zoom during the lockdown period, we have continued to run our Friday afternoon Handmade sessions via Zoom, which has been really interesting learning curve, especially for participants who have never used technology before.

This course has got me out of the house, it has been three years since my husband died, and I have been struggling to get out and about, I have met some great people and made new friends, learnt new skills, and discovered I am very creative.

(For The Whitworth, Beyond Dementia, see Partnerships, page 183.)

# 4.1.3 NORTH-WEST: Greater Manchester Elders Programme, Royal Exchange Theatre

Elders aren't just older – they're wiser. in a good society, older people are respected for their experience, for their knowledge and for everything they can teach us.

I am not the same person who joined The Elders on that very first day.

Nothing else I do in my activities or, indeed, have done in the past has brought my new found confidence I am now experiencing.

I want to shout from the rooftops, 'look out world, here I come.'
And if I can do it, so can you.'

The Elders is for older people in Greater Manchester who want to feel connected to new people and ideas, be creative and challenge the stereotypes of ageing.

The first step to becoming involved with the Elders is to take part in one of our regular Elders Mondays events (currently taking place online).

We also have an Elders Company. The 2019/2020 Elders Company took part in a year-long programme to develop their creative and theatre-making skills. This culminated with the creation of *A Funny Thing Happened in Isolation*, a new mocumentary following a local theatre group as they tackle lockdown narrated by Julie Hesmondhalgh.

Graduates of previous year's Companies continue to take part with us in special projects including as Leaders and by taking part in our intergenerational projects alongside our Young Company.

In 2019 we hosted our third Elders Exchange Day (to celebrate older people as makers and artists. Plans for Elders Exchange Day in 2020 were disrupted due to Covid and we are currently reviewing when we can next host Elders Exchange Day.

The Royal Exchange Elders programme is proudly associated with Age Friendly Manchester and the GM Ageing Hub. In 2019, we also led the Manchester Culture Champions programme.

# 4.2.4 NORTH-EAST: Tyne & Wear

Clare Smith, Learning & Engagement, Tyne & Wear Archives & Museums (TWAM) (Host A4D Sep 2020)

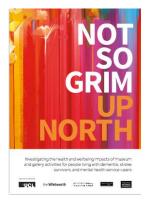
As the recently appointed Learning and Engagement Manager for TWAM, I have the privilege of managing our outreach team led by Zoe Brown and am immensely proud of the work Zoe and her team have continued to deliver with communities, care homes and professionals in the area of wellbeing, older people's health and social care, in these challenging times. TWAM consists of nine museum and gallery venues in four local authority areas, along with the regional Tyne and Wear archives. Our programming is developed for a diversity of audiences, including our Platinum Programme which focuses on older people. TWAM has understood for a long time how our collections can support people living with a diversity of life challenges, including dementia.

#### Create, Connect, Collaborate

In the *Not So Grim Up North* research, undertaken (2014–18) by Professor Helen Chatterjee and funded by Arts Council England, it was noted that these projects highlighted mood improvements in participants, reduced feelings of isolation, created new social connections, learning and skills acquisitions, and opportunities to get involved in volunteering. It has now never been more important to create, connect and collaborate in partnerships that maximise the benefits to our communities and utilise our available resources, and understand the outcomes and impact they can have. Collaborative working in our own museums has included partnerships with Age UK, NHS England and others, and our teams have engaged with people - including those recently diagnosed with dementia - in visits to our venues, object handling, storytelling, and creative activities, and there is a social aspect to this; fun and conversations, along with care that enables real tangible benefits for our participants.

Neil Churchill, the director of NHS England's Experience, Participation and Equalities group, contributed the foreword to our recently launched *Museums*, *Health & Social Care Service* resource, and described how in using our collections 'Precious memories will be sparked by images of Tyne bridges or old cinemas, the scent of traditional cosmetics or herb gardens [...] these will prompt reactions and stimulate conversation.' He goes on to recognise that activities such as these have relevance to specific health and wellbeing goals, such as pain management, cognitive stimulation or social interaction. The resource, created with Northumbria University, involved a multiple disciplinary steering group of health and social care practitioners, academics, an occupational therapist, a physiotherapist, a mental health nurse, social worker and older people's nurses.

Today's programme is a real opportunity to listen and connect across disciplines, and understand the work currently taking place, an opportunity to make new collaborations. Arts, heritage and culture can play such an important part in the wellbeing of all our communities and can have real practical benefits to individuals coming to terms with significant life changes, such as an early diagnosis of dementia.





# 4.2.4a NORTH-EAST: Newcastle uponTyne Zoe Brown, Outreach Manager (TWAM) Platinum Programme

With the Outreach team at TWAM, we work with adults who don't normally engage in the museum service - in four targeted community engagement programmes. The Platinum Programme and all our Adult Community Engagement programmes are health, social care and wellbeing focused. Using the collections as a tool, we devised them to support community organisations and services with social issues that affect people in the North-East. Addiction recovery, mental health, and an ageing population are all high on the agenda.

Platinum Programme is an umbrella title for a range of cultural and heritage projects we run working with people over 55, which also supports organisations, services and professionals working with those over 55. I am going to focus my talk today on some of the work, where our target audience is people with early-stage dementia.

This year, 181 staff completed the Dementia Friends training across the organisation - that is, front house and back of house. I know it is very basic training, but it is one mean feat to do that for a museum service. In every single venue now, we have people who are trained in that and have a basic understanding. We also run Slow Museums which is led by slowshopping.org.uk, which is quite prominent around the Gosforth area, but it seems to be going national. Slow Museums involves relaxed opening times, our front of house are trained and involved in how they can make their venues more welcoming, more dementia-friendly environment, and that is across all the districts that we work in. We have got monthly Slow Shopping events which happen at the Shipley Art Gallery and the Laing Art Gallery.

We also run number of closed workshops, such as Time Travellers, a partnership project with Age UK North Tyneside. Running since 2015, it came out of the Dementia Friendly Communities pilot in Wallsend. Time Travellers is a group of people recently diagnosed with dementia, referred to us by Age UK North Tyneside. The group comes to Segedunum Roman Fort every month. Some people are very independent and come alone because they know we are set up in case they have a wobble - as they call it. Others come with a family member or a carer. Each session involves an activity inspired by the collections - Roman pieces from ship building, social history, biology, geology, Egyptians. Object handling leads to discussions which can bounce off into lots of different areas, and normally we create something as well.

Time Travellers named themselves. Our working title was the Dementia Museum Group, but the group wanted to call themselves Time Travellers - we couldn't have come up with anything better, it is spot on! During 2018/19 we got additional funding and ran four extra groups. That was only across North Tyneside because there was a big waiting list for the group and we can only have a maximum of 12 for that quality experience. We want to roll out Time Travellers to different districts and in different venues, and to create a referral pathway. We also want to think about a digital pathway, because at the minute it's on hold because of COVID. There has been lots of testing venues, so we're probably just about to start some of that again.

4.2.4c NORTH-EAST: Newcastle upon Tyne Kate Parkin, Creative Age Programme Manager, Equal Arts, talks to Gill Taylor, Co-Founder and participant, Let's Meet Up.<sup>69</sup> (Co-host, A4D Sep 2020)

KATE: I am Kate from Equal Arts, and I am going to be introducing Gill, who is the co-founder and an active participant in the Let's Meet Up group, which are an inclusive, dementia friendly and cognitive friendly group based in East Durham. They have been in existence for a few years and are now a constituted the group. It is very much about the group, but they have been supported by the Council and Creative People and Places programme as well. Gill will talk about what the group means to her, and about what creativity means, and the value of it from someone with lived experience. So, Gill, can I ask, why is creativity so important to you?

GILL: When there are lots of things you can no longer do, something creative is actually something you can do, without fear of getting it wrong. Being diagnosed with dementia at 58 – so early – and eight years on, still with dementia, still having slight difficulties. You need something you can be inclusive with. I have had to give up so much in life because I can't understand it or can't follow the instructions. Art is something that I have started to do now. It is really important for me and for the people who come to our group because it has opened this new world of what you can do and can be proud of, and it doesn't matter if you're wrong – there's no right or wrong with art.

It is about creativity, and challenging your own perception, challenging what you can do. People who come to our group always start off with saying *I can't do art*, but we say 'It's OK, you can do this. 'It is the social aspect of it, because it's about doing things with people who understand that you can't always do things in the same way as other people do them. You don't have to feel stupid if you can't get something right. It's a complete lifeline. It takes you out of isolation, because there is something you can connect to on a broader level. There may be some art programme on television, and you say 'I've done that!,' or you might see something on Facebook and think, 'I might have a go at that', whereas I wouldn't have done that before. It is not about painting, it's not about drawing, it can be anything, absolutely anything!

**KATE:** It is so nice you talk about that lifeline, and the possibility of creativity to challenge whatever level, whatever ability you have. It is the enjoyment and at your pace you can still challenge yourself and express yourself. You picked up about the lifeline when you're feeling isolated, so I wanted to ask how the group have helped each other in a social and creative aspect over the last months of isolation. How have you supported each other?

GILL: When we weren't allowed to meet up, I felt quite fearful, fearful that I had lost that community, the community of people that understand who I am, what I can and can't do. So, our group took it online, and took it by post, so we would get a pack in the post. Our artist, Claire Ford, is brilliant. She will

<sup>&</sup>lt;sup>69</sup> Supported through the dementia-friendly Creative Age programme, Durham County Council and Equal Arts.

## 4.2.4c Newcastle: Equal Arts 'Let's Meet Up!

send us a pack and explain what you can do with it. I feel quite excited and childlike knowing that I'm going to get that envelope through the door, thinking 'What am I going to get this week?' Our recent one was art that you can do with what you can find in your home, so I had some acrylics - you can use anything from bubble wrap to string - and I am shocked at what I can produce! In our community, and on our WhatsApp group, we say 'Look what I've done!' and another might say, 'Well I'm not showing you yet', but then when someone shows you what they've done, you think 'Wow!' This is cool, it's about the group sharing what they have done. It is about, for me, living on my own now, connecting with other people. I know that there is a group of people out there who I am going to be seeing say once a week, or on WhatsApp or on Facebook, I've just set up a new Facebook page where we share our artwork. It is that connectivity and communication, that is important to me.

KATE: It is really important. And it is so nice to hear from you, and the group themselves, talking about what it means, and how you have embraced technology. I am always flabbergasted with your group, you say we're going to embrace this because we need it. You've embraced Zoom, you've embraced creative tutorials, you've taken postal packs, you've phoned each other, you've used WhatsApp, you've Zoomed each other to have meetings, all because of the value, to you, and you wellbeing, and the group themselves, so thank you so much for sharing that with us.

**GILL:** Without the group, this there would be nothing, each day would be the same. I have friends, but it is that group togetherness.

**KATE:** So it is the social and creative, and creating that support together.

#### 4.2.5 YORKSHIRE & HUMBER:

Gabrielle Hamilton, Head of Community Engagement, Leeds Museums & Galleries (Host, A4D Oct 2020)

We have nine amazing sites across Leeds, from country houses to art galleries, to industrial museums. This all helps to provide a range of opportunities across our services for people. Our team are funded by the Arts Council, with a remit to engage communities with our collections and sites; and we are committed to offering services geared and tailored to older people.

#### Age-friendly, Dementia-friendly, Connectivity.

We work to Leeds City Council priorities around being Age Friendly, Dementia Friendly and working towards Leeds becoming the best city to grow older in. We strongly believe in intergenerational work and have projects around that, which helps people feel connected and involved in current affairs.

#### Culture, creativity and heritage for wellbeing - belonging

We do believe in the positive contribution arts, heritage and culture can have on people's mental health, and we have a collaborative approach where people co-produce and co-design programmes for their enjoyment. We have three principles around wellbeing, creativity, and belonging.

#### Sharing experiences, skills, new learning

It is important for older people that we nurture that sense that they can contribute – as recipients of our programmes but also as active contributors, sharing life experience, skills, memories and new learning, it is a very reciprocal arrangement, and there are lots of activities they can join in with across our sites, and it's worth checking out with the individual what's on offer.

#### SP partnerships

We would love to have closer connections directly with health care providers, so we can receive referrals directly into our service. People can join under their own steam, but we do have tailored partnerships with organisations, care providers, third sector and visual arts charities. We provide participatory programmes over weeks or months; those partnerships work well for all. Our participants get involved in events, exhibitions and outdoors activities.

#### Volunteer opportunities

We have an active volunteer programme. Older volunteers provide and contribute so much, guiding research.

#### Peer support

Our peer support service enables people with dementia to experience their whole journey with us, from participating in regular adult programmes and then, perhaps as their dementia progresses, joining another regular well-established programme, so they can be familiar with us and their surroundings, providing what we would hope is that seamless transition.

#### 4.2.5a YORKSHIRE & HUMBER:

## Clare Jolley, 'Meet & Make' facilitator, Leeds Museums & Galleries

Meet and Make' is a friendly and welcoming group, aimed at adults and older people. It's a great place to learn about art, meet new people and create something as well. Prior to lockdown, the group met every week in the foyer, starting with warm welcome, where volunteers and staff would catch up with regular members and introduce new members to the group. It was a drop-in session, so you never knew how many people would turn up, and what their needs were. Activities are designed to be accessible, flexible, friendly and welcoming. Ordinarily we begin with an art chat, talk informally about a piece of art in an exhibition, thinking about a simple theme, like colour, material, technique, just to start those conversations, encourage people to share their thoughts and feelings, and create a safe environment for people to feel listened to, valued and respected.

Following that chat, we would go into the art space and create an artistic response; we would introduce the material, and encourage people to be playful, try something out, and take it in their own direction. That is something that when you get older, you do not often have the opportunity to do as much, it really does make a difference.

#### Confidence, friendship and relationship building

We have noticed people's confidence grow. Members who just listened at first, would begin to share opinions and find their own voice in the group. People have formed strong friendships through Meet and Make, and members outside of the group have been drawn to that. The group have had strong relationships with staff members too, which creates that sense of belonging, and they always have a familiar face when they arrive too.

#### De-stressing tranquility of creativity

Practical sessions have different elements. It is quite relaxing, so people feel quite tranquil after sessions. It is that quiet concentration when making that really helps with de-stressing and relaxing. Members also learn new skills and new techniques, and sparks things they've previously had an interest in.

#### Feeling valued and listened to - Time

Most importantly, it provides the space for people to feel listened to and valued, in what was, prior to lockdown, the hectic culture that we lived in. If you can give time to people, that is so important.

#### Online, outside and blended

We have moved online, and we have created a series of videos that have been focused on relaxation, and using things around the home for inspiration, or on walks. Feedback from online activities shows that though they are relaxing, therapeutic and spark new ideas, members are missing live connectivity. We plan more live formats and have started with a gardening project. We are looking at non-digital contact; and a potential blended format, when we can come together, and enjoy a conversation and a cup of tea together.

#### 4.2.6 YORKSHIRE & HUMBER:

Nicky Taylor, Theatre and Dementia Research Associate, Leeds Playhouse (A4D Oct 2020)

## 'Heydays' and 'Our Time'

Heydays, is the largest and longest-running arts programme for older people in UK theatre, and has been running for 30 years. A community of around 300 older people bring their skills and talent each week to take part in everything from drama and dance to sculpture and creative writing, visual art, through to talks and debates and is supported by a team of professional artists. Heydays is a vibrant, creative community where skills are developed, and stories are shared. There is something for everyone.

In 2014 we introduced a programme called Our Time, specifically for people with dementia, this was as a result of noticing some participants of Heydays were struggling with early symptoms of dementia, whether or not they had a diagnosis. We have done a lot of work over the years to reduce stigma, through open conversations, so that when people join Heydays when they are healthy and newly retired, they may stay with us for 10 or 20 years, but when things do begin to change, they don't lose that anchor of creativity and community. We value open conversations, so if contributing in Heydays sessions is getting more difficult, we can address that and guide someone to try Our Time, which is designed specifically to be on a smaller scale, for people living with dementia and their partners.

Creativity can really maintain positive brain health; and it gives people the opportunity to express themselves in new and different ways. For some people it might be a habit which has developed throughout their lives, where creativity has always been part of their experience. But for others, perhaps they haven't led a life which has involved the arts. Actually, the moment of diagnosis can be a moment of discovery – that there are new possibilities out there, to take a risk at being creative. It is a risk for some people; and arts organisations can feel daunting, but it is important to have a smooth accessible easy route in. We find that it really helps to work with social care partners, like the Peer Support Service in Leeds, who have a holistically nurturing offer for those newly diagnosed or who are seeking help after a diagnosis. We want people to feel energised by the sessions that we run, and to feel like their contribution matters. We always hope to hear from everyone in the sessions, but at the moment that is really challenging as we're using Zoom for all our sessions, but we have come on in strides over the last few months to get people up to speed with the technology, helping people get hold of iPads, and doing lots of coaching over the phone to assist people to use them in the most simple and accessible way.

Resource: Dementia-friendly performances guide

#### 4.2.7 YORKSHIRE & HUMBER:

# Opera North Alex Bradshaw, Family & Lifelong Learning Manager, Sing On! (A4D Oct 2020)

Sing On is a singing group for over 55's in Leeds – it is actually five group groups, which have been running since 2015; the numbers have grown over time, but before lockdown we were meeting with 150 people a week. Online after lockdown, we are back live, but online for those who prefer. During lockdown 100 people met every week online. We did a lot of work making sure people could access Zoom, and that they knew how to operate it, devoting time troubleshoot every week, and getting better and better.

#### Singing for wellbeing – not for performance

We're clear that this is not a choir. We don't practice for performances. It is about singing for wellbeing, togetherness and enjoyment. Sessions last about an hour and half, we have half an hour for social time and tea.

#### Choosing a variety of repertoire

We do gentle physical and vocal warm-ups at the beginning. We sing a range of genres including opera, classical, folk and traditional music, and various arrangements of musicals. It is very varied and people input their preferences.

#### Mini Opera North performances

We offer additional opportunities to engage with other work that Opera North does. Quite often we put on small performances, we use the same venue, and we bring in a cast and do mini opera performances for people, which is a fantastic way to come together.

#### Older singers, with or without early symptoms of dementia.

Our sessions are simply for older people, we know that a number of members are in the early stages of dementia, and who have told us that. There are some we gently support to attend, and we keep an eye out for them. It is a gentle environment, very welcoming. Nobody feels under pressure to attend every week. We are open to everybody and all abilities and welcome those who are at that pre-diagnosis stage.

We have been having new building work and are developing new ideas. Space is such a massive issue; and having a dedicated space for our learning and participation is exciting, we have been planning it for ten years now!

#### Feedback: Sing on! A lifeline, forming friendships even online

In terms of the outcomes and feedback, people tell us that Sing On! improves their mood, wellbeing, confidence. Their emails tell us that the sessions are a lifeline, that they are their only social interaction, and that is has really kept them going during lockdown. We just keep going on until we can come together again in a physical format. New friendships are being formed. Even online, people who haven't met each other in person, or who hadn't attended before, have met each other on Zoom and have formed relationships and friendships. That gives people hope and improves their wellbeing a great deal.

# 4.2.8 WEST MIDLANDS: Birmingham

# Rosie Barker, Senior Engagement Officer, Birmingham Museums Trust

(Host, A4D Nov 2020)

I want to welcome you all to this A4D SP meeting, its lovely to be part of it and to be asked to host, it would've been lovely to welcome you to one of our museums in person, but we are about to close again due to the pandemic. My role is to lead on, include and represent people who aren't engaging with our museums for whatever reasons. That could be financial barriers, language barriers, physical access; and, of course, health issues and wellbeing can be a huge barrier for many people. What many people aren't aware of is that engaging in arts and heritage activities can impact on wellbeing, and there are huge benefits. Lots of research shows that engaging with arts, heritage and culture would really help people.

This year has really highlighted the need for places and activities that bring people together, which unfortunately we've lost that this year. At Birmingham Museums, we run nine heritage sites across the city, which means for many people they have a museum on their doorstep, a home site, which, pre-Covid at least, people could pop in, have a cup of tea in a familiar space, feel welcome. For so many people this familiarity is really important, especially for those who later receive diagnosis, who have a safe art place to visit.

In a normal year, across our sites, we run regular tours and events, from lectures to family craft or picnics. We have weekly musical performances, Christmas choirs, dance performances, storytelling – the list is endless. We also have a fantastic volunteer programme, working with around 1000 volunteers a year, and our volunteering programmes not only offers the volunteer role, but the social activities, training, trips and most importantly, a sense of connection, which is increasingly important. This ties in with that sense of isolation that people can feel when they have a dementia diagnosis, or when symptoms arise.

#### Connection and Community - and volunteering

This year has shown people need to feel connected, to friends and family, peers, communities and the wider world for wellbeing. People forget the arts can offer this as well. If you volunteer with us you are part of a social network, we have trips for volunteers, coffee mornings, site visits, and a lot of this have moved online this year, but we're still maintaining this connection with our volunteers. This is as well as the benefits of doing the role itself, that can be very meaningful and worthwhile, and gives people a sense that they're contributing which I think is very important.

For those who have dementia symptoms, feeling anxiety pre or post diagnosis, that connection can so easily be lost, and visiting museums can help maintain that connection to the wider world, as well as volunteering with us or attending events or performance, people can of course drop in, have a look around, talk to our fantastic staff, and one thing that again can be so easily

# 4.2.8 WEST MIDLANDS: Birmingham Birmingham Museums Trust

overlooked, is the value of museum staff, particularly our Front of House staff. They are excellent in engaging people, they are engagement specialists, whether they are children, teenagers, adults, or non-English speakers, our staff are excellent at bringing people together, creating that bond, helping to meet peoples need and identifying what they are. Museums can provide a welcome to everyone, provide a safe space for people to visit pre or post a diagnosis. To ensure that those living with dementia have the best experience, regardless of a diagnosis or not, we have ensured that a large number of our staff and volunteers are Dementia Friends. We also had a mystery shopper group of people with dementia to assess our accessibility and give us opportunities to improve our offer.

At the moment we don't offer specific SP programmes. We have wellbeing programmes which are open to everybody, or some target a specific need, a specific client group, which people can self-select into. Ongoing we have programmes for carer wellbeing, we have a dementia-friendly programmes for people with a diagnosis, gardening for mental health, programmes for young carers — it is vast. For people pre-diagnosis, we have arts for wellbeing programmes. We don't ask for eligibility or ask people to explain why they've come. It can be very welcoming for those looking for that connection.

There is a huge amount of research that summarises how arts can improve wellbeing for so many people. The WHO report (2019) summarised hundreds of pieces of evidence on the value of arts to wellbeing. It covered everything from music for babies, to older adults and end of life. Using the Five Ways to Wellbeing measures, you can really see that visiting museums, going on tours, looking at art, volunteering, going on a nature walk, whatever it is, can support people to Take Notice, Give, Learn, Reflect and Be Active. There are so many links there which are forgotten about – people often think it is passive experience.

We have a huge amount of evidence from our own programmes at Birmingham Museums, where people have highlighted the value of feeling connected to people, feeling part of a community of their peers or visitors, or a community of arts lovers. People feeling welcomed and not judged, which is so important for those with a dementia diagnosis, who may be feeling increasingly isolated. A real benefit is that people talk about being able to come to a non-medical setting and take part in something, we've found this with carers as well, that so often so much of their lives moves to doctor surgeries and medical centres, and we can provide activities in that separate setting. At Birmingham Museums we're not atypical, we do what lots of museums do, but it's really important to talk to people about getting involved in the arts, we are currently closed, but we're still connecting digitally as much as we can, and when we reopen I really hope that the connection and support we can offer to help people's wellbeing can start up again.

# 4.2.9 WEST MIDLANDS: Birmingham

# Faye O'Connor, Dance artist. Xpress-Yourself\_

Xpress-Yourself has been running since 2013. We specialise in older adults and getting them dancing. We run weekly classes for active older adults and do creative work with frailer older adults in care settings. We are independently run, so we don't obtain any funding. Our  $\pounds 5$  charge per class sustains our ongoing classes.

I have completed various training – circle-dancing training, creative age dance training and postural stability training. My whole passion is about keeping people moving, getting them dancing and helping people maintain independence for as long as they possibly can.

We're in an interesting situation in that our classes have been running for seven years, and then they stopped running for people who couldn't access Zoom, so we used that as an opportunity to research the impact of not having their weekly dance class. 44% of people said that not dancing had a dramatic impact on their health and wellbeing, there was strands of people feeling depressed, people gaining weight, and little things like feeling stiff, or reoccurring injuries that they were managing have reoccurred and become quite painful, their balance was off, and a lot of them joked that their grey matter wasn't being worked – we like to say our dance classes give our brains as much as a workout and the body. Remembering steps and sequences, for a lot of people, is why they come to our dance classes, to get that different type of stimulation.

44% of people said that not dancing had a dramatic impact on their health and wellbeing

A little story: one of our dancers has been dancing with us every week since she lost her husband - we teach lots of styles and it is all without a partner, so it suits people who are on their own - she saw our classes on a poster in a bus shelter, she came when she lost her husband and needed some sort of social outlet, and yesterday I received an email from her daughter saying, *You don't realise the impact it has had on her life*. This is to the point where when she went into lockdown she was so scared of computers, she had her granddaughter go outside her house with antibacterial wipes and pushed her iPad through the letterbox for her to be able to download Zoom so she could access the dance class, because it was going to be a way she could connect with other people and her friends. We cover lots of different styles, [Faye leads a ballet exercise for the meeting.]

You don't realise the impact it has had on her life?

Our sessions are an hour long, we have two warm-up dances that are focused on mobilising the joints and getting our hearts racing and working on balance, we learn two routines and then have a cool down. We have the same playlist of music throughout the month - enabling repetition. Our aim each month is to get to the end of the dance, that's where the self-esteem boosting and confidence comes from. Our dancers can think that they're on Strictly Come Dancing for an hour, we encourage that and we also encourage the dancers who just come along for a bit of a giggle, we encourage whatever the needs are for the class. It's always fun, lots more people joined for lockdown, and lots more people again as we go into lockdown again.

# 4.2.10 EAST MIDLANDS: Nottingham

# Amanda Spruyt, Head of Learning, Nottingham Contemporary (Host, A4D Conf21)

Nottingham Contemporary is a free international art gallery in the centre of Nottingham, but more than an art centre. What we strive to be is a community hub. That is why the relationships and the partnerships that we form across our cities with groups and individuals are so important to us. It is through these relationships and connections that we define our purpose and our approach. That is connections between people, but also connections between people and artworks and materials, and connections to ideas.

#### A.R.T.S. for brain health

We have got a really experienced team of artists and programmers, who have a track record of supporting dementia work. Our Communities Programmer, Natelle Morgan Brown (see below) works closely with the Alzheimer's Society. She is a Dementia Friend trainer and has been part of delivering training and raising awareness across our team. She also works and brings groups from the Alzheimer's Society regularly to our venue and to our programmes, and together they review the work that we do.

#### Celebrating Ethnic Diversity

It is this reflection and research that is important to us. We recently led a research project about exploring the experience of arts programming on elders, and/or those people from African, Caribbean, South Asian or Southeast Asian heritage. The key finding from that research is what we all know right now, about the importance of direct contact with people, and of those social moments. Since then, we have been really trying to embed that in all our work and programmes.

#### **Exploring Materials**

We have developed Welcome Walkthroughs, where we bring visitors and staff together socially, to form relationships and connections. It is also an important strand within our Adult Lifelong Learning programme that we have branded Exploring Materials. These weekly sessions, in which participants explore drawing, sculpture, sound and collage, are open to everyone, but they are tailored to over 65s. That might be people who are pre- or early stages of dementia, but it is really important to us that those workshops are for everybody. The thinking is that they are inclusive, but they are dementia informed, that's very much at the heart of what we do.

#### Embedding understanding of dementia

What we want is for that knowledge, that awareness of dementia to be embedded as part of all our programmes and our thinking, so that it is core funded, and can happen regularly and routinely. That is where connections really come in. What we really want to do is be part of providing a network and working with cultural organisations and partners across our city to work together to provide a rich offer by connecting up and by programming collaboratively and promoting collaboratively.

# 4.2.11 EAST MIDLANDS: Nottingham

# Sharon Scaniglia, Arts Project Coordinator,

## ArtSpeak (A4D Conf21)

I work for Radford Care Group which now has a new purpose-built building for old people called 25 Prospect Street. We've got a Carers Forum, we look after people in a day care setting for people with dementia. We also have a Friendship Group for older people. At the moment, we have about 15 people in the building. When we knew we were having a new building, I wanted to make sure the building was well animated, and full of life, and we wanted to look at the arts as a way forward. We also saw there was such a lot of need in the city, and to just bring everyone into the building wouldn't be possible, so we decided we wanted a peripatetic art project, which we do now have.

We also worked a lot with Professor Justine Schneider at Nottingham University, as we were going to focus on older people with dementia. I felt that although that's a really good way to go, there are a lot of people we could help have a better life by staving off dementia for a lot longer, because they were active and using the arts as a wellbeing tool - that was important to me. Hannah Stoddart is our Project Coordinator, and together we run a lottery funded project called <a href="ArtSpeak">ArtSpeak</a>. ArtSpeak is a project where we have four different types of engagement, and we take people to lots of different venues across the city – or we did! – and we engage people with where they live, to try and get them to come, enjoy and join in, and get out of a loneliness situation and all the other complex conditions that you're well aware of.

We did that, and our project really is looking at forming hubs, where people can go on a regular basis, so if there is a diagnosis of dementia, then the people they're with know them, and that is much better than starting a new arts activity when you don't know anyone and you've got a new diagnosis. People are people, whether you have got a diagnosis or not, you have still got a cultural right. That has been with me the whole of my career, no matter what age you are, you have that deservingness and that ability to have a cultural opportunity, and society should provide that. So that is one of the big things that I feel keep people young, and that is engagement in the arts.

We have these four strands: Participate, Create, Meet, and Live. I'd like to talk about our Just Jamming which happens once a month, we have a lot of older people coming together to play music, and we have an octogenarian trombonist, and we have a lot of people jamming together who then become friends which is lovely.

We also had the Spiegel tent when I was working at city council, and it bought together a lot of people in several debates about older people in the city, and created a more joined up force, similar to how we're talking together now. That is the way forward, where we all work and we all collaborate to make life better for older people, whether they have got dementia or not. The <u>DAA</u> in the city is making good moves forward, and of course ArtSpeak is now virtual, so we're having lots of sessions online, and we have also created an art book which, if you don't have internet, you can ask us to post it out to you!

# 4.2.12 EAST MIDLANDS: Nottingham

# Kate Duncan, Programme Director for Wellbeing, City Arts (A4D Nov 2020)

<u>City Arts</u> in Nottingham has a long track record of arts and health work. Recently we have been funded by Arts Council England and the Baring Foundation and we seek funding from trusts and foundations. City Arts has a long record of working with people with dementia in care settings. We have developed an <u>Armchair Gallery</u> app and have developed a multi-sensory approach with people with more advanced dementia.

#### Green prescribing

More recently we have been exploring green prescribing in communities. We always consider the person, rather than the condition they come with. Often, we host mixed groups of people, who can come with carers and partners. SP really works well in terms of people keeping active and mentally stimulated. Exercise is a really good preventative factor for those in the early stages of dementia. We are exploring connecting with nature, walking, history, mindfulness, and meditation. It is very much an approach, in all the arts engagement that we do, about living in the here and now.

#### Co-production

We also work with a co-production format; so we would ask participants what they want to do, engaging with participants on an equal basis. Some of the partnerships and people we have been working with have included SPLW quite readily, which has been a great help in referring people to projects.

#### Partnerships

We have been working with health organisations and care professionals, the cultural sector and have found that the National Trust and Nottingham Wildlife Trust, Renewal Trust and the Canal Trust all really want to focus on this area of work. We also work strategically with large organisations like Age UK, tap into the Culture Health and Wellbeing Alliance (CHWA), and London Arts and Health. We often work with universities to evaluate work, so we are really well informed about the direction of travel and how we can improve our services.

#### Art forms

In terms of art forms, I think things that have worked well in the past are things like movement, dance, music, puppetry, poetry, carnival and outdoor events.

# 4.2.13 EAST MIDLANDS: Nottingham

# Angela O'Neill, Leader, Our Dementia Choir, and Chris Connell, former teacher, choir member

I lead Our Dementia Choir, which was filmed for television in the summer of 2018. Chris is one of the most memorable members, certainly one of the most enthusiastic, so I have been asked to interview him today and ask about his experiences, and how it helps or affected his life with dementia.

**Chris**: It is one of the most exciting things I've ever done, it was really inspiring and so beautiful being part of it.

Angela: It was so fun to do, we laughed all the time, and we still see each other every week on Zoom. Throughout the time we've been together, we've been able to do lots of performances, from a marquee in a muddy field through to the Royal Concert Hall in Nottingham. How does it make you feel when you perform on stage – or in a field!

**Chris**: It is really exciting, it is so incredible being part of this, it rolls and rolls. I thought it would wind down after the final performance, but it continues. Everyone's really keen and switched on, it's wonderful.

Angela: When you're on stage, what do you feel happening in your brain?

**Chris:** It is a real buzz, so exciting! It's like being with all my best friends on top of the biggest mountain, it is wonderful!

Angela: It is definitely a joyful thing to be a part of. I've noticed that when these guys are performing, there's no fear, there's no dread or stage fright, I'm shaking, and they just get on with it. You all amaze me, Jane, from your point of view, how have you seen Chris change since joining the choir?

Jane, Chris's wife: It has affected the whole family. It has given Chris a purpose. Since the diagnosis it can be difficult to look towards the future, so it has given us something to look forward to, and a belief in ourselves. It has enabled him to be challenged and take part in something. The music is now part of our lives, I've actually picked up a recorder and we play together at home, and sometimes that's easier than having a conversation, which get more difficult as time goes on. He just gets such a buzz from it all, we have experienced things we never have done in our lives.

**Angela**: Chris, talking about the music, how has your interest in music developed since joining the choir.

Chris: I can't believe what's happened with my interest in music I've recently taught myself the ukulele, and I'm now in a position where I'm running a class to teach other people how to play ukulele. One of them has dementia in the group, and it's a really lovely session. I'm completely overwhelmed with the music. I spend two to three hours each day involved with musical activities.

**Angela**: One of the people who is learning how to play is Julie from the choir, she has never played an instrument in her life, but we sent her a ukulele in the beginning of lockdown, and Chris has been teaching her how to play!

# 4.2.14 EAST OF ENGLAND: Cambridge.

# Miranda Stearn, Head of Learning, The Fitzwilliam Museum (Host, A4D Dec 2020)

The Fitzwilliam Museum is the principal museum of art and antiquities, part of the University of Cambridge. The museum is 204 years old, and in normal circumstances welcomes 400,000 visitors each year to be inspired by our collections which span from ancient world right up to contemporary arts. These all provide rich varied starting points for the work we do around culture, health and wellbeing.

The museum's mission is to touch people's lives by engaging powerfully, thoughtfully and pleasurably with as wide a public as possible, and to produce and promote innovative, relevant, and interdisciplinary research of the highest quality around our collection. Our work around culture, health and wellbeing, and, specifically, our work with older people, spans these two halves of the mission, but it is particularly around touching people's lives powerfully and in ways that are relevant and make real difference to their wellbeing.

We are not operating on our own, it is part of the University of Cambridge museums consortium, which is the eight museum collections and a botanic garden. We've been working together in a more formal way since 2012, with our partnerships outwards to health and wellbeing sector. Together we're funded by Arts Council England as a Band Three NPO<sub>2</sub> serving the community of Cambridge, Cambridgeshire and the wider region.

Our collections go from A-Z, from anthropology to zoology - when we are working with older audiences, including adults with a dementia diagnosis, the breadth of the collection is a real asset and offers us a variety of ways in. People will gravitate more towards art or science, but then they may then find pathways between. That variety is important from the participant experience, but it also means for us, that when we're developing our practice, thinking about the difference museums can make in relation to this agenda, we're able to test our approaches in relation to different kinds of collections, and hopefully that makes what we do a little bit more transferable.

Portals to the World, our programme for people with a diagnosis, began framed as an art appreciation course, now also running at the Zoology Museum - to test if it has to be a work of art, or might an amazing zoology specimen that serves a similar purpose -. and collections across the consortium. About 75% of our Portal attendees continued to engage through our virtual offer in lockdown. This is a combination of pre-recorded content, live interaction and art materials sent in advance, so that they can participate together in an art activity, inspired by what they've seen and heard during the sessions.

The University of Cambridge Museums mission is to activate the power of the University through our collections, sharing with our communities and networks to deepen understanding of our world inspire new thinking, and address local and global challenges. That is, local and global challenges around health, health and inequalities, around loneliness and around aging well – these are all things we feel we can contribute to.

# 4.2.15 EAST OF ENGLAND: Ipswich, Suffolk

# Chrissie Moore, Participation and Engagement Manager, Dance East (A4D Conf21)

<u>Dance East</u> is based in Ipswich on the waterfront. We offer a breadth of activity for a range of ages and abilities. I have been invited to talk about some of our work for those over the age of 50, and the type of work we are doing out in the community. To respond to COVID19, we had to close the dance house; and our focus and energy was channelled into continuing programmes out in the communities.

#### **Movers**

I'm going to talk to you about our Movers classes. These are funded by Babergh and Mid Suffolk District Council, as well as Dance East as part of our core funding. They offer a weekly dance session for men and women over the age of 55. They are designed to boost mental health, physical health and include a chance to connect with others, but most importantly, and more so than ever, have fun and meet new people.

#### Geographical reach

The classes are led by experienced dance artists, accompanied by assistant dance artists, and they are happening in Lowestoft, Hadleigh and Stowmarket. Working in all these areas in Suffolk, it enables more communities within the district to access the benefits of engaging with great dance. By ensuring that the good geographical reach and the spread of our outreach activities means that we are not restricted to delivering activity just within our own building. We understand that also brings up its challenges and some people are not so confident to come into the building and access our provision in our studios, so we have designed models to take it out into those communities. A lot of those venues are village halls and community centres, and we are working in partnership with the Seagull Theatre in Lowestoft, a peer-to-peer arts venue, hoping we can reach the right people.

#### Supporting dance artists

The Movers model has been designed in order to sustain the activity, and right from the get-go we contract the dance artists as part of the funding, and to enable them to continue running the classes in those communities themselves as independent artists and independent businesses. After the year's funding, we support them to keep enabling those programmes in those districts, and also enabling the workforce to earn a living and to making sure that these pop-up activities can continue as much as possible.

If you are a new participant, or signposting a new participant, I would say the offer is a trio of movement, dance and tea. The sessions hope to make dance and movement more accessible by pairing the activities together and making sure that it offers a safe and friendly environment for newcomers, as well as those who have accessed our provision for quite some time. Also, a lot of our volunteers are over 50 and would really like to continue to give something back to the community.

# 4.2.16 EAST OF ENGLAND: Ipswich Alex Casey, Co-Director, Suffolk Artlink (A4D Dec 2020)

Suffolk Artlink is a participatory art organisation. We deliver a programme of projects across Suffolk and the East of England that support communities' health and wellbeing. We're also the arts champion for the CHWA for the East. I should like to share a couple of our projects and use it to illustrate the challenges around SP within this area from an arts organisation point of view. One of the main projects I wanted to talk about is Make, Do and Friends. this is a Celebrating Age ACE and Realising Ambition (Lottery) funded project, targeting rurally isolated older people. It has included people with a diagnosis of dementia but has also tapped into some people who were probably at that earlier stage and certainly including carers too.

Pre-COVID19, it was all about bringing people together in a village hall to take part in different creative activities, which we very quickly had to adapt to be more of a remote offer. We looked at delivering online sessions, we've done phone support and posted out activities for people. As restrictions eased, we managed to do some face-to-face projects too. That project is really around supporting the wellbeing of participants, reducing isolation, There is also a skills element— where before we were looking at creative skills, we have now adapted to look at technical skills. We're doing Zoom sessions on how to manage Zoom meetings, which requires phone skills support to start with. Now we're using creative activities to lure them into taking part in virtual sessions.

The other project I wanted to mention is aimed at family carers; and we have evolved it to cater for family carers and the people they care for. In consultation, we realised there was a real appetite for something more respite and aimed at the carers themselves. We developed a project on food, and the culture of food, addressing something which can be a challenging issue when people become carers, maybe the role of who cooks food has changed or there may be particular dietary requirements that come with a diagnosis. Rather than it being a drudgery, tedious challenge on a day-to-day basis, we have looked at inspiring people to embrace it. These are both ideal SP offers, particularly at an early point in dementia diagnosis journey, or as an early point for a potential carer.

We have found it really challenging to connect with SP. We had huge enthusiasm from individual SPLW, which resulted in individual referrals, but one of the big things for us is finding a more systematic way for local knowledge of opportunities that we can provide arts and get to those individual SPLW who can then make those referrals. It is an enormous amount of knowledge they need to hold to get the breadth of the local offer out to potential participants. I think finding a way to support SPLW knowledge around those different opportunities is a real challenge. They're all individuals, and they will all have natural tendencies to use physical, creative or more social activities. I think it is about sharing the breadth of that offer to the link workers.

#### 4.2.17 EAST LONDON: Tower Hamlets:

# Khadeja Chowdhury, Project Manager Bromley by Bow Centre (A4D Conf21)

The Bromley by Bow Centre is a pioneering and vibrant community charity in East London, renowned for its radical approach to health and wellbeing, working with vulnerable people in an area experiencing high levels of deprivation. There is a strong sense of design, harmony, the fun of creativity and wellbeing.

Khadeja runs a team engaging elderly residents to become active citizens, sharing their wealth of experience and skills with their local community. Skilled in managing projects that deliver power back into communities, Khadeja has worked alongside Tower Hamlets Council to facilitate the award and implementation of small grants programmes that support local residents to set-up individual projects, activities and groups that improve the health and wellbeing of their local areas.

#### 'Space to Connect – creative activities and healthy lifestyles

Space to Connect is a service that promotes creative activities and healthy lifestyles. working with clients over the age of 50. It aims to connect people and help build friendships. It is very much a cultural and diverse group of people who meet on a regular basis across all our activities. 80% of our referrals are from our SP team; 10% are from our internal projects and as we have other projects on site, 10% are from our external partners. Clients can also self-refer, it is a very easy process for them if they want to join any activities, and they can take part just by speaking to one of the staff on the project.

#### Crochet, knitting, cooking, walking

These are some of the activities we have been doing online during lockdown, all of our activities have moved online, and clients have been able to access them through Zoom and WhatsApp. Some of things they have been doing is creative activities, things like crochet, knitting, cooking. When government guidelines have allowed it, we have been able to have some walking groups to meet on site.

#### Let's Stick Together - collage

Very recently we have been working on an arts project with some local artists for the Let's Stick Together project, which enables people to connect and reflect using the medium of collage and is on Instagram. Clients are very welcome to move across projects if they find it is not stimulating enough for them, or they are not interested in it and want to try something new. We can move them across different areas of the project, but also within Centre, because anything that they are interested in, they can get involved with. It is very easy to move from each activity, because a lot of them are very flexible.

Fun, Friendship, Compassion and assume it's possible! at Bromley by Bow



Bromley by Bow Centre



Japanese silk screen painting



Sheenagh McKinlay with her stained glass.

#### @LETSSTICKTOGETHER202



Let's Stick Together on Instagram

# 4.2.18 WEST LONDON Jenny Marshall, Head of Member Experience, Open Age (A4D Conf21)

Open Age runs a broad range of low cost, high-quality group activities – physical activity, informal learning and arts, culture and social groups – delivered by qualified tutors at our centres and at community venues – to go where the members are, as well as them coming to us. We deliver across 50-60 different venues.

This is a member led organisation, so members feel that it is theirs, they own it. We currently have 4500 active members aged 50-104, 1500 attending each week. They do not just go to a yoga class, they come to Open Age. They are part of a self-made community.

#### Our impact

We have increased wellbeing and social connections. Our members are more active, whether it is physically or mentally, less lonely, and as a result, access less health and care services.

#### Inclusivity, sustainability and choice

We provide activities at a low cost is to ensure older people, from all socioeconomic backgrounds are able to take part in our activities. The key is to have a variety of inexpensive classes, so generally we charge  $\mathcal{L}1$  per hour, per activity. We offer a diverse choice reflecting the diversity of our membership.

#### Linking to A.R.T.S.

If people have difficulty accessing our service, our outreach and support service offers a Link-up programme providing short term interventions to members to help break down those barriers to accessing our activities.

Time for Me, provides a wide range of activities and peer support for unpaid carers aged over 50. Men's Space, where about 25% of our members are men, this acts as a gateway in order to help them be introduced into the broader programmes. In the home are phone groups designed for people who are housebound or are experiencing mobility issues or accessing activities in person, so they can have a social group over the phone.

#### A.R.T.S. to preserve brain health

As well as running a broad range of arts and culture activities, we work with organisations to give members the opportunity to connect with local culture. We were one of the founding community partners of the nationwide public arts initiative to create extraordinary acts of theatre in the community, with performances of *Pericles* at the National Theatre and *As You Like It* at the Queens Theatre in Hornchurch. We've had 80 members exhibit their artwork at the Saatchi Gallery, a partnership that we continue to nurture, even online. Which brings me smoothly to our remote delivery. Since COVID19, we have transferred activities online and have upskilled 300 members on how to use Zoom and are offering 130 hours a week currently, growing by the week.

# 4.2.19 SOUTH-EAST LONDON: Lewisham Maddy Mills, Director, Entelechy Arts (A4D Conf 21)

Entelechy Arts (f.1989) collaborates with communities across the health, voluntary and care sectors to create pioneering projects, mostly with those experiencing barriers to their local cultural community. We have emphasis on co-production – our communities lead our process; and we refer to 'members' rather than 'participants', to reaffirm that ownership of the programme. That idea of agency and independence is core to us. Entelechy nurtures a community of activists, dreamers, thinkers, artists and doers.

Our work with isolated older people includes <u>Meet Me at the Albany</u>, in partnership with the community arts hub, <u>The Albany</u> (see below).

The key principle for our work is that the individual leads. We are not about changing the individual but trying to challenge the societal structure around them, to help them thrive and flourish. We don't label medical conditions, for example, the title of our artistic commission for Coventry City of Culture 2021, *The Theatre of Wandering* a project around dementia, co-curated and inspired by residents.

Entelection works with highly skilled artists trained to understand working with people experiencing various illnesses, the sensitivity of language, importance of repetition and familiarity, trust, very practical ways of working.

We have an access and relationship manager who builds relationships with the individual. The programmes people can engage with are varied depending on needs and desires - from nonverbal movement programmes, singing, music making, we recognise that people who are experiencing different challenges in life may engage better or worse with other art forms, so that is really important. If people are going to be diagnosed with dementia, we want a consistent programme that they can potentially be with for many years.

#### What if isolated and lonely older people had the opportunity to go to an arts centre instead of a day centre?

#### Meet Me at The Albany

One day a week for 50 weeks a year, formerly lonely older people meet at The Albany to work alongside artists and create their own art. They could be suspended on silks in a circus workshop, enjoying a performance of jazz, creating sculpture, writing poetry or singing in the weekly choir.

Meet Me at the Movies is a film club, with screenings for and chosen by older people. For cultural destinations there is Meet Me on the Move -: monthly trips across London, from the Houses of Parliament to the Royal Festival Hall.

Befriending supports volunteers to connect with isolated older people and introduce them to creative activities. Volunteers develop skills to work alongside members who may be in need of someone to listen and support.

Our new club, Meet Me in the South at Downham Health and Leisure Centre, supports people with dementia and companions. We're also building on a recent pilot Meet Me Round Yours, experimenting with new ways of working with members who are no longer able to get out on a regular basis. We are connecting with specially designed individual projects, increasingly involving the use of technology, to create ways to communicate which combat isolation.

I feel I've got a voice and I didn't even know I had one. I've never looked back. We've done public performances and had standing ovations. Meet Me Choir member

Coming to Meet Me has given me the confidence to take back control of my destiny

It's given me a new zest for life, and a new determination that I can do things for myself if I try, I'm a different person, more able, more confident.

# 4.2.20 SOUTH-EAST LONDON: Southwark Elders Company and 'Encore' at Southwark Playhouse (A4D 2020-21)

"I always found a welcome at the Elders Company and enjoyed the creative activity, a sense of belonging & pride in what we have achieved together - and I have made new friends!

## **Elders Company**

Southwark Playhouse is extending its popular <u>Elders Company</u> for people aged 65 and over to two weekly groups. Participants work with theatre professionals in workshops to develop new skills, devise, rehearse and stage productions at Southwark Playhouse and in the local community. Participation is free. There are no auditions, and no previous experience of drama is necessary - just enthusiasm.







'Muse of Fire'
with A4D at
Southwark Playhouse.



Enthusiasm permeates 'Encore', the Playhouse's continuation of A4D's weekly 'Muse of Fire' SP drama programme for people experiencing Mild Cognitive Impairment or awaiting memory assessment for dementia, referred or self-referring to the Playhouse through SPLW (see page 231), now continued as 'Encore'.

Led by Artistic Director David Workman and working with theatre professionals, drama and medical students, participants explore a range of techniques, respond to drama challenges, improvise, interact, create scenarios and perform to each other.

This free programme offers an engaging opportunity for those with all experiences and none. The ultimate aim is to provide a space for participants to retain and build their confidence and sense of achievement.

Each workshop is self-contained, opportunities to perform each week. On Zoom during the pandemic, Southwark Playhouse plans to reopen 'Encore' in the new theatre building.

The programme was designed for people awaiting appointments for memory assessment and on diagnosis, for referral through GPs and SPLW and has been proven to preserve, even restore brain health. A participant diagnosed with vascular dementia has recovered her memory and reading ability and another who still awaits diagnosis, continue to interact with participants with a diagnosis.

#### 4.2.21 SOUTH-EAST LONDON:

'The Body-Full Movement Class', Siobhan Davis Studios (A4D 2020-21)



A free weekly online, creative dance class for older adults wishing to preserve cognitive function and to engage the body and brain through movement and co-created choreography. These classes offer time and space to stretch, breathe, move and socialise. Participants will be supported to develop confidence and articulacy in dancing through improvisation and developing dances as a group. This class offers a social environment with space to meet and get to know one another.

Dance artist Cheryl McChesney, who led A4D's weekly 'Dance for the Brain' – (see page 230) – believes passionately that dance can offer huge benefits to people of all ages and abilities. She has taught and choreographed for over 20 years with a variety of organisations, such as Sadler's Wells, East London Dance, Southbank, Artis Education, Rambert, Indep-dance, Trinity Laban and London Councils.

Siobhan Davies Studios is an artist-led organisation that advances the art forms of dance and choreography, involving interdisciplinary artistic activity. In February 2020, Siobhan Davies was commissioned by A4D to run a weekly Dance for the Brain class for people awaiting memory assessment or on diagnosis of dementia and their family carers on. Classes for people with dementia are a new area of participatory work for Siobhan Davies but align closely with our participatory pedagogy. The focus of the sessions will be engaging participants in kinaesthetic and embodied processing, honing in on the fact that whilst in dementia cognitive capacity deteriorates our kinaesthetic and embodied capacity does not. We are making plans to restart classes in Autumn 2020 and depending on available funding may continue this work in future, as part of the central SDD participatory programme, designed to connect more closely with our geographically local community.

# 4.2.22 SOUTH-EAST LONDON: Lambeth A4D at National Poetry Library, Southbank Centre



The National Poetry Library at Southbank partnered with A4D in 2018 to run a weekly poetry and creative writing programme re-energise and inspire people with early-stage dementia and carers.

The atmosphere was electrifying as internationally renowned poet Nick Makoha and Rachel Long, founder of Octavia – Poetry Collective for Women of Colour, each led four remarkable sessions.

Participants explored the most comprehensive collection of poetry in Britain. Encouraged to read their favourite poems, singling out the best lines, they

looked at how to analyse a poem, discussed Nick's *King of Myth* and learned how he writes poetry. They responded to artistic challenges, created and transformed stories into poetry, visionary, sensual, pungent expression, some highly political poems, stirring controversy. They merged each other's incidents and were moved to continue writing during the week to recite at the next workshop.



A4D at National Poetry Library (Photos: Jon Holloway).

The National Poetry Library gave each participant a library card and

after the eight-week programme Southbank Centre continued the workshops for a further ten weeks in 2019, as (B)old Words, commissioning A4D to provide training for the Southbank team who were also running a (B)old Moves dance programme, alongside monthly *Social Tea Dances* for 300-400 people.

Transforming people's relationship to language Nick Makoha

I have a tale to tell
the chap we know Charlie
suddenly ping
a ball in the head
a bad tonk
cricket is a very hard ball
I was busy playing cricket.

#### Arts Together

Arts Together is a pioneering charity which works to improve the health, well-being and quality of life of older people through the provision of a range of participatory arts projects.

Since 1999 Arts Together has been bringing together professional artists and older people for weekly arts workshops, creative activities and cultural events throughout Wiltshire.

Through its creative approach Arts Together plays an important role in countering loneliness and isolation and enhancing the well-being of older adults.

Arts Together groups have a maximum of 12 participants aged over 60 – there is no maximum age limit.

Groups meet once a week, 30 times a year, punctuated with Christmas, Easter and summer breaks.

Sessions last for two and a half hours (11am - 1.30pm) and include the serving of lunch by the Arts Together team.

Artists are employed to run a block of five consecutive sessions. This enables the planning of a creative project that progresses week by week. Examples of what we do can be seen throughout the Arts Together website. The variety of projects is reflected in the following sessions held at Devizes:

- Painting
- Paper making and casting
- Matisse style cut-out collages
- Ceramic Houses and Streets
- Soap making group cathedral
- Papier Mache bowls

Arts Together can provide free accessible transport for members from outlying villages and hamlets.

My mind is sharper. I am able to take part in conversations about things I never did before.

I know it keeps us healthier

Arts Together has given me confidence to try new things. Nobody judges what you do or make,

Once you start you don't want to stop. I've learnt so much and got so much pleasure and fulfillment.

I've done so many things I never thought I could.

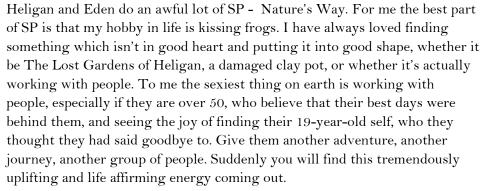
It's getting out and meeting people and it's relaxing and fun.

#### 4.2.24-25 SOUTH-WEST: Cornwall

#### Sir Tim Smit, founder of The Lost Gardens of Helligan and The Eden Project (A4D Conf21)



The Eden Project



#### Picking wildflowers and rolling in the meadow



The Lost Gardens of Heligan

At Heligan we are working with Lucy Loveday, our Wellbeing Guru inresidence. Forest bathing, that's cool, people like going down into the deep
woodland. What they cannot get enough is going into our wildflower
meadows and being told they have to pick flowers. They have got to go down
and roll on the flowers. Do you know how delicious, how almost erotic it is to
go and what people used to do hundreds of years ago, but now is forbidden.
They go and they come back with posies of flowers just giggling, laughing
and happy, in the way you can't lie, there's the happy where they just can't
control the creases in their eyes.

#### Stroking lambs



Dealing with the animals in the rare breed park. We have a barn where the youngsters can harden off before putting them in the raw Cornish weather. I have seen people very distressed come in amongst the lambs, and they will be there for an hour, with a lamb on their lap, just stroking it. Getting lamb on their hands, being connected to something that doesn't question them, that just likes being with them. The most extraordinary thing is that people who come on our SP programmes, beg to have the chance to put their hands underneath a chicken in really nice straw, and pull out an egg.

These are joys that are about being human. It is essential to get people back on some sort of notion of normality. The most extreme example is in Heligan Gardens, there is one place which has the effect of making everyone feel as if they are a cat being stroked. It is in the Melon Yard, the smallest of our walled gardens, there is an area called the potting shed. It is the area where all these terracotta pots are lined up in relative sizes in this cabinet on the wall. There are stools that are worn with wood that has got the grain of dirt, then there's the zinc tabletop where the potting takes place, and you find the odd fallen bird's nest, that's been left there. You will find sweet peas in the right season. People go in there. It is funny, that smell of soil and creosote in the background, ground terracotta, it leads to something in the sensory tract which just gets you going.

# 4.2.25 SOUTH-WEST: Cornwall The Eden Project.



Connecting people to each other and the living world.

At the <u>Eden Project</u> we believe in the power of connecting people with each other and nature—the power of people collectively doing things to improve their lives and the lives of others around them. That's why we're making use of our safe, inspiring and therapeutic site, and the skills in our team, to support and treat people with a range of conditions through <u>SP</u>.

We want to transform our greenspaces and inspire others to do the same.

SP gives people permission to access

nature.

The Eden Walk & Talk Lunch Club and Tea at Three provide opportunities for local people over 65 who live alone to get together weekly to walk, talk and share food. Run by friendly, supportive volunteers and trained walk leaders, these clubs provide a safe environment where members undertake regular exercise, socialise and share food together at Eden. We asked members how the programme had impacted their life – 94% said their outlook had changed and they felt happier.

We would like to broaden the conversation around health and well-being.

Eden's horticultural therapy programme offers people with anxiety and depression the opportunity to develop a range of horticultural skills and aims to develop a sense of value and respect for the participants. Physical benefit and increased independence, confidence and self-worth are goals frequently felt by the programme.

We want to be part of the solution to the current health and wellbeing challenges

.

#### 4.2.26 SOUTH-WEST

## Active Devon: <u>Connecting Actively to Nature</u> (CAN) Tom Mack, Programmes Manager (A4D Conf21).

CAN supports and inspires inactive people aged over 55, in Devon, Torbay and Plymouth, to connect actively to nature. This includes people with multiple barriers to activity such as: health conditions, poor fitness, isolation, too busy to get outdoors, or considering activity is 'not for them'.

Here in Devon our work has backing from the health and SP sector. It is a shame that we need to prescribe nature and physical activity, but some people are disconnected with nature and physical activity in everyday life. Inequalities in society play a great role in this disparity. Poorer communities, ethnically diverse communities, people living with disability, with long term health conditions, are more likely to be less active, and less likely to connect to nature. Groundwork UK's report *Out of Bounds: Equity in Access to Urban Nature* (2021) is all about access to urban green spaces.

We need to prescribe it and do a lot more to help people overcome barriers they're facing. We need to enable them to change their behaviour, to create new habits and to normalise it, for people to reap the benefits. It is only by making things regular and habitual that we see the transformative change. We also need to support the provider and the sector that provides these activities. Joining those two things together is so important.

The health and wellbeing benefits are almost infinite and well proven, with ongoing research ranging from prevention, through to managing conditions such as dementia, improving wellbeing, tackling obesity, mental health, anxiety and depression, preventing or managing pain, long term conditions, social isolation, improving sleep. They are all linked in a lot of ways.

CAN is an example of our approach in Devon to try and address inequalities, helping people accessing nature and being more active. We're trying, specifically, to increase the numbers and frequency of over 55's connecting actively to nature. Our particular focus is on inactive people, those from lower socioeconomic groups, those with long term health conditions, experiencing poor mental health or those who are socially isolated as well.

This five-year programme, supporting new initiatives across Devon is a cross-sector partnership approach. There are dozens of partners involved in delivering CAN, right from the bottom up, to a strategic level in Devon, and that is a real strength of the programmes. It is all based on local insight and there is a big focus on sustainability, because without that it just stops, and that is no good. We measure wellbeing using the Short Warwick Edinburgh Scale, we measure actively levels and we measure people's connection to nature at baseline, three, six and twelve months across the programme. Here are examples of the activities, all outdoors, ranging from walking groups, to yoga, tai chi, cycling, beach activities, sea swimming, water sports

#### Connection to Nature

There are proven benefits to just spending time in nature, let alone being active. There is a double benefit in that it increases people's willingness, and the joy they derive from caring for their environment as well.



Connecting Actively to Nature.

It is not a pill or potion, but we should consider connecting with nature as a prescription. Simply being in the natural environment is clinically proven to improve your health and wellbeing.

Dr James Szymankiewicz GP, Chair, CAN



Nature – People – Body – Mind.

#### 4.3.26 SOUTH-WEST

#### Connecting actively to nature in Devon.

#### Connecting to people

Social connection is the thing that keeps people turning up, motivates them, gives them the joy. It is such an integral part of what we deliver. It is massive in sustainability. People make new friends, join new groups, and so it rolls on.

#### Connecting to your body and mind.

We are increasing the awareness of the body, and what its capable of, as well as the other physical benefits. Connecting to the mind. There are loads of benefits for brain health, cognitive development, mental health, anxiety and depression and so on. These elements are all part of what it is to be a human being. Being in nature should be an integral part of being a human being.

#### Blue, green and grey.

Blue for water, green for forests, moors, countryside, fields and grey - it could be for grey hair, because we're targeting over 55's, or grey matter, in relation to brain health. But actually, I put it as an example of urban green spaces, so it's really important that we allow people to access the nature they're closest to.

#### The Chill Project

Initially the Chill Project was a lifeguard in North Devon to enable more people to benefit from cold water immersion, or sea swimming. We connected with him and Chill for over 55s was born. We linked it to the local SP teams, so each participant was directly signposted. They had a focus on mild to moderate mental health issues. The impact has been huge. Independent research from the University of Plymouth is soon to be released. Sustainability of that project is great, because there are these informal groups and people just exit straight into these community groups and swim together. Inflammation in the body is linked to depression, Our research has shown that for many participants with high levels of inflammation along with mental health issues, their inflammation results have massively lowered, with increased wellbeing across the programme.

#### Forestry England

Our green project with Forestry England, involves a suite of activities for over 55's in the forest. Really successfully, and well sustained through informal ongoing social activity groups.

#### Grey – walk and stretch

In Plymouth, in Devonport Park, a local yoga instructor in the city, trained to become a walk leader and led a Walk and Stretch programme in the local park. She was embedded in that local community and knew a lot of the people.

Our CAN programme research data shows that people's wellbeing scores increase over the months of people being engaged. Blogs, videos and inspiring stories inspire new participants and attract new investment and funding.

Being in nature should be an integral part of being a human being.

My endorphins are having a party in my body, and I love this feeling. It makes me happy, something my depression was getting in the way of. My mood is high, my back pain doesn't feel so bad, and I have found another coping mechanism.

Open water swimming with Active Devon.

#### 4.2.27 SOUTH-EAST: Oxford

Beth McDougall, Community Engagement Officer for Older People at the University of Oxford's Gardens, Libraries, Archives and Museums (GLAM), The University of Oxford (A4D Conf21)

The projects I am going to talk to you about today are Messy Realities and In Control by Design.

#### The Triangle of Power

These community engaged research projects work to the triangle of power - an

equilateral triangle that brings together people with lived experiences, researchers with a research question, and creatives and designers to think through and solve that question together.

### Objects – museum and found



We were working within the

museums to bring together objects from the museum collections, and found objects, seen through the research that each of the researchers was conducting as being in use with people with long term health conditions. The question we were asking ourselves is, 'Why are we prescribed medical objects and technologies that don't necessarily work within the context we find ourselves in?' Often the researchers were finding that prescribed objects were either at the bottom of the garden in the garden shed, or they had been Robison Crusoed into new adapted objects, or they have just been totally discarded. We are working together to look at how we can ensure better uptake of those medical or healthcare technologies, or technologies that actually improve and fit in with our everyday lives.

The activities and workshops that we delivered together were all based on the themes coming out of the research, so things like progression, adaptation, identity.

#### In Control by Design

Then within In Control by Design – (partnership with the university's Brain Networks Dynamic Unit) – looking at medications, how we take them, how we eat, how we move around, so that we can really start to break down what types of technologies are useful for people with lived experience of neurological healthcare conditions. Over time, the workshops changed, we went into the conservation labs to understand how they would diagnose and treat an object to make sure it lasted over a long term. In Control by Design, by contrast, people really enjoyed creativity and the artist, Susan Dyer, created different types of activities including a bricolage activity, where people created their

#### 4.2.27 SOUTH-EAST: Oxford (GLAM)

own new technologies that helped with their individual challenges. Over the workshop programme, we realised there was a couple of different outputs, that included an exhibition with the Messy Realities team, and in the In Control by Design team, we worked to create a library of things where people could test out and trail technologies that help with their condition before they ended up taking them home, because a lot of these technologies are expensive, and it is good to be able to hear from other users before you end up purchasing them. Over the last couple of years, and definitely over lockdown, we've managed to have those conversations with the In Control by Design team, so that we're still working in that set relationship.

What is next? We are hoping to create an exhibition over the summer based on the themes that came out of In Control by Design and Messy Realities. We are creating a co-produced booklet and we are looking at creating an in-person event series and opportunities to celebrate, because we have been waiting for a couple of years now to get to that celebration, because of the pandemic. Our findings from these two programmes are helping with my community engaged research.

We also run Meet Me at the Museum, a social group taking older people and those living with dementia behind the scenes in the museum, through object handling, gallery tours and special talks from the Ashmolean team.

My next project will be working with the Department of Psychiatry and the Centre for Evidence Based Medicine with people living with MCI issues.

#### 4.2.28 SOUTH-EAST: Isle of Wight

Hannah Griffiths, Community Engagement Manager, Independent Arts. (A4D Conf 21)

#### A.R.TS. to Preserve Wellbeing

The main remit of our charity, Independent Arts, is to improve health and wellbeing and reduce social isolation using the arts and creativity. We run the SP Creative Community Hub, which provides gallery and workshop space on the High Street, an Anxiety Cafe and

#### Time & Tide

This pre-COVID19, scheme paired local history and the arts, enabling older people to engage with cultural pursuits. Art and Identity was the first foray into portraiture for the artists, many of whom had not even picked up a digital camera before being involved in Time & Tide. Their portraits, inspired by the pioneering Victorian photographer Julia Margaret Cameron, were exhibited at her Freshwater home, Dimbola, a museum dedicated to her work.

#### SingAbout

I should like to focus on our singing for wellbeing project SingAbout, and how that works with the SP scheme. Ten years ago it was based on the Singing for the Brain model, but we soon adapted the singing to be more inclusive.

#### SP referral

The referral route is from the surgery SPLW and other SP routes refer into our project. If you have had a recent dementia diagnosis and you were referred into SingAbout, you can come to one of six weekly groups — this was pre-COVID19. Each group has round about 30-40 participants, including people with dementia, chronic respiratory problems, recovering from stroke and cancer treatments, anxiety and depression. Some participants come because they really enjoy singing.

#### Co-production

We have a wonderful blend of people, who are encouraged to co-produce the sessions. When we set up the groups they choose where we meet, the times we meet, and the songs we sing in the sessions - there is a little bit of something for everybody. Our practitioners who run the groups are all trained to work with dementia and other long-term conditions, and because there are such wonderful communities within those groups, we actually know each other really well. We do talk about the SingAbout groups as a SingAbout family.

At your first session, you will be welcomed in by our practitioners and our lovely volunteers will help you get settled in. You will be able to sing along to your favourite songs. There are also extra activities to help reduce anxiety, so we do breath work, which strengthens your lungs. As dementia progresses, our volunteers can help make sure that you are in the right place at the right time and find where we are on the word sheets. We welcome carers to come along and join us!

#### 4.2.29 SOUTH-EAST: Kent, Faversham Sian Stephenson, Creative Director, Moving Memory Dance Theatre (A4D Conf21)

Moving Memory Dance Theatre is a company whose vision is of a society within which older people lead longer, healthier and more fulfilled lives, because they participate in artistic, creative and physical activities. We achieve this through offering high quality performance and participatory opportunities. Animating autobiographical stories through movement, music, spoken word and digital forms. Empowering our participants to tell their own stories, express their individual identity and become the makers and the producers of the work.

#### Cracking the Crinoline

Our core performance company currently comprises seven women aged 50–87, who have been collectively devising and performing for over ten years. All identify a renewed sense of purpose, self, community, and creativity through sustained engagement with the company. Much of what the company stands for is captured in the core signature piece, 'Cracking the Crinoline', which placed the company centre stage on public platforms, streets, car parks, protest marches, shopping centres all over the UK and beyond. Celebrating the vibrancy of our performers and confronting ageism. A late member of the core ensemble, while undergoing medical tests, told me that at each appointment she brandished the publicity shot of 'Cracking the Crinoline' to ensure that clinicians knew they were not dealing with an old woman on her way out, but a dynamic, creative person. A person of value, purpose and skill. An artist in her own right.

Not an old woman on her way out, but a dynamic creative person, but a dynamic creative person

A person of value, purpose and skill. An artist in her own right.

#### Moving Well

Sidney De Haan Research Centre led on the evaluation of our early work Moving Well: A Prosper Adventure Project (2014), concluding:

The social impact outcomes of the project are far-reaching. They relate to the development and refining of a model of participatory performing arts that can contribute to national targets for supporting older people's health and wellbeing and consequential prolonged independence into older age.

We have gone on to extend our offer, to developing a distinctive peer led programme which focuses primarily on Moving Well workshops. These inclusive, non-prescriptive workshops engage people in a movement-based practice that has multiple physical and emotional benefits. We start with people in a room, encouraging a theatre approach to animating experiences, culminating in some form of performance wherever possible. We believe it is this combination of creativity and performance that is the cherry on the cake. Engaging people at a very deep and meaningful level, resulting with a wide range of participants reporting a sense of fun, liberation, wellbeing and community.

# 4.2.29 SOUTH-EAST: Kent Moving Memory Dance Theatre

The company has created an online training programme, which enables the establishment of sustainable <u>Moving Well</u> groups across the country. The work has a strong inter-generational element.

Sport scientist Ian Farr, *The Intergen31 Intergenerational - Theatre Project Reduces Implicit Negative Age Attitudes* (2016), noticed that we offer an alternative to other forms of physical activity, ultimately the development of positive social identity, self-concept and quality of life is evident.

#### Connection, Creativity and Community

The past year has seen the work shift online, extending our reach and our practice, and to our delight, current and new groups report a sense of connection, creativity and community. Serving as a positive and sustaining experience during the pandemic. Our distinctive, peer led, collaborative approach, with its embedded element of public performance, exhibition and installation feeds the brain, the body, but also, the soul. Making space for new and different conversations, giving a creative expressive voice to those who have been marginalised. The older body, brain and soul is given pride of place and validated.

#### 4.2.30 HISTORIC ENGLAND

#### Dr Desi Gradinarova, Senior Policy Advisor, Wellbeing & Inclusion (A4D conf21)

I think it is important to talk about what is heritage, and what it means when we talk about heritage activities. Is it a visit to a historic house, a trip to the museum, volunteering at an archaeological dig, or going through you family archive? I would say that it is even more than that. We have buildings and sites, but we also have historic landscapes, including hidden ones under the ground, intangible heritage, consisting of people's memories, stories and significant histories, which may transform the most humble church house or even a bench in a heritage site. Heritage is all around us, and it belongs to all of us. At Historic England we try to encourage everyone to maintain good mental health and social connectivity through engaging with the historic environment.

Our Wellbeing and Historic Environment (2018) assessment presented six routes to wellbeing through heritage. Heritage as:

#### **Process**

Volunteering is a great example there, as an active and committed relationship over time, it is the process of being involved that promotes those wellbeing outcomes.

#### Participation

Visiting sites is the most popular form of engaging with the historic environment

#### Mechanism

Using heritage assets to bring people together for therapeutic or social purpose provides a common point of interest or experience. Benefits can include social interaction, creating opportunities while memory and the sharing of experiences can contribute towards social cohesion.

#### Therapy

Experimental assessments of patients handling museum objects revealed benefits such as thinking and meaning making, self-esteem and increased confidence.

#### Belonging

Reclaiming a sense of place as a potential solution to social isolation. By engaging with the heritage of the places we live in, we also increase our feelings of pride, belongs and identity.

#### The environment

Heritage is one whole thing, including both the natural and the historical elements of it, and appreciating it as a whole will help us reap the associated benefits in a holistic way.

#### 4.2.30 HISTORIC ENGLAND

#### Love of Place

People are emotionally connected to places. Historic England and the National Trust carried out research in 2019, Heritage and Society, which demonstrated that 75% of members of the public wanted to pass on their love of place to significant others. 92% agree that they would be upset if their meaningful place was lost. The research actually used MRI scanning and found that key areas of emotional processing in the brain are activated by places which are considered special by the individual which provide a deep connection.

#### Constancy

The historic environment can also provide constancy. Community wellbeing is high in places that offer a degree of constancy in the physical and social environment. Aspects that remain constant all the time can be reassuring in our fast paced and changing world, especially as we get older, where we may find it challenging to keep up. Evidence shows that specifically reminiscence activities can reduce withdrawal from daily life and improve cognitive function in patients with dementia. However, it is also suggested that sustained intervention may be necessary to maintain the effect over time.

#### Connection through volunteering

This means that it is great to take action today, by visiting your local heritage site, but for enduring positive effect on your mental health, it is better to connect with heritage on a regular basis - becoming a member of a heritage organisation for example, becoming a volunteer at a local heritage site, or joining your local history society could make a massive difference.

Historic England supported one very original reminiscence project, led by Worcester City Council and the NHS Trust, called Worcester Life Stories. By creating web platforms where people can access the wealth of historic photographs and maps contained within the local historic environment records, they can share their local knowledge, memories and images and in this way create and share their own life stories, which is especially beneficial for older people and those with dementia.

#### Heritage, Health and Wellbeing

Wellbeing benefits of heritage can be delivered through SP pathways. Historic England started a partnership with NASP, by establishing a relationship and working alongside other arms-length bodies to create a vision of SP infrastructure and to promote SP projects (see SQW report *Social Prescribing and the potential of Historic England's local delivery* (2020). This is also part of Historic England's forthcoming heritage and wellbeing strategy, which supports mental health and work with older people as two of our four main priorities. The wider heritage sector have their own developing SP such as, Museums on Prescription. There are community archaeology projects, sensory parks, heritage walks and even yoga classes in historic houses (Heritage, Health & Wellbeing report, Heritage Alliance, 2020).

#### 4.2.30 HISTORIC ENGLAND.



We can all benefit from a healthy dose of heritage and using the <u>Five Ways to Wellbeing</u> (that you all aware of), we can give a little prescription to ourselves today. So:

Connect - with your local heritage, with inspirational people and places around you.

Be active - go out there and explore what is outside, visit your local heritage site and parks, but also be active in asking questions to find out what activities there are around you.

Keep learning - keep your brain in top form and improve your mental abilities by learning more about the past, including your own. Acquiring new skills and knowledge helps massively.

Take notice - of what is around us, the historic environment is often in front of us, we just don't see it. Look up when you walk down the high street to appreciate the building on top of that shop, you will be amazed what you will see. Beyond the buildings and bridges, there lies another layer of our intangible heritage - the memories and the stories, including those unheard stories, forbidden stories, and hidden people, try noticing these, they will reveal much more about our own selves, and what we keep hidden inside.

Give - whether by volunteering or simply by giving some of your time to pass the stories to the next generation. It is the stories of our past which have the power to make us stronger and wiser. Life is not always easy, as we have witnessed in the last year. It can be full of challenges and hardship, so we need that strength and that inspiration - not just to survive and carry on, but to keep our humanity alive.

#### 4.2.31 SCOTLAND: Glasgow

Jane Davidson, Director of Outreach and Education, Scottish Opera (Host, A4D Scotland, Feb 2021)

Where we are coming from, a lot of our work is post diagnosis, so opera to preserve brain health at the onset of symptoms is a particular area of fascination to me, and how do we get into that and access that? The work we are doing during the pandemic is minimal in terms of our *Memory Spinners*.

#### Memory Spinners

Our Memory Spinners opera group for people living with dementia and their carers was founded in 2010. Three groups now meet weekly in Glasgow, Edinburgh and Airdrie. Using music, storytelling, movement and the visual arts, the programme helps participants relax, get creative and form new support networks. We're about to partner with our lovely friends and colleagues at the in The Byre Theatre in St Andrews, and they're going to make a Memory Spinners programme, and we're going to help them, so it has got a life. The fact we started long ago means there is a limit with what we can do because it is so man heavy.

The whole concept is about sharing, and about making something that you didn't have at the start, and most importantly focusing on what people can do, not what they can't do. We have always taught sections from operas, no one has ever said that is too hard, so we've always chosen stories and plot lines, and developed the programme over the years, and tried to bring as many different types of artists in as possible.

When we began to look at the main house of Scottish Opera, and what we are doing for patrons who could no longer come to performances of opera, we began to look at the idea of developing dementia friendly versions of pieces, which involved a narrator and scenes in chronological order, and space for people to vocalise and feel at home in the theatre.

#### Early beginnings with Edinburgh Festival

We started that journey with Edinburgh Festival Theatres who were fantastic, because at that point they had the only dementia coordinator in theatre in Scotland. So for them to work with us and to help us on a whole range of things, everything from customer service — customer service for people living with dementia is what I call good customer service — and that would be good customer service for everyone, so much was common sense. But I think we've gone from strength to strength with our performances.

#### Opera to preserve brain health at the onset of dementia

Next year we're hoping to be able to open this out more and look at a whole range of people who for a whole range of reasons might not be able to come to the theatre and sit for nearly three hours. That's something we're looking forward to, and I hope that includes people at the very start of their journey with dementia.

#### 4.3.31 SCOTLAND: Glasgow, Scottish Opera

#### High quality

The qualitative thing is fascinating, especially coming from an opera world, it is an endorsement, because people come from across all walks of life, and many people will still say *I'm not sure it's for me*, but when you realise it's qualitative, it makes such a huge difference. So many people struggle with self-esteem issues, so in many ways you invert the snobbery if it, and you say, so if it is a high art form, what does that say about you, we're here working with you, surely that means that you're as entitled as anyone else. If you bring in a broad range of experienced artists, they must be ten times as good as the ones on the main stage because they have to do so many other things as well! But it is about the high-quality art, and integrity, and artistic aspiration. If you're singing once a week with Memory Spinners, singing your own version of an opera, it sets aspirations, everyone has creative aspirations, and they should always be high. That is a really crucial point.

Scottish Opera's Community Choir, (conductor: Katy Lavinia Cooper, on Zoom during the pandemic, meets at the Theatre Royal in Glasgow, to sing a mix of opera, classical, popular, folk and world music, our Community Choir currently meets online via Zoom on Wednesday evenings (previously in the Robertson Trust Education Rooms at the Theatre Royal in Glasgow). Participants do not need to be able to read music or have any previous experience and are invited to come and enjoy the fun of singing.

#### 4.2.32 SCOTLAND: Glasgow

Lisa Sinclair, Dance Health Manager, Scottish Ballet (A4D Scotland, Feb 2021)

Scottish Ballet is Scotland's national dance company, our mission is to inspire on stage and beyond - that beyond part is really important for our engagement activity. Everything that we do is inspired by the company repertoire, so it always has creativity and artistic excellence at the core of everything we do.

Similarly, our engagement programmes also inspire our company, and can help to affect change company wide. For example, making our building more dementia-friendly, even down to changing our toilet seats, and changing where the photography is displayed, and through to having inclusive performances of our winter production. The Scottish Ballet Health team is part of the wider engagement team; and our programmes support the life cycle - so that can be from our younger people's mental health and wellbeing project to resources that support the wellbeing of health and social care staff, and our three neurological programmes, one of which is *Time to Dance*.

Time to Dance is our dementia-friendly dance class. It features live music, social cafes before and after. Open to the whole family, it is intergenerational, and really fun for the whole family to do together, should they wish to.

In terms of Scottish Ballet Health, our vision is to be a global centre for dance health - that is something that we really strive to work towards, so that there comes a day when we're recognised as a go-to for SP, and that we can continue to offer really enriching programmes that compliment a wider package of support that might already be out there for individuals at whatever stage in their journey.

#### No need for formal diagnosis to dance with Scottish Ballet

Our participants are dancers, they don't need formal diagnosis to take part in our programmes, some people do have one and some people don't. All levels are welcome. We work with a great range of people in the class. Although it is a carefully considered environment, and we have undertaken a lot of research, training, and consultation with specialists and people with lived experience, it is important for me to stress that we work beyond a diagnosis, that we leave that at the door - at that those people that come into that space are dancers. It is a very equitable environment, and that patient/carer dynamic shifts, so for a person coming with their spouse, who might be used to providing care throughout the week, that is all but gone, they can just enjoy being in that space together, and creating new memories together, and knowing that there is a staff team in place to support and empower them to do that.

#### Participant recruitment and SP

In terms of how we recruit dancers to the programmes, we do that in different ways. We have our own marketing channels, so social media and our website, and the information films that we put out. Word of mouth, that testimonial, is hugely important. A really wonderful Community Link Worker (SPLW) actually bought eight of his GPs to the studio, and we did an awareness raising cognitive behavioural therapy session with them, so that they could

understand what we meant by dance health, and so they could then speak about it in a more accurate way and make a more accurate referral. Informal signposting through organisations and allied health professionals are also effective.

#### Dancers to feel empowered

It is really important that people feel empowered. We take a real asset-based approach to the work that we're doing, so it doesn't matter where someone is on their journey, on that given moment, they can reach their fullest potential in the class. It might be different from someone across from them, but it is unique to them. For us, creativity, fun, empowerment, autonomy and expression are the most important thing in that moment.

#### Dance to optimise brain health

There is a lot of research that shows physical activity is vital, and that it is important to brain health and overall wellbeing, but we know now that dance particularly is really effective at reducing aging in the brain and optimising brain health. This is because it is so holistic, it engages the brain fully, there is decision making, spontaneity, mirroring, creativity, expression, but also that relationship with music, which we know is stress reducing, but we know have that emotive quality. Of course, not to forget the impact of social connection, not only connecting to yourself, but connecting to the wider community.

#### Collaboration

We believe in collaboration, it's really important we work across sectors, because that way, together we can join up our thinking, we can understand the needs of all these different stakeholders that can bring us together and move towards models where this work isn't other, but is very recognised and automatically referred to place that people can be sent to have a wonderful enriching experience.

#### Involving medical students to embed culture change

We're really delighted to announce that just this week we're starting to pull together a schedule for two Scottish medical students, coming to us from the university of St Andrews, who will be spending 20 hours each a week with us, on placement with Scottish Ballet Health. It is a first for us, and we really delighted that they are embracing that way of working, ensuring the future of medicine has this opportunity to be exposed to this in their training we believe that long term change can happen if we can help embed it within undergraduate training, so we can change the culture long term.

#### 4.2.33 WALES/CYMRU: Cardiff

Eleri Evans, Head of <u>Learning</u>, National Museum Wales / Amgueddfa Cymru (Host, A4D Wales Mar 2021)

I'd like to start this afternoon by introducing some of the work that National Museum Wales has done with and for people living with dementia. There is growing research that shows that visiting places like museums and taking part in creative and cultural activities can be linked with positive wellbeing for them. Historic spaces and collections can stimulate memory and discussion, and through our work we have seen the difference that our activities and programmes have made to them and their families.

#### Consulting people with lived experience

One of the most important aspects of this work has been involving people with lived experience in developing this work with us. They have worked with us to develop our programmes. They have initiated ideas, shaped our training and raised awareness of dementia across the organisation. In 2015, the first Dementia Friendly audit took place at the <u>Big Pit National Coal Museum</u>, and since then, all our seven venues have been audited by individuals with dementia, carers and organisations who work with them. Over 400 museum staff and volunteers have been trained as Dementia Friends.

The range of activities we've developed include creativity sessions at the <u>National Museum Cardiff</u>, inspired by our collections and exhibitions, workshops in historic buildings such as the <u>National Slate Museum</u>, dementia walks around the grounds in <u>St Fagan's National Museum of History</u>, and Dementia Friendly underground tours at Big Pit.

#### Adapting underground Big Pit National Coal Museum tour

This is a really good example of how we thought this wouldn't be something that people with dementia would want to do. Our feeling was that the space underground was too confined and dark, and that this might be uncomfortable. However, we were advised that we could adapt the experience, for instance, describing beforehand what would happen, by slowing down the pace of the tour, and allowing time for people to ask questions and share memories. We also considered physical aspects such as changes in floor surfaces, noise and light. This then became a regular feature in 2017, and we have had some really good feedback, especially from individuals who once worked in the coal mining industry in South Wales.

#### Objects of Comfort.

By listening to our partners about how isolated people living with dementia have felt, during lockdown we have created digital resources which are called *Objects of Comfort*, which provides opportunities for them to respond to items from the Museum's online collection and to share their own objects, things that bring solace, evoke memories to help improve their mood and wellbeing during times of stress and hardship. This resource is being developed further over the next twelve months.

#### 4.2.33a WALES: Cardiff

Sharon Ford, National Museum Wales / Amgueddfa Cymru interviews Gavin, Big Pit Museum participant and group leader

**Sharon:** Thank you Gavin for coming along and speaking to us today. Gavin, you were diagnosed with early onset dementia in 2014. You came to Big Pit first from the Alzheimer's Society to help with our dementia-friendly audit, and you have helped us develop programmes and gone from being a participant in programmes to a volunteer - to leading arts and crafts sessions yourself. How has that involvement has been for you over the years, with the museum?

**Gavin**: It helped me a great deal, to keep occupied, to keep my brain functioning, and to keep going. It is very satisfying.

Sharon When you first got diagnosed, how did that feel?

**Gavin**: It was terrible. It was like being hit by a ten-ton truck. You just didn't know what to do, where to go. We had no information on anything. Someone just said here's your tablets. I'll see you in a months' time.

**Sharon** That affected every aspect of your life? ... You first got involved in 2015 through the Alzheimer's Society, how did that help you?

**Gavin** It has been a fantastic help to me. If it hadn't been for your group and the Alzheimer's Society, I don't know where I would be today.

**Sharon** When we spoke earlier, you said it helped you come back to yourself. Is that right?

Gavin That's right. I locked myself away, I did absolutely nothing, I wouldn't talk. The only conversation my wife got out of me was, 'Yes', 'No', 'Good night'. I just didn't want to know or do anything because I was so depressed.

**Sharon** You also talked about the satisfaction and achievement being a big part?

**Gavin** From what I used to do, to what I do now, I still feel satisfied in what I have achieved. It doesn't matter how simple it is.

Sharon I know in your previous work life you were an engineer?

**Gavin:** From what I could do then to what I can do now are totally different. I have forgotten so much of my job and past, but now I still feel satisfied with every achievement I do. It doesn't matter how menial it is, it's still an achievement.

**Sharon** Back before lockdown, you joined the intergenerational group, and went from a participant to a volunteer, to leading an arts and crafts session - how did that journey feel?

Gavin It was rewarding. It wasn't just myself. My wife was my carer. She was there supporting, but it was so rewarding to be able to do that, and to see the enjoyment from other people getting from what I was giving them.

**Sharon** Everybody did enjoy that, I can vouch for that. Thank you again, Gavin.

#### 4.2.34 WALES/CYMRU: Flintshire

#### Gwennan Mair, Head of Creative Engagement, Theatr Clywd: (A4D Wales March 2020).

Arts from the Armchair has now been running for around four years, and it is about creating new memories within our building. We are a producing house. We make theatre here, from the costume design to the props and the wigs, and one of the massive important things about this programme is that it introduces those skills of theatre making for people with early onset memory loss. Arts from the Armchair runs for two sections of the year, for 16-week terms. We now have two groups with an additional Memory Arts Cafe which runs alongside it.

This is a programme is in partnership with Betsi Cadwaladr University Health Board (UHB), and they have funded this programme with us for the last four years, so it is a longstanding relationship. We get referrals through the memory clinic here in Mold, and we have continued these two groups through lockdown – I think we had a two-week break – running all of them on Zoom. This has only been possible with the delicacy of those relationships that we already had with existing participants. Our incredible facilitator has been working so beautifully with the participants, using individual phone calls to really bring the theatre back to people's homes. We have still engaged with professional singers and set designers, costume makers and stage managers to come to the session still, and to still engage in different art activities. Obviously, it's not the same as being in a different space, and being at the theatre, but we have really tried to continue a little bit of that magic through this time.

#### Elders companies

On top of this we also have two elders' companies as well. We have Cwmni 65Theatr, for people aged over 65 to explore their creativity and learn about theatre making and CompanyZ. They have opportunities to try different experiences, from acting and dance, to music and script work, get behind the scenes and learn new skills. They have just done an intergenerational film with our youth theatre over Christmas, and they are now working towards staging some professional production short scenes in the summer. I am mentioning this because it fits in with early onset, and how all our programmes can bleed into one. You don't have to just be part of Arts from the Armchair. You can also be part of our Elders company. It is an interesting conversation at the moment because theatre is in that shift and in that transition, but I wonder what the future is for arts and health work within theatres? Even more so, because we are asking the question, what is the purpose of theatres, and asking should they be more of a civic centre?

#### 4.2.35 WALES/CYMRU: Swansea Swansea City Opera and Men's Sheds Cymru Robert Visintainer, Men's Sheds Project Manager (A4DConf21).



Men's Sheds Cymru offers space, activity, and camaraderie to men, many of whom have found themselves with time on their hands, especially after retirement or through a change in their life circumstances. Men's Sheds like to think they offer a 'health by stealth' approach to overcome mental and physical health problems. Men talk shoulder to shoulder, not face to face, so

they will have a more honest conversation if they are working on something together. It is how they worked in the mines and factories and informs the title of The Men's Sheds Cymru Opera, <u>Shoulder to Shoulder</u>.

We were approached by Swansea City Opera back before lockdown who showed an interest in finding out what Men's Sheds were. They recognised that the sheds were doing good work, and they wanted to help us in fact promote the Men's Sheds movement in Wales. Bridget and Brendan from Swansea City Opera explained to me how they wanted to write an opera about Men's Sheds, and to do so they wanted to visit Men's Shed in Wales and interview the participants. They knew, like us, that there were lots of life stories of the people who attend Men's Sheds, and they thought that would make a good topic for an opera. I have never been involved with music before this point really, so I was quite excited and curious as to what we're going to do.

In early 2020 I visited a few sheds with Brendan, and they interviewed participants and heard their stories, and after a few months Brendan had produced a piece, which included a chorus and a scene for an opera based on Men's Sheds. The first scene is about a daughter and her father just before he joins the Men's Shed, and the chorus is about three men in the shed singing, and it is shed related. The goal for both us and Swansea City Opera was to create an accessible opera, which involved an amateur chorus including some of the men from the sheds, along with professional singers and musicians.

Shoulder to Shoulder is now touring Welsh village halls and community centres with the local sheds appearing, whether as part of the chorus or audience. Then the audience can talk to actual Men's Sheds members and hear about the work that is going on in the community. It has been a really good and interesting collaboration. Unfortunately, lockdown restrictions delayed it quite a bit. But we're hopeful to visit a few more sheds so Brendan can gather a few more stories and put those to music.

# 4.2.36 NORTHERN IRELAND: Derry Professor Dolores O'Reilly, The Millennium Forum, (Host, A4D Northern Ireland Mar 2021).

The Millennium Forum are the virtual hosts so on behalf of the trustees I'm delighted to welcome everyone from here in Derry to A4D's Northern Ireland meeting. It's a special day as its International Social Prescribing Day. We hope to advance, in the course of this meeting, SP, particularly in the arts world. We at the forum have long recognised the need for SP in our community – we just did not call it that.

#### Access to Arts for All.

In response to the needs of our community we set up widening the access and participation to the arts, and wherever possible we would hold this in the Millennium Forum and the adjoining studios. Our aim is to ensure that no one is left out of art world. To that end, we have created a charity called <u>Access to Arts for All.</u> It's housed in the Forum. We have developed events on a regular basis, as well as hosting events, using our theatre space to help fulfil our ambition of enduring that there is access to arts to all.

#### Access for All Membership Scheme

To highlight a couple of things we do, we provide membership scheme which has been designed for people with physical, sensory, or cognitive additional needs. It is free to join, and it's based on the belief again that there should be access to everyone at our theatre. It helps clients by giving them the best possible service. Each time a booking is made, details are sorted out and kept and stored noting requirements, making sure that when we ring back, they know we're able to give them a wheelchair access seat, and we also provide a seat for carers free of charge.

#### Moves and Melodies

Our newest initiative, before the public health crisis, was Moves and Melodies, this was very much based on music for all. One of the organisers who facilitates the event has done research into the effect of music for people living with dementia, so that research expertise is bought along to these sessions. The initiative provides the opportunity for participants to learn new dances, skills, and sing a range of song styles. It is another activity that restores self-esteem and improves mental outlook and wellbeing.

#### Dementia-Friendly Tea Dance.

One of our highlights has been our Dementia-Friendly Tea Dance. It is a key highlight every month for people with dementia, their carers and family members. This has been running for four years, and we have an average of 60 people coming along per dance. That equated to about 750/800 people per year, and we touched and made connection with over 20 care homes. It became obvious to us how small things do make big differences, we witnessed first-hand how these events reignited the mind and energised and stimulated the participants.

#### 4.3 A.R.T.S. practice to preserve brain health

For people experiencing early symptoms of MCI or a potential dementia, leaving the safety of home may be a challenge. Their concern, and that of their partner or family, is to preserve their brain and to lead as normal a life in the community as possible. But they may be self-conscious, aware of stigma. As apparent inertia conceals the fact that they are still able to revive and develop new skills and to enjoy A.R.T.S. activities need to not only make them feel welcome, but to offer compelling interest.

Weekly ongoing programmes of workshops, tours, activities provided at A.R.T.S. hubs, Active or cultural and creative organisations' learning or community participation programmes – as a natural outgrowth of existing practice, or creative ageing –as we have seen, offer inviting opportunities to restore wellbeing. They reawaken creative activity individuals and their companions can pursue together to override cognitive challenges. (See Early-stage dementia training, below).

Whatever type of A.R.T.S., programmes offer an individual experience, with the common aim to re-energise and inspire, restore shared cultural and creative interests, sense of purpose, identity, joie de vivre and on-going interactive involvement.

#### 4.3.1 Most valued qualities

- Inspirational A.R.T.S. settings and artists, tour guides, group leaders experienced in their art form, informed by early-stage dementia awareness training, flexible and open to developing compelling A.R.T.S. programmes to preserve brain health.
- High quality A.R.T.S. materials, masterpieces of art, music, dance, historic or the best contemporary practice as the innovative spark for new creativity.
- Co-production from the outset consult and share ideas with potential participants, people with lived experience
- Timing:
  - Weekly programmes are the most effective at protecting against cognitive decline.
  - Ongoing is needed for SPLW short projects may be over by the time the person decides to take up the SP offer
  - O Tie in with university terms to involve A.R.T.S. and medical students for mutual benefit. (see next page 177).

#### 4.3.2 Volunteering opportunity for older people

The 2015 NICE guideline NG32 (recommending arts activities for older people included the idea of volunteering for older people, for the opportunity to socialise, have an enjoyable experience and to help others to do so and acquire knowledge and skills. A consortium of Greater Manchester Museums found that Volunteering benefited participants' mental and emotional health and

#### 4.3.2 Volunteering for older people

led to significant improvements in their creativity, aspirations, life satisfaction, social connections and reductions in stress.<sup>70</sup>

<u>ArtsPAL</u> (on the A4D website, see page 180) coordinates an A.R.T.S. Befriending Network by UK region. Whether as an ArtsPAL accompanying someone to – mindful to have shared mobile contact also with the organiser – or assisting at an A.R.T.S. programme builds both personal confidence and artistic friendships.

#### 4.3.2 University involvement:

As arts universities prepare students for portfolio careers, to use their art in the community, and medical education focusses on more advanced dementia, it is of mutual benefit to involve arts and medical colleges:

- To assist and help guide evaluation.
- To share arts expertise as volunteer, as training to run their own A.R.T.S. programmes for brain health
- For medical students, insight into people's challenges and existing skills in early dementia, to inform communication as doctors.
- Their youthful spring inspires older participants.
- The A.R.T.S. programme as subject for dissertation.

#### 4.3.3 Early-stage dementia training

A.R.T.S. programmes for wellbeing, for people at the onset of a potential dementia, by nature need imaginative strength, to re-energise and inspire participants. To appear natural, artists, A.R.T.S. group leaders, their team, arts and medical students, all involved need insight into the challenges people face as symptoms of MCI or the various dementia types set in. Even if the diagnosis may not be a dementia, training is valuable. (See Appendix 1, page 216).

4.3.4 SP Partnerships - for sustainable SP referral and funding, see pages 187 and 189.

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 $<sup>^{70}</sup>$  Inspiring Futures: Volunteering for Wellbeing, Final Report, Social Return on Investment 2013–16.

#### 4.4 Access

Access for all, discussed by many contributors, is carefully considered by A.R.T.S. organisation, notably, Access to Arts for All.in Northern Ireland. The Museums, Libraries Archives 'Access for All Tookit: Enabling inclusion for museums, libraries and archives (2004) addresses barriers and to access and invites organisations to consider:

- 1. Physical Environment
- 2. Sensory
- 3. Intellectual
- 4. Cultural

- 5. Attitudinal
- 6. Financial
- 7. Technology

#### 4.4.1 Physical Environment

Derive maximum benefit from experiencing A.R.T.S in their natural environment, whether in nature, up close to pictures or objects in a museum, in a spacious dance studio – a cramped setting can bring on anxiety, similarly mirrors may cause concern, but the feeling of being in a dance studio, for maximum enjoyment of the space, to be creative and interact is valuable. Risk assessments for wheelchairs suitability or availability, hearing loops, braille signage are helpful. Although our programmes are for people pre-diagnosis, Dementia-friendly internal environment guidance is given on page 228 and the following guides are helpful:

- Groundwork UK (2021) Out of Bounds: Equity in Access to Urban Nature
- Historic Royal Palaces (2017) Rethinking Heritage: A guide to help make your site more dementia friendly.
- Taylor N. (2016) West Yorkshire Playhouse Guide to Dementia Friendly Performances

### 4.4.2 Sensory – adaptation for people with hearing or visual impairment

Dance for the deaf guidance can be found in

- Park, Y. H. (2008) Effective dance instruction for individuals with hearing impairment
- Techniques from the Department of Art, Communication and Theatre from, with useful resources the Gallaudet University in Washington.
- Redeafination: Sinapore Deaf Dance Crew 2014, Pointers for Instructors Teaching Deaf Dance Part 1: Top 10 Guidelines.

Music and the Deaf is a UK charity dedicated to using music to help people with a hearing loss unlock their potential.

Some museums – for example, the Design Museum, British Museum and Tate – offer tours in British Sign Language for deaf and hard of hearing visitors as well as tours for blind and partially sighted visitors, providing opportunities to touch and discuss objects,

Cailin Lynn describes the fascinating programmes Ulster Museum ran for people with sight loss, under their ongoing Access for All programme.

#### 4.4.2a NORTHERN IRELAND

Cailin Lynn, Programming Development Manager Museums of Northern Ireland, (A4D Conf 21)

#### Access for All at National Museums Northern Ireland.

Our Access for All initiative at National Museums NI (Ulster Museum, Ulster Folk Museum, Ulster Transport Museum and Ulster American Folk Park) was developed in the first lockdown, when we could see how the pandemic was impacting people's mental and physical health. What stood out most was that people with disabilities were being disproportionally affected, at a time when meeting their needs was most difficult. We decided to rethink how to put disability access needs on the top of our organisations' agenda, to engage with disabled audiences with a sustained approach, not just as a pandemic project.

#### **Partnerships**

However, we cannot claim to be experts in disability access. Rather than make assumptions, our first steps were to begin conversations with other organisations who had the expertise and existing relationships with service users. We reached out to a broad range of partners, Leanne McBrearty at SPRING SP (see page 103) spoke earlier, we also reached out to the Healthy Living Centre Alliance, the Alzheimer's Society, Guide Dogs NI, RNIB, the University of Atypical, the disabled-led arts charity in Belfast, Age NI, just to name a few. We were open, honest and transparent with these partners from the get-go, that this was the beginning of our journey of understanding broader access needs, and that we really needed their guidance.

#### Collaborating to adapt

We collaborated with our partners to facilitate focus groups with service users with museum visits whilst it was still closed so that we had a better understanding of the change in environment. So much had changed as we all know, signage had changed, movement around the physical museum had changes, there were no physical maps to hand out. These are the small things a nondisabled person may be able to find mildly annoying but is something that could have a detrimental effect on the experience of a disabled person coming to site, possible even for the first time.

#### Positive ageing programmes

In collaboration with our partners, we actually designed a suite of <u>Access platforms</u> that we began to prototype from September last year. They were Slow Down afternoons and Positive Ageing programming aimed at older people and their families, relaxed mornings which were exclusive early access openings to the museum for those with learning difficulties.

#### Sensory science

SP is a broader initiative that we have been developing in partnership with SPRING SP (see next page. We collaborated with the NI Science Festival to deliver a first for all of us, a sensory science programme designed for disability access as a starting point.

Creative
Curious
Challenging

#### 4.4.2a NORTHERN IRELAND

#### Access for All, Museums of Northern Ireland

#### Remote access for audiences with sight impairment

Today I am going to focus on remote sessions for audiences with sight impairment, developed in partnership with RNIB and the Guide Dogs NI, and their service users. Conversations with the organisations and service users were really interesting.

#### Accessing objects on permanent display

Things that were identified were identified as collections of interest were pieces that were on permanent display in the Ulster Museum. Participants explained that the inaccessibility of the museum has meant that they don't get to see or access these permanent displays. Items that we take for granted, that I've seen since I was a child, some of these people hadn't seen at all, and had only heard about or read about.

#### The Takabuti mummy at Ulster Museum

The Access for All sessions focused on certain collections, including Takabuti, our mummy, and the Girona in the Spanish Armada that sank off the coast of Northern Ireland near the Giants Causeway in 1588. The sessions took place weekly, and were facilitated on Zoom by our engagement team, and when restrictions allowed, on site visits took place. For the online sessions, participants received sensory packages in the post, these packages contained a range of different items that engaged the participants wider senses.

#### Sensory packs and object handling on site

The Takabuti pack for example contained scraps of linen that emulated bandages, smooth beads to represent the beetles that were engraved on the coffin, and even baklava to give a sense of Middle Eastern deserts and engage taste. Our site visits also included handling collections, each family or friend bubble, which is how we facilitated the visits, were given their own items to engage with as part of the visit, so there were no worries with sharing and cross contamination. These items enhanced the participants overall engagement with the collections and stories being explored.

#### Enduring value of digital engagement

The sessions were really popular, over 95% participants felt that they had learnt something new and felt they were valuable for people with access needs. Over 60% said that they were unlikely to attend a physical session without having attended the Zoom session beforehand. This demonstrates value in digital engagement, not just as pandemic engagement, but as long-term gateway engagement when considering outreach to audiences with additional needs. It builds confidence and encouragement to visiting in person, however we do need to acknowledge digital poverty issues.

We worked across internal multidisciplinary teams to deliver our access prototypes, because our intention from the beginning with this access work is that is that it would be owned by the organisation, not by an individual or



Above: Gold and ruby pendant from the Gironda

Below: Takabuti Mummy





The information was excellent, and the way the presenters described the paintings helped me visualise them in my mind.

I really enjoyed it, if you couldn't see it on your screen, you had it in your hand.

As a visually impaired person, the use of the tactile goodie

### 4.4.2a NORTHERN IRELAND Access for All, Museums of Northern Ireland

team. The long-term ambition is that thinking about access and disability needs becomes part of the fabric of the cultural working of the organisation. The great news is, that I have never worked in an organisation where an initiative has been grasped so quickly, and so completely organisation wide. The initiative has been championed from the get-go by our executive and senior management team. In fact, the reopening of our museums last year was used as a platform to launch the <u>Access for All</u> initiative, and our Chief Executive invited all our participants to the lunch to launch the initiative and celebrate the work that we are doing together, and it got really good press coverage, particularly across partner websites and social media. This is great because there is an awareness there then.

#### SP Access

Access is now embedded in our new <u>Corporate Strategy 2021–25</u>. The strategy has four aims, the first is that we champion inclusion, diversity, and accessibility. Our business plan has specific activities that will drive forward our initiative. I have mentioned SP work, and we will be looking to roll this out with SPRING SP and the <u>Healthy Living Centre Alliance</u> and look forward to furthering initiatives. There is always more to do, always. But I do feel that we have taken the opportunity presented to us in the first lockdown to take our first steps in this work, and with the incredible partnerships that we have developed, we can continually improve and have fun testing new ways with and for people with additional access needs.

#### 4.4.3 Intellectual access

Adjustment for cognitive challenges is addressed both in training (see Appendix 1 page 219), as well as in consultation with people with lived experience and with SPLW whose Community Builders are keen to bridge gaps to fulfil people's interest if a service is not available.

To ensure social inclusion, all ethnicities are encouraged at A.R.T.S. programmes – or, if preferred, cultural groups also offer A.R.T.S. (see pages 176 ff). For people whose first language is not English, David Trussell (2020), the focus of whose book *Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change*, is chiefly post diagnosis, but with useful tips, gives participatory A.R.T.S. guidance for ethnic diversity:

#### 4.4.3a Intellectual access: Ethnic Diversity

#### David Truswell, Executive Director of the Dementia Alliance for Culture and Ethnicity. (A4D Conf 21)

Let us start with a blank piece of paper. A lot of people when they think of arts and creativity in relation to dementia in relation to dementia and later life, may not consider that people have gone through their lives without thinking they are creative, or that the endeavours they are in involved in are not creative. They can't see themselves as being artistic or creative in those endeavours. A big challenge across the board, but especially for minority communities is to say, how do you understand yourself as being creative?

What is being creative? If you are somebody who writes, draws or paints, you might start with a blank piece of paper, or if you're going to be digital, a blank computer screen. It is important to understand that whatever language you speak, it is the same blank piece of paper. When you are working with people, with limited verbal methods of expression, they're often more comfortable in expressing themselves in their mother tongue. Giving someone the opportunity to write things in English, for example, if it is not their original mother tongue, may not seem as important to them in terms of developing their creativity in a way that is helpful and beneficial for their wellbeing, as an opportunity would be to write and be read in something like Arabic.

In many cultures a blank piece of paper is an opportunity to create something folded like origami, or if I had different coloured sheets, cut it into strips, or mash my paper into papier-mâché and create puppets - for some cultures, communicating about stories and lives through puppetry is very significant.

The important thing about approaching creativity in relation to people worrying about dementia is to think about how they might understand themselves as being creative, and how important that might be in thinking about how they can improve their wellbeing and engagement in creativity. They might manage to get on to some photo books. I have some here created by people affected by dementia in a project with my colleagues Ellie Robinson-Carter and Ronald Amanze. We posted disposable cameras to people to take photographs in their own environment of things that were important to them and asked them to write where they describe what the pictures mean to them. They take the pictures. We developed their pictures to create photobooks, so they discover themselves as creative artists, in a way that they may have never thought of before. One woman contributing to the photobook project, her illness was so advanced that she cannot communicate verbally, so it was a real revelation for her to participate in this project.

The unknown country is everybody who steps through the door who is from a place that you are not familiar with. My question is can you take a blank piece of paper at the end of this, and write down what is important in your life, how you express your creativity and what that means to you? Having done that, think how you ask a person from an unknown country that same question, to indicate or show what is important to them in their life in relation to their creativity, and how do you think how you are going to help them embrace and develop that creativity?

#### 4.4.4 Cultural Access – Ethnic diversity

A decade ago, it was hard to attract a diverse group of participants, not least because some cultures fear the stigma of dementia and avoid the use of the term – in India, for example, they refer to it as a brain condition which perfectly suits our campaign for people to take up A.R.T.S. to preserve brain health pre diagnosis and continue for years. But with arts organisations reach out with the Museums Association (2020) A manifesto for museum learning and engagement, to provide a framework for museums to develop their practice for ease of access to people the African Diaspora, South, East and South East Asia, they now being a rich mix to A.R.T.S. programmes.

Dance and music are especially popular and with less call on language are more immediately accessible. Cultural groups offer A.R.T.S. within their organisations.

### 4.4.4a YORKSHIRE & HUMBER:

Pam Charles, Older Persons' Advocacy Support, Leeds Black Elders Association (A4D Oct 2020)

Leeds Black Elders Association (LBEA) started in 1991 by a small group of residents, who realised that the needs of the local older Afro Caribbean community were not being met by Social Services (now Adults and Health). These were cultural needs, such as food, language, entertainment and general care needs. As time went on, the need for LBEA's services grew and they began to receive local government funding, gained status as a charity and were able to apply for funding from various streams. Although our name says 'Black Elders', we cater for all elders who may need support – we are very proud to be an inclusive service.

LBEA is part of the Leeds Neighbourhood Network schemes which is made up of various over 40 projects based in local communities; and work with the elders within that community to reduce social isolation and improve their health and wellbeing. We have now been in operation for almost 30 years providing advocacy, social activities, gardening, decorating, delivering hot meals to elders homes seven days a week and we are also a 'gateway' to the services the elders may need to access. We are the first point of call for many when they do not know where else to turn and have an open-door policy to cater for any needs the elders within the community may have.

My role as 'Older Person's Advocate' is to support the elders in ensuring their voices are heard in the services which they access such as health, housing and finance. We will discuss what their desired outcome is and work towards that. I will work with them until a satisfactory resolution has been reached. My role is extremely interesting as no two days are the same – not 'one size fits all'. Every elder is an individual and they are treated as such.

#### Reading group

The activities we provide are at the request of our elders, for instance, we had a few elders who were keen readers and requested a reading group. They told us how they would like this to look; and we provided the space and support for

#### 4.4.4a YORKSHIRE & HUMBER:

#### Leeds Black Elders Association

#### Inclusivity – breaking down barriers in the activity club

them to do it. They took complete ownership of this group and we only got involved at their request. This was a successful group and enjoyed by all who took part.

#### Activity club – art, dance, music and information

We also run a weekly activity club where we have up to 40 members in attendance. Here we do a variety of activities including dominoes, knitting, different forms of art, we have guest speakers delivering information session on subjects such as health, scams, Wills, and we also do an hour of exercise. This is led by a local gentleman who is a professional dancer and exercise coach. He plays the music that the Elders know and love and all of his exercises can be done either seated or standing, whichever the elders choose.

We used to run a dementia and stroke club some years ago and then decided that it would be nice to bring all the elders together under the banner of the activity club. We have people who are at different stages of dementia, people who have had strokes, people who have various illnesses, people with various mobility needs and people who just want to get out and socialise.

The beauty of this is that a lot of the elders had worked together in the many different industries in Leeds from the 1950's until retirement. We've seen the benefit of bringing everyone together as it creates a wonderfully stimulating environment. It has created a relaxed and open place to learn and understand various illnesses and conditions which can affect people. It arouses the interests and discussions of those who used to work in the medical field, of those who may be experiencing the same conditions and of those who are not experiencing any serious medical conditions. It breaks down barriers and allows those who may need a little extra help to be cared for by their peers.

#### Music

The music, both live and recorded, is an extremely important part of our activity club. We have seen the positive and energising effect it has on all elders but particularly all those elders who are struggling with their mobility or have dementia. We have seen those with dementia sing a song from beginning to end with lucidity. We have seen them get up and dance while smiling and engaging visually with others. We have seen those with mobility struggles move in ways they thought they couldn't and report relief from some aches and pains which they have been experiencing for some time.

#### 4.4.5 Attitudinal access

Arts organisations are moving away from the acronym BAME (Black, Asian and Minority Ethnic), which was originally intended to proclaim inclusivity and diversity, but is now seen as identifying people as 'non-white, as if white is the standard'<sup>71</sup> - unless an organisation supports a specific community, as for example Leeds Black Elders or BME Touchstone.

#### 4.4.5a A4D YORKSHIRE & HUMBER

# Ripaljeet Kaur of BME Touchstone Dementia Service in Leeds (A4D Oct 2020)

We try not use BAME term anymore because we're not putting everyone together under one umbrella term. 'Ethnically diverse' is something most people agree with. Even though our project works with wider ethnically diverse communities, even when we talk about South Asian – our café is for South Asian people – there is just not one community, there are communities under communities, we have around seven different cultures and seven different languages that they speak in the café. The idea when we started the café was for it to be run in mother tongue, but all these languages come under 'South Asian'.

#### Adapting to cultural, religious and language needs

We've done a lot of work with arts and music, because I know it's really good for dementia, but then you need to mindful about being inclusive of their cultural needs, and their religious needs and their language needs. So you just can't have one activity which fits in with everyone, we did a music session during one of the cafes, and we went with one of the old traditional folk songs, because people could relate with that more, rather than referencing Hollywood or Bollywood. For the people who couldn't understand the language, we still tried to get them involved by using instruments or humming, there are ways around it. We just need to know the cultural differences in different communities, because if we don't know as professionals, then it is going to be hard to make our offer inclusive. That is something we work hard on, to make it inclusive for everyone. We all need to think about this with new services, especially around arts.

#### Body language

I had a colleague who did not speak any South Asian languages, but she still connected with people in the cafe, but it was her body language and her showing an interest, they loved her. So, when you're engaged with arts and music you don't have to know language, it is about the approach.

<sup>71</sup> Belgrade Theatre, A statement on eradicating the use of the term BAME.(2020)

#### 4.4.5a A4D YORKSHIRE, BME Touchstone Dementia Service in Leeds (A4D Oct 2020)

We have done a lot of work around art, music and creativity, especially in the last two or three years. I've worked closely with Leeds Playhouse, Leeds Museum and Leeds libraries to introduce people to different arts activities. As professionals we often assume, especially with ethnic minorities, that people probably won't like it, but I wanted to give them the opportunity to try new things - that is how our Leeds Playhouse visit came along. They went to watch a play, *Chitty Chitty Bang Bang*. They were unsure about it at first. For many the only plays they seen was Bollywood movies at Hyde Park. It was new for me too, and at the end of the play, couples had recognised a song they used to sing when their daughters were younger, so it sparked memories for them, and that spark for me to introduce them to different plays, museums and libraries.

We've also done drumming sessions, a pilot music therapy session where we worked with an artist who spoke the language as well, we did four sessions with the dementia café, and it was brilliant. What we noticed is that their mood was uplifted by the end of the session, and they were engaging people who didn't normally engage, so music is part of our dementia café now. I want to include music or drama in some way once a month.

We have managed to move our dementia café online during lockdown, and I'm really proud because it took me three months, especially because most of my clients aren't tech savvy, and I saw it as a challenge, I needed to get them online because some of them haven't been out since March, so it is still a hassle each week – someone's audio might not be working etc. One session I spent 45 minutes getting someone online, it is a struggle but it's doable. It is not about them coming to us, it is about us reaching out to the community and finding different ways to get them engaged, and they really enjoy it!

We were part of the <u>Every Third Minute festival at Leeds Playhouse</u> – our café members actually co-produced a play around their life experiences, and it was performed at the festival. It was brilliant to see their expressions when they were watching their stories performed.

To finish, we just need to be aware of people's religious, cultural and language needs, for example, within the South Asian community, they do have different cultural needs still, so just be mindful when you're working with people

# 4.4.5b Professor Stephen Clift, chair, A4D Yorkshire meeting (Oct 2020)

Professor Stephen Clift explained that the Muslim Heritage Centre in North Kensington., as a community centre provides an astonishing range of activities for people in the local community, and they work very hard to encourage anyone and everyone in the local community to come along, they have a very full programmes including creative activities. It tends to be women who engage rather than men, but there are various aspects of the centre and the mosque which are segregated by sex, so you have to take it in a culturally sensitive way:

#### 4.6 Financial access

A.R.T.S. organisations and performance venues offer free or discounted tickets for carers. The National Trust, for example, offers an Essential Companion card to bring one or two carers or campions free of charge. To qualify for an Essential Companion card or ticket, requires registering with the venue's access team in advance.

#### 4.7 Technological access

Dr Alison Dawson, Senior Research Fellow and Co-Leader, Dementia and Ageing Research, University of Stirling (A4D Conf 21)

What I want to talk about is technology and social connectedness, and how that has implications for SP To give you an idea of where this is going, we're going to question that availability of service and interventions, and how that is a key challenge, and the potential for online services to overcome peri pandemic challenges to provision access, and to ameliorate postcode lotteries in service provision. I will talk about the challenges that remain to be addressed, and to give encouragement about resources that are available to guide online service development and talk about one I have been involved in.

The first thing to talk about is looking beyond lockdown to potential challenges downstream. One of the big challenges is going to be not just the availability of places for arts-based intervention, but also some of the ways the pandemic will affect people's confidence to use those places and spaces. I think that is one of the ways in which digital services might be helpful for us. I am involved in a project, which is going to look at the ways in which people's fears, concerns, anxieties, and feeling of unease means they're less willing to go out and use services in person than previously.

In addition to those sorts of challenges, there are challenges which existed long before the pandemic in relation to digitising the services, those relating to digital access. The Office for National Statistics, <u>Internet access – households and individuals, Great Britain: 2020 (2020)</u> suggests that at the beginning of 2020 96% of households had access to internet, but only 80% of households with one or more persons aged 65 or over had access. There are issues of access, issues around digital literacy, there are issues around service availability. You can see from a map of events from <u>A4D</u>, it indicates that by just looking at Scotland, there isn't a consistent spread of services, they're very much concentrated in different places. Digital services could potentially overcome these postcode lottery issues.

There are attempts to address those challenges both top-down attempts through things like funding different organisations to support people to get online, that's the <u>Connecting Scotland</u> approach, and bottom-up approaches through <u>Community Makers</u>, a network of community groups support people affected by dementia to reconnect during the COVID crisis. What I want to talk about is a resource developed just before the pandemic, a project that I

#### 4.7 Technological access

#### Dr Alison Dawson, University of Stirling

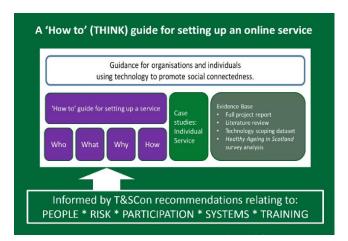
was involved in, it finished in November 2019, <u>Technology and social connectedness project 'TandSCon'</u> (2019). It looks towards potential technologies to address and ameliorate social isolation. But from that, we have produced evidence-based guidelines working with different stakeholder groups, which will be helpful for organisations thinking about how to think about setting up an online service. I urge you to look at the guidelines.

In relation to this, the plan, do, study, act cycle of process improvement - which will be familiar to many people in different health care settings - would be one of the ways in which to think about

where our guidance could be useful. It is particularly useful for planning, how

to think about setting up a guide, as opposed to doing these things and suddenly a service will appear. We need to ensure there is sufficient capacity if we want to make SP of arts-based interventions a reality. Digital will need to be a part of that process.





Alison was a Co-Investigator on three recently funded projects: The impact of COVID-19 Fear: evidence to inform social, health and economic recovery - a Healthy Ageing In Scotland (HAGIS) study (2021) funded via the UK Research and Innovation (UKRI) COVID19 Open Call, and two projects funded as part of the UKRI Healthy Ageing Challenge Social, Behavioural and Design Research Programme: Connectivity and Digital Design for Health and Well-being Across Generations, Places and Spaces (2021) and Designing homes for healthy cognitive ageing: co-production for impact and scale (DesHCA) (2021).

See Appendix 5 page 228. for technical guidance for A.R.T.S. participants.

#### 4.8 Access: A.R.T.S. Befriending

To enable individuals to access A.R.T.S. with a cultural or creative companion, A4D has coordinated a nationwide ArtsPAL befriender network.

#### 4.4.8.1 ArtsPAL Befriender Network



#### ArtsPAL (Preserve Active Life)

## Empowering individuals with a dementia to thrive through shared creative interest.

The ArtsPAL Befriender Network coordinates cultural and creative befriender organisations who provide services to enable individuals to access A.R.T.S. as pre- and post-diagnostic support for dementia. The idea is to enable and empower them to take up SP opportunities from the outset, to combat loneliness and preserve their brain health and resilience in the community.

This A4D webpage acts as a directory of befrienders who can accompany individuals to A.R.T.S. events face-to-face or help to guide them online. In the same way that A4D signposts events for dementia, the network links to befriender organisations, to enable individuals and SPLW to discover their services. ArtsPALs can follow up the organisations' links to register.

Over 200,000 people are diagnosed with dementia each year. A dementia diagnosis has a devastating impact on them and their families. One-third live alone.

- Nurturing an individual's interests, SPLW can direct them to local arts and wellbeing opportunities. However, for people living alone, the anxiety of travel and motivation to leave home can prove a challenge.
- Befriending services for dementia are often offered further down the line as home visits. Help is needed at the outset of symptoms.
- ArtsPALs can enjoy weekly activities of creative and cultural interest together, the befriender providing pre- and post-diagnostic support in enabling the individual to revive access to A.R.T.S. to preserve brain health and resilience in the community

#### Who can be an ArtsPAL?

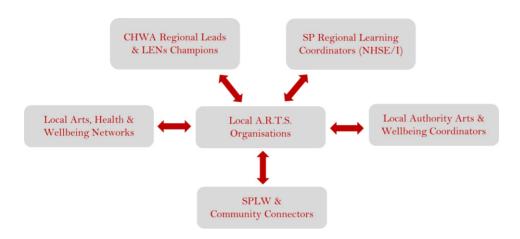
- A.R.T.S. befrienders trained by existing organisations.
- Museum and heritage volunteers.
- Arts and medical students consolidating dementia awareness training.
- A.R.T.S. facilitators consolidating dementia awareness training.
- Culture Champions, Age-Friendly Champions, NHS Health Champions, Dementia Champions.
- A.R.T.S. lovers whose spouses have died of a dementia
- Individuals with early symptoms of a dementia, for mutual support

#### Befriender organisations are classified by region:

- London
- North West
- North East
- Yorkshire
- West Midlands
- East Midlands

- East of England
- South East
- South West
- Scotland
- Northern Ireland
- Wales

#### 4.5 Raising awareness of A.R.T.S. offer – SP links

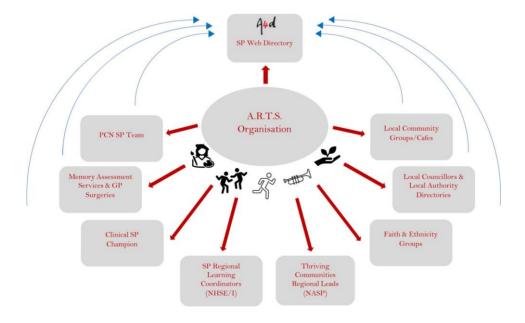


A.R.T.S. raising awareness.

The key to successful, sustainable A.R.T.S. programmes is to allow time to build relationships with all stakeholders, to plan content with potential participants – contacting the LENs network for example – and to build relationships with all stakeholders, to see if anything similar is on offer nearby and to raise awareness – for funding more formal partnerships are advisable.

#### LENs (Lived Experience Network)

The LENs is a network of people who believe in the benefits of creative and cultural engagement to individual and collective wellbeing. Working in partnership, acting as a critical friend, the LENs can champion access to creative and cultural opportunities. Contact with the LENs will help ensure that the voices of those with lived experience remain at the heart of the arts, health and wellbeing programme.



A.R.T.S. raising awareness.

#### 4.5 Raising awareness of A.R.T.S. offer – SP links

To spread awareness through their networks, the arts organiser will wish to

- Notify and potentially invite to a taster session:
  - o PCN SP champion and SPLW to notify all neighbouring surgeries and especially for their own patients.
  - o Regional Culture, Health and Wellbeing [CHWA] lead there is a museums champion and creativity champion for each of the nine English regions: North-East, North-West, Yorkshire and the Humber, West Midlands, East Midlands, South-West, South-East, Greater London and East of England. They link with LENS champions (see page 184).
    - Arts Culture Health Wellbeing Scotland
    - Wales Arts Health & Wellbeing Network
    - Arts Care (Northern Ireland)
  - o Local Arts, Health and Wellbeing network
  - Regional SPN Lead and Learning Coordinator regions as for CHWA and Scottish SPN, SP in Wales Primary Care One, All-Ireland SPN.
  - o Local Age-Friendly Culture Champion.
  - Local arts and medical colleges for volunteer and evaluation support.
  - Local ethnic, cultural or religious organisations, churches, synagogues, mosques, mandirs, Gurdwaras
  - o Local authority.
  - Local libraries.
  - o Local newspapers and radio.
- Upload programme to arts for health networks:
  - o Arts 4 Dementia SP web directory of A.R.T.S. events
  - o Age of Creativity website and ACE Arts News listings
  - Local web listings.

## 4.6 Cross-sector partnerships and funding for sustainable A.R.T.S. prescription programmes.

In December 2018, the Healthy London Partnership, supported by the Mayor of London, issued a comprehensive strategy: 'Social prescribing: our vision for London 2018-2028, aiming for every Londoner to have easy access to SP, with a focus on developing Healthy and thriving communities, calling for local innovation and coproduction between commissioners, VCSE and service users. Local authorities and VCSEs across the capital were developing SP opportunities. HLP sought to build on existing assets and strengthen the infrastructure that supports high-quality provision. The strategy set out the core building blocks for partnership development.

Wendy Gallacher, when Arts and Health Partnerships Manager across the Whitworth and Manchester Museum, organised a curatorial partnership programme giving people living with dementia a remarkable opportunity to select from the museum collection, assist with exhibition labels and the display. Prior to SP, the museum was focusing on building arts and health relationships and training, in a compelling partnership with Together Dementia Support, and their Fabulous Forgetful Friends:

# 4.6.1. NORTH-WEST: Manchester Museum: Wendy Gallagher, Head of Learning & Engagement (Host, A4D Greater Manchester, Sep 2020)

<u>Beyond Dementia</u> (2017-18) was a collaboration with Together Dementia Support (TDS) and worked with the Fabulous Forgetful Friends. This two-year project was very much about learning about those individuals and their interests.

#### Arts Health Collaboration

We used our funding to pay for a coordinator within the TDS team, to know what transport was needed, what to bring to the session etc. Having a coordinator on the other end made the project successful. Being able to ensure that it wasn't just a six-week project, that we could offer something where we could really build relationships with these individuals, and get to know their carers as well, they were very much involved in the programme.

#### Co-Curating

What we ensured was co-curation. We didn't plan this programme ourselves, within the organisation, months ahead. We wanted to do it with the group themselves, and gauge what their interest were, and what artists they wanted to work with, and really get to know them. It was challenging but absolutely worth it: and culminated in an exhibition that was co-produced and co-created, so the Fabulous Forgetful Friends selected works, we took them behind the scenes of the gallery. We built up a picture of these people, and what they might be interested in, and we presented that to our curators, and the curators spoke to them.

A small selection of art works was shown to them so that they could pick what spoke to them. They wrote down their own interpretation, and it culminated in an exhibit, and alongside it we did produce a little handbook here. I would say that this project was successful because TDS obviously realised that we couldn't work with that group in such a sustained way all the time, because we work with a lot of people. They took it upon themselves and set up their own art group which is still continuing today.

#### Cross sector training

The Museum holds regular dementia training for their staff and provides arts training for medical teams. The day starts with something quite medical, and gradually becomes more art focused; it is very much about providing non art trained people with those things that they need to feel confident that they can actually engage their patients in art activity.

Alexandra Coulter, Director of Arts and Health South West, project manager of the All-Party Parliamentary Group's *Creative Health: The Arts Health and Wellbeing* Inquiry Report (2017) and now as Director of the National Centre for Creative Health, chaired arts and health partnerships at our conference:

## 4.6.2 Alexandra Coulter, Director, National Centre of Creative Health (Chair: A4D Conf 21)

At the launch of the National Centre for Creative Health, Esme Ward of CHWA said that 'the future is collaborative.' We know that the experience of pandemic has made some of us feel more connected than ever, yet more physically confined to our place than ever. The experience has been isolating and damaging for many others, and particularly hard for those living with dementia or with the fear of a dementia diagnosis. I would suggest that many of us feel a collective responsibility, energy, and determination to work more collaboratively in order to confront the many challenges and inequalities that the pandemic has laid bare. Neither statutory nor the voluntary sector can do it alone, nor any single organisation.

I like the concept of collective impact as a way of us thinking about joining forces to achieve better outcomes for people and communities. Helping us to shed our historic territories and divides, many of the barriers to collaboration seem to be structural, to do with funding streams, lines of reporting, as much as to do with territorialism or competition. Many smaller arts and cultural providers struggle to make the time and space for collaboration, but as we work collaboratively across arts and health, the difference in scale, power, money, and language are being confronted and bridged in some pioneering places.

In order for creative health to be embedded in systems, in the planning and the operational models we need to span the boundaries through shared purpose, finding shared language and understanding, through co-production and genuine engagement in the personalised care agenda. Putting individuals and communities centre stage in every way we can, and including those who are marginalised, and wouldn't necessarily be around the voluntary and community sector table. Let alone around the table where decisions are made at an Integrated Care System (ICS) level for instance.

To make the work sustainable, we have to work in partnership, and share our knowledge, resources and experience. I believe that thinking about place is helpful. In England the 42 ICS will provide opportunities for partnerships to develop across sectors. Within them there will be different geographic levels of partnership working, and now at every level we need partnership working. Place can mean different things for different people. There seems to be a move towards a relatively permissive and flexible approach to show how ICS will evolve at a local level. The mechanics are complex. There is no easy solution.

#### 4.7.3 NASP Thriving Communities initiative

The collaborative place-based NASP Thriving Communities Fund, administered by Arts Council England, offered in 2020, set a fine sustainable A.R.T.S. prescription programme model. Aiming to increase SP and community activities for SPLW to connect to, NASP called on the arts, heritage, creativity. libraries and culture organisers to collaborate with local sport, nature, faith and wider voluntary and social enterprise and health teams, with a social in a joint bid to plan and deliver community activity and a local SPLW was to sign a statement of support.

# 4.6.3 Arts Council England. John McMahon, National Policy and Strategic Lead for Arts & Health, (A4D Conf21)

In January 2020 we published our 10-year strategy, Lets Create, our strategic vision and the key outcomes that we hope to deliver over the next 10 years, serving as a blueprint for creativity and culture for communities across England. *Let's Create* strongly foregrounds the contribution culture and creativity can make to health and wellbeing.

To make SP work, and more generally to create the shift in understanding and practice through which the contribution of culture and creativity to public health can be fully realised, partnerships are essential. Collaborative networks within broader movement. Really strong national partnerships are already formed, and NHS England lead a National SP Task Group which includes all the main Whitehall bodies, and arm's length bodies like Sport England, Natural England and Historic England etc.

Intermediate parentships, regional and sub regional are really important in this space. ICS, larger NHS Trusts, that cross regional footprint, care providers and structures of national agencies like the ACE, Sport England. Bodies like the Wildlife Trust which operate regionally or county wide. Most important is to be local. How cultural organisations collaborate and partner not only with each other, but with adjacent sectors like sport, nature, the wider voluntary sector, GP practices, PCNs, care networks, other local health care providers, and of course the SPLW as well.

#### Thriving Communities Fund

Over the past twelve months, ACE co-designed and is now administering the Thriving Communities Fund - in partnership with NASP, NHSE, Office for Civil Society, Historic England, Natural England, Sport England, the Money and Pension Service, and NHS Charities Together. That is an incredibly broad range of partners for us, for a single fund. In terms of both design and reach the programmes would not be possible without collaboration across all those agencies. Likewise, in terms of budget and management of the programme, we have been able to pool the resources of all those partners and their capacity to build a  $\mathcal{L}1.8$  million fund. As above so below, so from that foundation of national partnership, the programme is investing in 37 projects, involving over 200 named partner organisations. Mobilising the capacity of partners across health, culture, nature, sport, community advice, the faith sector and beyond to meet the need of communities hardest hit by the pandemic.

We required a minimum of three partners across those different sectors, so a different model of working, and a statement of support from a local SPLW. That has been a really effective way to foster strong local connections that we believe will endure past the end of project funding. At a national level, the partnership model has also proved to be effective in leveraging additional resources locally. We set a target of 20% cash match for every applicant to put forward. They have actually hit as a cohort 35% additional cash injection to the programme, and a similar amount of support in kind. So, we have built a  $\mathcal{L}3.1$ million activity pot from that  $\mathcal{L}1.8$ million national fund. Resource is excellent, the cohort will engage at least 8,000 people over 12 months.

Getting involved in creative activities in communities reduce loneliness, support physical and mental health, sustains older people and helps to build and strengthen social ties.

ACE, Let's Create., 2020.

#### 4.6.3 ACE, Thriving Communities

We have seen the partnerships who weren't successful with their applications due to high demand, are in many cases continuing to work together, so that's exciting. Key questions are how do ACE and other partners facilitate more of this sort of granular partnership working at a local level?

VCS umbrella organisations were the most prevalent lead applicants for successful projects and across the applicant field, so they have obviously played an incredibly strong convening role in this space. This is something that we should continue to foster. Also, it is really important to help people understand who the local anchor institutions are in the place are where you are working, who have that interconnectedness, not just to convene organisations to work together, but with that visibility and reach for patients and audiences as well.

As well as raising awareness between A.R.T.S. providers, health teams, local authorities and potential participants, encouraging the involvement of ethnic groups, this unprecedented initiative provided funding for A.R.T.S. organisations who traditionally fundraise to provide free learning programmes as time-limited projects, whereas SP requires reliable ongoing programmes to refer into. Partnerships linking A.R.T.S. to provide prescription programmes to relieve GP time attract NHS funding to enable this, NHS Charities Together is a Thriving Communities funding partner:

#### 4.6.4 Ian Lush, Chair, NHS Charities Together

NHS Charities Together, which I chair, on top of my day job of being Chief Executive of one of them, is an umbrella body. There are 240 NHS Charities throughout the UK. We have a status written into legislation, which is official NHS Charities, that means that should someone leave a legacy to a hospital trust, it goes to that NHS Charity, even if it is not entirely clear who it is meant for. We support every part of the NHS, hospitals, community care, ambulance trusts and mental health trusts and are focused on post-COVID9 reset and recovery, and partnerships with VCSE.

We know that art projects are already featuring in NHS Charities. VCSE partnerships, and SP are already being identified as a good way to embed this into local healthcare, though not all NHS Charities were working in this space before this last year. Some of these relationships were quite early, but they are developing, and starting to expand. Some good examples are emerging.

My charity, Imperial Health Charity, based in West London is the only NHS charity nationally with that museum accreditation for our art collection and exhibition programme. We have over 2,000 works displayed across five hospitals and an extensive arts engagement programme, which has grown considerably over the last two or three years, including an intergenerational project bringing together primary schools with older patients with dementia. We have also worked with the South Indian dance company, Akademi, on falls-prevention workshops, Dance Well; and with a poet in residence, delivering through Zoom and other platforms.

#### 4.6.4 NHS Charities Together

We launched a funding scheme, Compassionate Communities, aimed at supporting VCS projects in West London, including SP. The Essex Partnership NHS Charitable fund, a community NHS fund, is launching an Open Arts project with NHS Charities Together funding. This is aiming to enable wellbeing and recovery through creativity and community engagement. It is a wide- ranging project, hoping to engage the public in creative and expressive work, and importantly, to engage with local and professional artists who have had a tough time. Giving them the opportunity to lead studio placements with patients and other members of the community. In mid and west Wales, Hywel Dda Health Charities are piloting arts and wellbeing activities for staff. One of the key parts of the funding we have given over the last year or so is to support staff welfare, this arts project is very much aimed at that. When they have run the first phase of it, looking at stress relief, creative workshops, and arts engagement, they very much hope to roll it out into community work, with a dementia framework as well.

Other NHS charities actively engaging include UCLH, Derby and Burton, Newcastle Upon Tyne, Brighton and Sussex, South Western Ambulance, Shropshire Community Healthcare and CW+, which is a very active arts engagement charity, part of the Chelsea and Westminster hospital charity who have been working in this space for quite some time. As part of our intergenerational programme we worked with Vauxhall City Farm, bringing animals in with children and older people.

#### Encouraging engagement with arts organisations and health

What happens next? Well gradually NHS Charities are developing their stronger links with ICS in their areas and with the wider VCSE. We hope that this will be something where people can realise the potential of engagement with the arts organisations and health. It's fair to say that knowledge of SP is variable, but we're getting there: and the more good examples we see, the more we'll be able to encourage others to take part.

Here are two examples of Thriving Communities projects under way:

## 4.6.5 Kate Parkin, Creative Age Programme Manager, Equal Arts.

Equal Arts is a creative ageing charity which supports older people with long term health conditions and dementia. We reach about 2,000 people across the country per year. I am going to talk about the beginning of our SP programme in Sunderland. In partnership with about five other organisations, we formed the Sunderland SP Thriving Communities partnership and are just, six weeks in. I shall give you an overview of where are, and how we're supporting some of the outputs towards pre-diagnostic dementia support and for their carers.

We are one of the partnerships based in Sunderland. We received in £50,000 towards our programmes, also matched by the partners. Sunderland Culture is the lead partner, who are a consortium of five cultural organisations across

## 4.6.5 Kate Parkin, Creative Age Programme Manager, Equal Arts

Sunderland. Sunderland Carers Centre provides advice and support to carers across the city. Groundwork, a community and environmental development charity, delivers poverty reduction, conservation and eco health initiatives across Sunderland. Finally, Sunderland GP Alliance are implementing a new SP model across the city, working with SPLW, health coaches and care coordinators. We have also been working with other community-based agencies, such as the Essence service, which is part of Ag UK.

We have come together in response to a call out to support environmental aims, cultural and sport previsions, so we can support a multi-agency mechanism to support the service.

Our purpose is to establish a city wide, strategic partnership to improve the range, quality and reach of SP activities in Sunderland, especially for those impacted by COVID19 and health inequalities. The programme will help us to align to the single integrated SP service for Sunderland. Our aims are to enhance collaboration and networking between organisations, strengthen local SP activity and enable Sunderland GP Alliance SP team to connect people to more creative community activities and services. The final aim is to support this to be a sustainable programme over time. Our key beneficiaries will predominantly be carers, including people living with dementia, their care givers, and old people with long term conditions. We will be working with the GP Alliance, GPs, and other health professionals to improve carer identification and support by GP awareness and training.

Provision is split between the priority target groups. For those living with dementia, or a diagnosis in terms of cognitive brain health, and for care givers, Equal Arts and Groundwork are building that programme. For Groundwork we have, plans to develop a Men's Shed, working with Sunderland's recycling unit to create different projects. There will be outdoor volunteering, conservation and creating habitats.

For Equal Arts, our offer will be to provide an inclusive and imaginative based provision for people with dementia and their carers. This will include delivering activities on people's doorsteps, socially distanced activities involving textiles, glass making etc. We will deliver our Singing Hinnies doorstep service and online activities. We will be support dementia friendly sessions for people pre-diagnosis, carers and former carers from our Sunderland Museums and Arts Centre Washington, Creative Age programme for people with dementia. We also know when people have not received a formal diagnosis but have been in touch with a GP and want to access a group. A pre- diagnosis session will be open to all, and an inclusive session. We are looking to expand this to make sure we have got three different groups.

Our ambitions and output overall are to engage 600 people from across Sunderland, to use the carers referral pathway to test the partnership, to align with a single integrated SP service, and to evaluate success for service users to become more sustainable pathway. We are about to recruit for a Programme Manager to support referrals and a wider partnership. We are set to complete by March 2022. We are looking forward to starting to deliver the service.

#### 4.6.6 Nature Buddies - Julie Hammon, Stepping into Nature, with the Arts Development Company, Dorset

I work with Dorset Area of Outstanding Natural Beauty (AONB) and I am going to tell you about our Thriving Communities project, Nature Buddies - Reconnecting to Nature through Creative Activity, about our partnership, how we worked it up, how we got here in the first place, the aims and outputs, and elements we shall be delivering over the year. The key themes overseeing our vision and mission statement, are that connecting and engaging with art, nature and physical activity should be accessible for everyone. Our Thriving Communities partners are

#### The Arts Development Company

Our partnership culture lead, The Arts Development Company, is a Dorsetbased social enterprise and community interest company, whose aim is to strengthen the arts and culture sector and develop collaborative and creative solutions to people's lives, places, and community through using the arts

#### Stepping into Nature

Our programme, led by Dorset AONB and funded by the National Community Lottery since 2017, works collaboratively with organisations and providers to open up opportunities for people to connect to nature, especially for those over 50, or living with a long-term health condition, such as dementia, or are carers.

#### Active Dorset

One of 43 of the Active Partnerships across England, Active Dorset work they work collaboratively to create the conditions for an active nation, using the power of sport and physical activity to transform lives.

#### Help & Care

Help & Care is a registered charity working with older people, carers and communities to live the life they choose. Awarded the non-clinical health coaching and SP NHS contract by the CCG in 2019, in partnership with Dorset Mental Health Forum and Dorset Care, they oversee SPLW.

#### **Dorset CCG**

There are also SPLW within GP practices in Dorset's 18 PCNs. Dorset CCG, the commissioning organisation for the county, pulled everyone together.

That explains the strengths and skills we are all bringing in. We have all worked separately together, but not actually together as a group. we chucked ideas around the table. Our aims for the project as a whole are to increase knowledge and networking for SPLW, enabling more efficient communication about what is on offer, especially around the benefit of participating in creative activity.

We are looking to upskill communities to deliver creative activities promoting inclusiveness, and to develop new or enhance existing initiatives to widen

#### 4.6.6 Nature Buddies – Stepping into Nature

reach and ability, but also to show how they can bring professional artists in to help deliver some of their work, or to get training to carry it out themselves.

#### Nature Buddy volunteer network

We will work with PCNs and social organisations to deliver a Nature Buddy volunteer network, a one-to-one volunteer support unit for people with anxiety about getting out again, or with low confidence, or who are not sure where to go. That initial one-to-one support that people can receive from a volunteer to help them take those first steps. The Nature Buddy network will not necessarily be nature based. Somebody may want support to go to the museum or to a gallery. Nature Buddies is driven by the recipients of the Buddies, to enable them to do the things that they want to do. Organisations in contact with people in need of support, and organisations with volunteers, will link in together through this network. A Nature Buddy supports people on their journey to living happier and healthier lives. That could be sitting out in the garden feeding the birds, going on a three-mile hike, or going down to the local museum or for a history walk - whatever the recipient wants to achieve. We will also develop and deliver Nature Buddies volunteer training to increase confidence and cohesive universal message of nature-based wellbeing activity.

#### Creativity accessible to all

Having had an earlier project with The Arts Development Company offering a range of participatory creative taster sessions, we are strengthening this relationship and understanding of how everybody's work is important holistically, and that we can use each other to deliver something good.

#### Our cross-sector partnership

We have been working on various projects, between ourselves over a period of time. We have invested a lot in forming those contacts, going to each other's meetings, finding out how each organisations works, looking for opportunities to work together on projects, especially across the health sector, with health and wellbeing being one of our key areas of work. We have to understand the language and acronyms used by the health sector. Getting to understand the language breaks down barriers. Timing for the bid was tight, but the strength was the positioning, the similar ethos, ideas and outcomes of the partners. We were on the same page and ready to pull together and run with existing initiatives. We are about amplifying our voices rather than competing. We were all working together; and it is a real equal partnership each contributing for different sections of the bid to bring it all together within the deadline.

We don't just want to deliver arts activities, nature activities or physical activities, we want to bring all the elements together, to deliver a creative activity out in nature, getting people to be physically active. It is about looking at it from that holistic point of view.

The Arts Development Company was doing the final edit, so it came across as one voice completely. Support was crucial to show funders that we had support from the CCG in our area. We worked really hard to secure equal amounts of match funding from all four partners and the CCG, as well as letters of

#### 4.6.6 Nature Buddies – Stepping into Nature

support. One of the biggest things is that we all had belief. As a partnership we vowed we would try seeking alternative funding and make the idea happen, even if our Thriving Communities bid did not succeed.

#### Sustainability - meeting market needs

There were key alignments within our partnership that we all openly agreed to — that we would align to meeting market needs. Rather than produce something that wasn't usable or what people wanted, our concern was to add value and promote collaboration wherever possible, bringing in community organisations as we go along.

For instance, we are working with Dorset Race Equality Council to deliver training. Rather than do it ourselves, we're seeking organisations with strengths in those areas. We wanted to deliver something sustainable, effective and inclusive. Sustainability within project delivery is massively important, so we are not repeating ourselves, we're creating something that changes the system. We can then move forward and change the next bit of the system.

As this is cross sector partnership, it is important to be open, honest and transparent. Working together on funding bids, we are stronger; and by having a shared vision, we are all delivering along the same lines, but each keeping our own identity.

#### Outputs

- 30 trained Nature Buddies positioned within care organisations.
- Socially engaged artists linked to work with community groups.
- Taster sessions for community groups, both nature- and art-inspired, around what kind of thing they can do, and the differences they can make by bringing art and creative activity within their delivery.
- Training programme for SPLW and community groups, around participation, mental health awareness and equality.
- Evaluation for impact and potential improvements with a toolkit to enable similar initiatives in other regions.

We want to showcase and share our learning. We feel that is the way people can grow, and we can learn from other organisations and other initiatives as well. it is about working with the community groups to offer that suite of activity, enabling self-sufficiency and increasing inclusivity. We will help support communities to co-design and deliver new initiatives for wellbeing, using a landscape theme that encompasses nature, arts, culture, food, heritage, and physical activity. Giving them that taster session means that both they and SPLW can experience them, so when SPLW recommend an activity, they can really talk about how it has affected and uplifted them.

#### 5 The Way Forward

#### A4D proposes:

- Place-based partnership funding continues on the lines of NASP Thriving Communities, to ensure supply of A.R.T.S. to preserve brain health (and other needs)
- Longitudinal academic research on the efficacy of A.R.T.S. to preserve brain health, from the start of symptoms and for three years.
  - UCL and the universities of Oxford, Cambridge and Trinity Dublin have expressed interest.
- Adaption to NICE guideline 97 for dementia, 1.2 Diagnosis.

# Proposal for adaptation to NICE guideline 97 to reduce loneliness and fear at the onset of dementia and transform diagnostic practice:

Everyone has the right freely to participate in the cultural life of the community. Yet referral to arts support for dementia is not recommended until diagnosis. In light of the availability of SPLW to every GP, to relieve the strain in the isolating, fear-filled months/years leading to diagnosis and to empower individuals and their partners to preserve brain health, we propose an amendment to the NICE guideline 97 (published 20 June 2018) 'Dementia: assessment, management and support for people living with dementia and their carers' 1.2 Diagnosis: Initial assessment in non-specialist settings, page 15:

Before 1.26, it would enhance the lives of people awaiting memory assessment and enable them to preserve identity and wellbeing, and live healthier, happier, lives in the community, if a recommendation were inserted to:

• 'Refer the person to social prescriber for re-energising weekly arts and wellbeing activity tailored to the person's preference, to preserve brain health'.

NICE recommends this post-diagnosis in 1.4.1:

 Offer a range of activities to promote wellbeing that are tailored to the person's preferences

Our recommendation tallies with NICE Quality Standard 137 Mental Wellbeing and Independence for Older People (Published date 05 December 2016), Quality Statement 3 Social Participation.

 Older people most at risk of a decline in their independence and mental wellbeing are offered a range of activities to build or maintain social participation.

#### NICE adaptation to reduce loneliness and fear at the onset

Recommending SP – recognised for its transformational effect on the mental health and wellbeing of the nation – at the onset of symptoms, would help reduce loneliness and fear and keep individuals and their family partners living healthier happier lives in the community for longer,

<sup>&</sup>lt;sup>72</sup> (Universal Declaration of Human rights, Article 27).

## Gareth Presch, Chief Executive and founder, World Health Innovation Summit

This is an introduction the Sustainable Development Goals (SDG3) Good Health and Wellbeing. I wanted to pick up on SP and the opportunity for A4D to support good health and wellbeing. In September 2015, 193 heads of state pledged their commitment to implement the 17 sustainable development goals at the UN. My role as Chief Executive of the World Health Innovation Summit (WHIS): It is a platform, focused on prevention. I advise the UNGSII Foundation on SDG3, good health and wellbeing. Their role is to accelerate and implement the SDG process across the world. This brings a huge opportunity. In terms of A4D, what is the context here in terms of why do we need to work together? What's the opportunity? Well, the scale of the challenge is quite daunting. You can see from the numbers, 850,000 people are living in the UK with dementia at today, by 2025 there will be a million, by 2040, 1.6 million. Globally, this is an enormous figure with an increase of 50 million. The backdrop of this is terms of the health sector is that we currently face challenges with COVID19, but going forward, by 2030 we will have 18 million staff shortage: rising expectations, ageing populations and growing population. It is a big challenge but that also provides an opportunity.

I want to focus on the opportunity for A4D and look at a model for value creation. Really, if we look at the pathogenic approach, which is the whole structure of our health service at the moment, and the work of NASP, focused on process of health and wellbeing, this provides us with a massive opportunity. It is why we launched the Global Social Prescribing Alliance; and we believe we can create new and meaningful jobs, while strengthening existing health services and improving people's health and wellbeing. There is opportunity for arts and dementia, if you look at it in terms of growth and recovery from COVID – music we know has an enormous benefit for those with dementia – but also within the community settings we can stimulate growth within health and wellbeing.

We held a mass event in Nottingham – see it as a GP surgery at scale, where you can promote good health and wellbeing while creating value in a community setting. If you look at what we are doing in terms of arts and creative arts, we have an SDG orchestra which is supporting our implementation in the cities.

We're also working with Pope Francis' COVID19 commission around concerts for humanity. We believe there is a significant opportunity to support people's wellbeing in this space and look at the value we can create as a society. With Pope Francis' <u>Vatican COVID19 Commission</u> (2020), we produced 'Corona Perspective' reports looking at the challenges, chances and the learning; and if we look going forward, SP presents us with an enormous opportunity to support those who need our help to improve their health and wellbeing.

#### World Health Innovation Summit

What is the economics of SDG3 Good Health and Wellbeing? As I mentioned, WHIS is a platform, an opportunity to improve health and wellbeing. We started this movement in Cumbria, prototyped in the UK. We demonstrated £1 investment £36 back in value created. How big is that opportunity for the arts and dementia and healthcare to create value together? That is the question that I put to the audience. I would say it is substantial. Also, with the support of NASP and the Global SP Alliance, we can do some great work together to demonstrate that value and drive investment into this area, so we can grow the sector. Some of the activities we are working with the WHO - we have an arts event coming up with NASP, these are opportunities to showcase the impact, the evidence base and this will be at the Palais des Nations at the UN in Geneva.

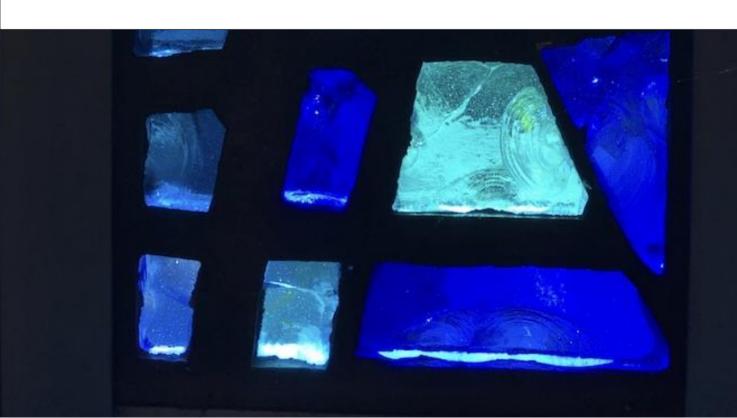
Finally, the Global SP Alliance we launched with the Department of Health recently: We've had tremendous support (G20 support) where we look at putting further investment into these sectors. Next week, we meet with G20 leaders in Berlin, where we will present moving forward with COVID while implementing SDG3 good health and wellbeing. There is no doubt that there is opportunity for the arts to be involved in this and to create a substantial impact on improving health and wellbeing.



# Arts 4 dementia

Empowerment through artistic stimulation

# SP programme 2019-21



#### A4D SP Programme 2019-21

## A4D.1 A4D Best Practice Conference 2019 'Towards Social Prescribing (Arts & Heritage) for the Dementias'.

A4D held the first UK conference on social prescribing (SP) for the dementias at The Wellcome Collection in London on Thursday 16 May, with a key policy debate and presentations by leaders in social prescribing, arts for health and social care, to drive forward direction to arts on diagnosis.

Conference presentations are available <u>below</u> – please request presenters' permission if you wish to use their material.

Each year over 200,000 people develop a dementia – one every three minutes. There is no cure, but widespread evidence that engaging with arts and heritage helps protect against the risk of cognitive decline and empowers individuals and their carers to override anxieties caused by dementia, develop new creative experiences, preserve speech and language skills and nurture resilience in the community, despite dementia.

On diagnosis of a dementia, people need direction to the arts to counteract loss and preserve cognitive function. SP, whereby surgery case managers, health support workers and link workers encourage people to choose their own arts programmes, can achieve this. But the focus of social prescribing is rarely on dementia.

Although there is not yet a cure, I believe we can do more to improve the lives of people with the condition. We can and should harness the incredible power of the arts and social activities to help people cope better with symptoms and stay connected to their communities. This is the kind of good-value, easy-to-use social prescription that I'm fully behind, helping to achieve a shirt to more person-centred care as part of our NHS Long Term Plan.

Secretary of State for Health and Social Care, Rt. Hon. Matt Hancock

'Towards Social Prescribing (Arts & Heritage) for the Dementias' looked at the evidence, the process and impact of SP arts as non-pharmaceutical interventions for the dementias and how this can be measured.

- Keynote speeches by Dr Michael Dixon OBE GP, National Clinical Lead for Social Prescription, NHS England and Co-Chair, Social Prescribing Network and Baroness Greengross, co-chair of the All-Party Parliamentary Group on Dementia, led to the health and social care plenary debate to steer the drive for SP for dementia as universal post-diagnostic support.
- Presentations from surgery SPLW to prescribed arts programmes, outlining the process, were followed by cultural companion training and launch of a volunteer creative companion consortium, ArtsPAL.

#### A4D.1 2019 Conference Programme

**Veronica Franklin Gould**, Arts 4 Dementia, introduces the social prescribing conference for dementia and creative befriender consortium, ArtsPAL

Chair'; Alexandra Coulter, Chair, Culture, Health and Wellbeing Alliance

- Christine Maddocks, environmentalist and former police officer, living with Young Onset Dementia.
- Dr Daisy Fancourt, Senior Research Fellow / Wellcome Research Fellow, Research Dept of Behavioural Science & Health, University College London, 'Arts, cultural engagement, cognition and dementia'.
- Professor Sebastian Crutch, Professor of Neuropsychology,
  Dementia Research Centre, University College London, 'Implications
  for social prescribing of the lived experiences of people with rarer
  dementias'.

#### Keynote Speech

**Dr Michael Dixon OBE GP.** National Clinical Lead for Social Prescription, NHS England and Co-Chair, Social Prescribing Network, 'Social Prescribing for Dementia in Practice'.

#### Keynote Speech

**B**aroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia

#### Plenary Debate

Chair: Dr Marie Polley, Co-Chair Social Prescribing Network

- Dr Charles Alessi, Dementia Lead, Public Health England
- **Dr Michael Dixon OBE GP** National Clinical Lead for Social Prescription, Chair, College of Medicine.
- Professor Martin Green OBE, Chief Executive, Care England
- James Sanderson, Director Personalised Care Group, NHSE/I
- Georgia Chimbani, Dementia Lead, Association of Directors of Adult Social Services (ADASS)
- Ian McCreath, Personalisation Lead, Alzheimer's Society
- Dr Richard Ings, Arts in Health Arts in Health, Wellbeing and Criminal Justice lead, Arts Council England

#### A4D.1 2019 Conference Programme

#### Arts for Early-Stage Dementia

**Chair**: **Dr Trish Vella-Burrows**, Principal Research Fellow, Sidney De Haan Research Centre for Arts & Health, Canterbury Christ Church University

- **Dr Sophia Hulbert,** Neuro-physiotherapist, Pavilion Dance South West '(A4D) Reawakening's Project: Dance for Dementia at Pavilion Dance South West'.
- **Gemma Dixon**, Director, Music for Memory, '(A4D) Choir and Organ at St Peter's, Bournemouth'.
- **Grace Meadows**, Programme Director, The Utley Foundation 'Music for Dementia 2020'.
- Lucy Wells, Communities Education Manager, Southbank, and Nick Makoha, poet, '(A4D) Poetry for dementia at the National Poetry Library'.

Social Prescribing (Arts & Heritage) for Dementia Models of Practice, Partnerships, Creative Companions & Training

#### Chair: Wendy Gallagher

- Nicky Taylor, Theatre and Dementia Research Associate, Leeds Playhouse, with recorded message from Deborah Marshall, Peer Support Co-Ordinator, Leeds City Council. 'I see land ahead. Life goes on... Theatre, dementia and hope at Leeds Playhouse.'
- Dr Richard Hooker, Clinical Lead and Paula Morrell, Health & Social Care Assistant, My Care My Way, Kalwant Sahota, Self-Care and Third Sector Commissioning Development Manager, NHS West London CCG, Royal Borough of Kensington & Chelsea, 'My Care My Way'; with Kathryn Gilfoy, Director of Resonate Arts and Emma Nutland, Projects Manager, 'Resonate Arts: Creative Wellbeing for People Living with a Dementia'.
- Wendy Gallagher, Head of Learning & Engagement, Manchester Museum, Arts & Health Partnership Manager, The Whitworth and Manchester Museum. 'Beyond Dementia'.
- **Kate Parkin**, Creative Age Programme Manager, Equal Arts, 'How can Social Prescribing enhance the lives of older adults?'.
- Bogdan Chiva Giurca, Founder & Chair, NHS England Social Prescribing Student Champion Scheme, 'Harnessing the Untapped Potential of the Younger Generation'.
- Professor Helen Chatterjee MBE, Head of Research and Teaching at UCL Culture and Professor of Biology, University College London. 'Museums on Prescription: The bio-psychosocial impact of museum participation for isolated and lonely older adults'.
- **Nigel Franklin**, Chief Executive, Arts 4 Dementia. 'Find your local arts opportunities for dementia and post your arts events for dementia on www.arts4dementia.org.uk'.



#### A4D.1 Conference 2019 – issues raised

The conference took place in May, two months before NHS SPLW were to be introduced. Key concerns were sustainability and funding. While we showcased best examples of NHS-supported arts prescriptions, most arts programmes are short-term projects funded by trusts and where possible, local authorities. The arts organisations themselves were concerned about the onus of fundraising to provide free NHS services and how to cope with rising demand; whereas the medical profession was concerned that arts programmes had to be reliably longer term than time-limited arts projects. As little was yet known about SP's cross-collaborative approach and learning and support networks, delegates asked:

- How can we ensure SP is done with care and collaboration to succeed, rather than break under the strain of expansive referrals without support?
- How SP would work nationwide in terms of funding, training, monitoring, follow-up?

There was much enthusiasm for SP, delegates were keen to learn more but concerned to ensure all would be in place to provide the best service and the capacity to do so.

#### **Funding**

- It's great that NHS England will fund link workers, but funding is needed for the organisations who will receive these referrals through SP.
- Transport costs.
- How will artists/practitioners delivering services get paid?
- Small person-centred prescriptions were seen as not income generating enough.
- Charities/organisations with a UK wide reach, who run projects in postcode areas outside their organisation's postcode need funding on the project value rather than postcode.
- With expanding uptake in a difficult financial environment, greater community involvement requires new and continued funding.
- How much money will be available to fund SP services? When will it phase in and how this can be secured?

Financial support for arts prescription programmes needs to be provided for delivery of quality consistent programmes, mindful that increased arts prescriptions will require more venues, transport, staffing and volunteer costs.

#### **Arts Prescriptions**

- Would there be a nationally available menu of projects to be prescribed?
- Arts projects would need to be appropriate and meaningful
- Quality assurance: professional expertise of arts teams, dementia friendly venues and training to ensure best practice.
- Arts teams would need to create links with SPLW and ensure that
  people affected by dementia, partners, families and carers know how to
  access arts programmes.



#### A4D.1 Conference 2019 – issues raised

#### Creating local cross-sector links to arts prescriptions

Arts organisations asked how they be sure that SPLW would know about the relevant programmes they provided and

- GP awareness of community arts facilities.
- Ensure effective referral by SPLW or others.
- Standardise SP links between local cultural organisations, GP surgeries, SPLW, memory services and SP Network, so that people experiencing dementia are aware at the outset of symptoms.
- arts4dementia.org.uk provides national SP directory of arts programmes for dementia by postcode, art form, dementia need.

#### Training

Delegates asked that SP training for both sectors would include:

- Professional guidance
- Therapeutic understanding
- Menu of effective, meaningful activities
- Quality assurance.
- Guidance as to create cross-sector SP links for self/referrals to arts.

#### Capacity

- Will the participatory arts sector be taking the role that public services can no longer provide, and that the arts are not equipped for?
- Do arts organisations have the capacity for increased demand for arts prescriptions?

The training of SPLW would indeed be provided – see page 219 – and although NASP's Thriving Communities Fund established a collaborative model to fund sustainable A.R.T.S. prescription programmes. Without it, A.R.T.S. for health funding does need to be addressed, mindful that these programmes are keeping people healthier, thereby saving health and social care costs.

#### A4D therefore planned

- Pilot SP programme in the London Borough of Southwark to run the first year's weekly programme in partnership with the arts organisations, who would continue these for at least a further year.
  - Involving arts and medical students
  - Training for arts, medical teams and SPLW.
- Regional cross-sector museum-based meetings to address issues raised at the conference
- Fortified by a campaign image to highlight the benefits.
- Final cross sector best practice conference of experts to share findings, present and debate nationwide developments in SP, creative ageing, culture, health and wellbeing and cross sector partnerships for sustainable A.R.T.S. programmes to preserve brain health.
- This report as a resource to advance A.R.T.S. for Brain Health as diagnostic practice for dementia and foundation for further research.

#### A4D.2 SP pilot - A.R.T.S. for Brain Health, London Borough of Southwark, 2020

A4D's overall aim for the Southwark pilot was to create an SP referral model whereby people would be referred to weekly re-energising arts activity as natural practice at the onset of MCI or symptoms of a potential dementia and to continue post diagnosis, whether or not the diagnosis is confirmed as a dementia. Early referral is crucial because each later stage means worsening stress at home, participants are actively preserving resilience, brain health and staying connected in the community.

As arts support was not offered until diagnosis, we needed to establish:

- The SP pathway from GP surgery, SPLW and memory service to the arts organisations
- How arts and VCSE sector can collaborate with clinical services to produce sustainably funded A.R.T.S. prescription programmes
- Awareness among health teams that A.R.T.S. plays a vital role in reenergising people at the onset of dementia, that participating in challenging creative endeavour preserves their health in the community for longer.
- Longer-term weekly A.R.T.S. prescription programmes
- Arts and medical student involvement to spread the practice
- A4D Training for arts team, to include medical students and SPLW
- NHS funding to match local authority, Big Lottery and trust funding.

#### A.R.T.S. prescription programmes

Southwark Playhouse and Siobhan Davies Dance each agreed to run two-year programmes (2020-21), the first year in partnership with A4D, for participants referred by GPs and SPLW while awaiting memory assessment or on diagnosis, with A4D managing participant recruitment.

Muse of Fire and Dance for the Brain each provided

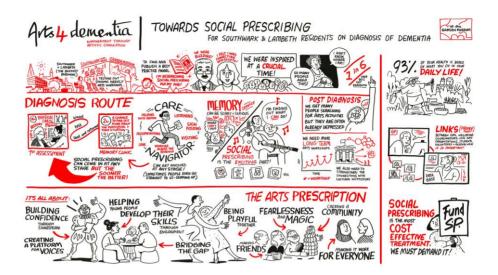
- Three terms of eight weekly two-hour workshops per year
- Assisted by students in the art form and medical students interacting together with participants to inform their ongoing careers.
- To up encourage to eight participants with symptoms, ideally with partners, to develop new creative skills, make creative choices, stretch mind and body, interact with, co-curate and perform to each other

A4D and students interviewed participants, in shared creative discussion for evaluation over refreshments at the end of each session.

Both programmes were free to participants, with the arts organisations each charging around £8,000. With the cost of A4D co-ordination, each programme cost £16,000 per year, £2,000 per individual with dementia and partner per year, or £1,000 per person with dementia and partner.

#### A4D2 SP Southwark pilot - preparation

#### Cross sector launch at Garden Museum, Oct 2019





A recent A4D participant living with dementia and her husband opened our cross-sector meeting at which stakeholders presented their part in the programme or support for it, including local council cabinet leads in culture, health and social care, dance and drama programme leads, London South Bank University (LSBU) and King's College London (KCL) professors whose students were about to take part, the memory service, an Age UK care navigator and Lambeth GP and his practice SPLW, and our council, Southwark's GP SP champion, sent a valuable presentation in her absence. There was a sense of adventure, that we were all reaching out, keen to make links and pull together.

#### Dr Nicola Weaver, GP Social Prescribing Champion

Patients present to me as a GP in very different ways, over short or long periods of time and may be at very different stages and with different concerns. Some say they are worried about their memory. Or their relative or partner might make an appointment to say they are concerned about their mother or partner. The standard time allotted for GP appointments is ten minutes. To do our best for dementia – I speak from family experience too – we often find ourselves giving more time, but that means overrunning for other patients. This is why SP is helpful for all.

At the patient's first assessment, I would take a history of the person's concerns and do an examination to look for physical factors that may be contributing. For some patients, I may already have some of their history. But for example, it is necessary to make a cardiovascular assessment, as circulation (vascular) problems are a common cause, and a more general examination to check for other signs of serious disease. There are a huge number of health conditions, particularly depression, which may contribute to poor concentration rather than true memory loss and this may be evident but always needs to be considered. It is usual to carry out a simple memory test

#### A4D2 Southwark – GP at pilot launch

(one of a variety) and discuss how much their condition is impacting on their ability to function, for both them and their family.

It is impossible to fit this complex assessment into a standard appointment (and this is the sort of reason why GPs always keep you waiting), so plans often have to be made for follow-up appointments, and blood tests need to be carried out. In North Southwark blood samples are usually taken at Guys Hospital but if this is not possible due to mobility issues an appointment can be made with the practice health care assistant.

Blood test results are sent back to the GP. If no obvious treatable condition is found (such as hypothyroidism), I would refer patients to the memory clinic for further assessment. At any stage we can refer patients to SPLW, hosted by Age UK Southwark Safe and Independent Living (S.A.I.L.). for help. In order to deliver SP, a lengthy in-depth conversation—longer than ten minutes is needed—is essential to establish the priorities and interests of an individual and the best way to help. This is where SPLW come in. I could refer to S.A.I.L. for the hugely valued and respected interventions, such as arts and exercise.

#### A4D Training, Tate Exchange, January 2020

Arts facilitators students and mental health practice nurse, two health and social care assistants, LSBU professor and four drama students and Roehampton University dance student, three from Age UK Lewisham and Southwark SAIL (SPLW) attended A4D training to give insight into the challenges for potential participants as symptoms of MCI and the various dementia subtypes set in, their existing skills and how best to access these, with dementia friendly environment training for the arts organisations. Training delegates were invited to attend the launch of our regional cross-sector tour (see page 207) that followed, raising greater understanding of our national campaign to bring arts to people at the onset of dementia.

#### Funding

Southwark Council offered £10,000 to support the programme, giving £5,000 straight away and seeking NHS charity support on our behalf. At this early stage, NHS funding was not forthcoming. Our hope was that by the end of the year, NHS would match fund, and indeed NASP initiated the Thriving Communities Fund for this purpose. In the meantime, our SP programme was supported additionally by ACE, trusts and significant donations.

#### Participant coordination – Cicely Ryder-Belson

Participant referral to A.R.T.S. programmes for early-stage dementia are generally a challenge. Southwark's GP SP champion Nicola Weaver came up trumps straight away, sending our first newly diagnosed participant and his wife, who joined both programmes, and informed her PCN GPs, one of whom immediately referred a participant who still awaits a diagnosis – perfect!

Our coordinator Cicely Ryder-Belson was in weekly contact with GPs and memory services and participants, guiding them to access Zoom post lockdown.

#### A4D2 Southwark – A.R.T.S. programmes

We achieved six enthusiastic participants with dementia and three carers for the drama and five with dementia and six carers for the dance. However, Southwark's PCN teams of SPLW (four for South Southwark and six for North) were not appointed until April – ie, for the second term, the start of lockdown. Southwark has since doubled their SPLW capacity.

Our coordinator Cicely Ryder-Belson was in weekly contact with GPs and memory services and participants, guiding them to access Zoom post lockdown.

#### The A.R.T.S. programmes, January – December 2020

There was a sense of camaraderie, creative energy and innovation at both programmes, as participants drew on imaginative skills, with a joyful sense of creative space and youthful interaction in both programmes. Encouraged to stretch, co-create, rehearse and perform their scenarios to each other every week, stimulated by the youthful inspiration of arts and biomedical and



SOCIAL PRESCRIBING



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Free, weekly creative dance classes for adults wishing to preserve cognitive function & to engage the body and brain through movement & co-created choreography. Led by a professional dance artist.





Arts 4 dementia

One hour workshop, held via Zoom, which

enjoy completely. It is pure joy.

For Adults with mild cognitive impairmer and their companions. Open to all abilities.

**On** Tuesdays, 2.15pm - 4pm, 29 Sep - 17 Nov.

By Zoom A4D with Siobhan Davies Studios

Contact Veronica on 07713 636381 veronica@arts4dementia.org

neuroscience students. They improvised and surprised each other in the theatre and studio, and during lockdown were encouraged to use the screens in ever more inventive ways,

Both courses encouraged the use of other art forms – poetry painting, art objects, feathers, to inspire creative scenarios.

Creative discussion continued with A4D and students for the evaluation over chat at the end of each workshop.

#### Returning to the Stage

While 'Dance for the Brain' participants continue to meet on Zoom for the renamed 'The Full Body Movement Class' The actors are delighted to return to Southwark Playhouse's magnificent new theatre for 'Encore' (For details, see pages 229-32).

#### A4D 3 D-IAGNOSIS! From Despair to Desire, Arts to Preserve Wellbeing cross-sector campaign



Jane Frere, D-IAGNOSIS! From Despair to Desire – Arts to Preserve Wellbeing 2019, pastel.

A4D planned a series of regional cross-sector round-tables at the major museums, to address issues arising from A4D's 2019 SP conference. To raise awareness to health and wellbeing teams of the vital role art can and should play in the wellbeing of people from the outset of dementia symptoms, we commissioned the art activist Jane Frere to create a campaign picture to hang at the museums. No shrinking violet, *D-IAGNOSIS! From Despair to Desire - Arts to Preserve Wellbeing* was designed to show the impact engaging in arts at this vulnerable stage actually plays in their lives, if given the chance.

A dual profile of a person living the experience, on the left fearful of diagnosis, on the right enchanted by having taken a range of A.R.T.S. The Spirit of the A.R.T.S. extends a hand of comfort to the Diagnostic Head, whose other eye courageously swims over waves of dementia to take up A.R.T.S.

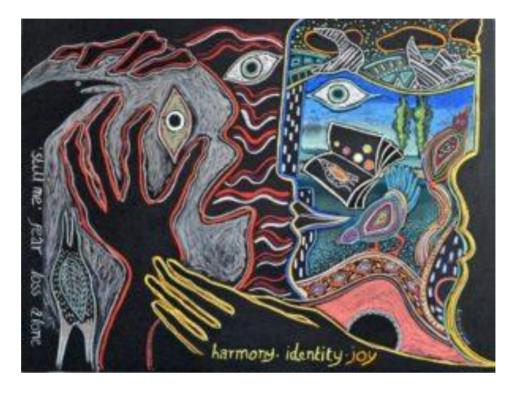
The picture was intended also as a catalyst to stimulate A.R.T.S. programmes, to enable people perhaps unable to voice their feelings, their fears about their potential or actual diagnosis, with high quality prints available for the purpose.

#### D-IAGNOSIS! Campaign launch at Tate Exchange

At the social reform space Tate Exchange, our campaign tour was launched in January 2020. A4D's patrons HSH Dr Donatus, Prince von Hohenzollern, whose generation fortified our SP campaign, and Baroness Greengross, Co-Chair of the All-Party Parliamentary Group on Dementia, by James Sanderson, Head of Personalised care at NHS/I, now also CEO of NASP, by Georgia Chimbani, Dementia Lead at ADASS. The art activist Jane Frere explained the campaign picture. Veronica outlined its purpose and curated a digital exhibition *D-IAGNOSIS! From Despair to Desire, Arts to Preserve Wellbeing*, to explain its purpose and creation.

In the event, A4D held 15 cross sector meetings – the first three at museums, thereafter convened by Zoom - for every NHS England regions and one each for Scotland, Wales and Northern Ireland, to encourage GPs to refer patients at the onset of symptoms, to re-energising weekly arts to help preserve their brain.

## A4D3 Kent response to *D-IAGNOSIS!* From Despair to Desire – A.R.T.S.



Jane Frere, *D-IAGNOSIS! From Despair to Desire -Arts to Preserve Wellbeing*, 2019, pastel.

Chris Norris, living with frontotemporal dementia, sees the Arts head on the right as a caricature of the world we live in, whereas:

'The left to me is what it feels like when I go into my fogginess and can't get a grip on anything. See the hands. Screaming out to get out of the confusion and into normality. It's alarming. It reminds me of Munch's Scream – not an area I want to be in. The right is the public me, coping with everything, but underneath it is as on the left. These are two parts of me – superman!'

Reinhard Guss, a consultant clinical psychologist, Chair and Dementia Workstream lead of the National Committee of Faculty of the Psychology of Older People in the British Psychological Society, sees a commonality of human experience, applicable in a wide sense. Of the left, diagnostic head, he says: 'As professionals it is all very well making things better but there is something truly awful and this encourages us to engage with the awfulness. It ensures the experience is not belittling the experience.'

Alison Culverwell, Chair of trustees of Bright Shadow and retired consultant clinical psychologist sees the picture as 'Useful for health professionals, for all conditions, not just for dementia, in that sense it breaks down the 'us & them' between patients and professionals.'

*D-IAGNOSIS!* enables people to engage in ways that are not verbal:

#### A4D 3 D-IAGNOSIS! on tour

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Now that every GP has access to NHS link workers, who can empower patients to choose their rehabilitative social prescription, Arts 4 Dementia has been holding meetings gathering together leaders in academia, social prescribing, culture, health and wellbeing in every NHS region. The idea is that if GPs refer patients to link workers to choose weekly arts programmes early in the diagnostic process, by sharing cultural interests, learning new skills, the shock of diagnosis will be less, as they co-create dance, drama performances, discuss and create art, despite dementia, they can preserve identity and enjoy life in the community for longer.

Arts 4 Dementia has brought together leaders in culture, health and wellbeing, GP clinical and social prescribing leads, memory services, link workers and community connectors to connect those involved and drive forward social prescribing as pre-diagnostic practice for dementia. D-IAGNOSIS! hung at leading UK museums, who during the pandemic have hosted meetings by Zoom to drive forward the practice:

CANTERBURY: The Beaney House of Art & Knowledge

BATH: The Holburne Museum

LONDON: The Wallace Collection, National Social Prescribing Day

OXFORD: Ashmolean Museum of Art & Archaeology, Age of Creativity Festival

SOUTH-EAST, HAMPSHIRE: St Barbe Museum, Lymington

SOUTH-WEST, DEVON: Royal Albert Memorial Museum, Exeter

NORTH-WEST, GREATER MANCHESTER: Manchester Museum

NORTH-EAST, TYNE & WEAR, NEWCASTLE: Equal Arts & Tyne & Wear Museums

YORKSHIRE & HUMBER: Leeds Museums & Galleries

WEST MIDLANDS: Birmingham Museums

EAST MIDLANDS: Nottingham Contemporary

EAST OF ENGLAND, CAMBRIDGE: The Fitzwilliam Museum

SCOTLAND: GLASGOW: Scottish Opera

WALES: National Museum Wales (Brain Awareness Week)

NORTHERN IRELAND: The Millennium Forum (International SP Day)

#### A4D.4 A4D Best Practice Conference 2021

# Arts for Brain Health: Social Prescribing (SP) as Peri-Diagnostic Practice for Dementia

20-21 May 2021, 9.20 am – 5 pm.



Jane Frere, D-IAGNOSIS! - Arts to Preserve Wellbeing, 2019, pastel.

'You have got to start with the person not the patient, prioritise social, cultural and creative interventions to prevent the risk of cognitive decline. In a 21st century NHS we need to turn things around. Social prescribing needs to be at the heart of the system. It has got to be about that wider holistic support for people with dementia, not just post-diagnosis, but from the onset of symptoms. I think 'care' is helping people do what they love to do, allowing them to connect with their passions, what animates them in life. empower them to do what they love doing. That is the starting point for dementia care. It is about the vision of promoting independence, creativity, empowering people to interact and enjoy activities to preserve their brain health.'

The Rt. Hon. Andy Burnham, Mayor of Greater Manchester.

Cultural and creative activity can be transformational for those at the start of their journey with dementia. In this conference we explore how social prescribing (SP) can unlock access to the arts and improve wellbeing and brain health.

Leading experts in innovative and creative ageing, dementia and its prevention, NHS personalised care, SP, arts, culture, health and wellbeing, educationalists and local authorities and policy makers joined forces to revolutionise the world of SP for brain health.

Their talks, accessible by name below:

- Presented evidence for creative ageing to protect against cognitive decline,
- Examined the potential for normalising SP as diagnostic practice
- Demonstrated cross-sector referral and funding partnership practice for sustainable social prescription programmes
- Debated the way forward.

#### A4D.4 Arts for Brain Health Conference Programme, Thursday 20 May 2021

Veronica Franklin (VFG), President, Arts 4 Dementia.

Baroness Greengross, Co-Chair, All-Party Parliamentary Group on Dementia.

VFG, 'From Despair to Desire, SP to Relieve Strain from the Onset of Dementia'.

Keith Oliver, Alzheimer's Society Ambassador 'Give me Identity & I will Shine', with Jen Holland.

James Sanderson, Director, Personalised Care, NHSE & I; Chief Executive, National Academy for Social Prescribing (NASP).

Chair: **Professor Alistair Burns**, National Clinical Director for Dementia & Older People's Mental Health, NHS England & Improvement.

#### PREVENT WELL - Creative Ageing

**Professor Helen Chatterjee**, Professor of Biology University College London & UCL Arts & Sciences. 'Community engagement during the COVID pandemic: how can community assets & SP redress health inequities?'

Fergus Early, Artistic Director, Green Candle Dance, 'An inspiration, not a burden!'

**Dr Virginia Tandy**, Director, Creative Ageing Development Agency. 'Making the case for creative ageing'

## Arts for Brain Health – SP as Peri-Diagnostic Practice for Dementia

**Professor Craig Ritchie**, Chair, Psychiatry of Ageing, Dir, Centre for Dementia Prevention at the University of Edinburgh & Brain Health Scotland, 'Brain Health Clinics: The Scottish Model & Points for SP'.

**Dr Bogdan Chiva Giurca**, Global SP Alliance, Clinical Champion Lead, 'Arts for Brain Health – SP as Peri-diagnostic Practice for Dementia'.

## PLENARY DEBATE: 'How to Achieve SP at the Onset of Symptoms'

James Sanderson, Director, Personalised Care, NHS EandI, Chief Executive, NASP.

Alexandra Coulter, Director, National Centre for Creative Health.

Maddy Mills, Director, Entelechy Arts.

**Georgia Chimbani**, Dementia Lead, Association of Directors of Adult Social Services (ADASS).

**Dr Kalpa Kharicha**, Head of Research, Policy & Practice, Campaign to End Loneliness.

**Dr Jonathan Kaye,** Dementia Clinical Lead, Manchester Health & Care Commissioning NHS Manchester CCG.

#### Arts & Health Funding for Social Change

**John McMahon,** Arts & Health Lead, Arts Council England, 'The changing landscape for arts & health through the lens of the Arts Council's new 10-year strategy, *Let's Create*.'

**Ian Lush,** Chair, NHS Charities Together 'A Growing Partnership – NHS charities & the arts sector'.

Gareth Presch, CEO & founder, World Health Innovation Summit, 'Introduction to UN Sustainable Development Goal 3 Good Health & Wellbeing'.

#### A4D.4 Arts for Brain Health Conference Programme, Thursday 20 May 2021

#### Cross-Sector Partnerships for Sustainable Arts Prescriptions

Chair: Alexandra Coulter, Director, National Centre for Creative Health.

**Claire Stevens**, Chief Executive, Voluntary Health Scotland 'Keeping the Conversation Going: an intermediary's story of collaboration'.

Bev Taylor, Operations Director, NASP, 'Communities in the lead through cross-sector partnerships.'

**Kate Parkin**, Creative Age Programme Manager, Equal Arts, Thriving Communities 'Our journey so far: SP in Sunderland'.

#### **REGIONAL:**

Chair: Dr Michelle Howarth, University of Salford.

#### GREATER MANCHESTER

**Andrea Winn**, Curator of Community Exhibitions, Manchester Museum, 'Made to Measure: Inclusive programmes for Older Adults at Manchester Museum'.

**Dr Jonathan Kaye GP**, Dementia Clinical Lead, Manchester Health & Care Commissioning, NHS Manchester CCG.

Heather Etheridge, Be Well Service, Big Life Group, 'SP & dementia'.

**Dr Mehran Javeed**, Consultant Old Age Psychiatrist, Clinical Lead for Salford Memory Services.

#### EAST OF ENGLAND

**Dr Miranda Stearn**, Head of Learning, Cambridge Museums, 'Partnerships for ageing well: Promoting older people's psycho-social wellbeing at the University of Cambridge Museums'.

Dr Dean Dorsett GP, SP Lead, NHS Ipswich & East Suffolk CCG.

Kelly Austin, Social Navigator, Granta Medical Practice.

Chrissie Moore, Programme Manager, Dance East.

**KENT** 

Elizabeth Taylor Services Manager for East Kent, Alzheimer's Society.

Monica Boulton, SP Lead, Red Zebra Community Solutions. 'Connecting people to their community to support their wellbeing'.

**Sian Stevenson**, Creative Director, Moving Memory Dance Theatre. 'Challenging perceptions of self: Feeding body brain & soul'.

**Dr Patricia Vella-Burrows**, Principal Research Fellow, Sidney De Haan Research Centre for Arts & Health, Canterbury Christ Church University.

#### REGIONAL:

Chair: Professor Carolyn Wallace, University of South Wales.

WALES

**Laura Rehman**, Age Connects Torfaen, interviews **Nicky Deacon**, who is living with Young Onset Dementia.

Robert Visintainer, Project Manager, Men's Sheds Cymru & Swansea City Opera.

Gwennan Mair, Head of Creative Engagement at Theatr Clwyd.

**Andrea Davies**, Arts in Health Wellbeing Coordinator, Betsi Cadwaladr University Health Board.

#### A4D.4 Arts for Brain Health Conference Programme, Thursday 20 May 2021

#### SCOTLAND

Rachel McLellan, Culture Policy Officer, Scottish Government.

**Robbie McGhee**, Chair, Arts, Culture Health and Wellbeing Scotland, 'How can a national network help support SP to culture as peri-diagnostic practice for dementia.'

Jan-Bert van den Berg, Director, Artlink Edinburgh

**Susan Grant & Ian Mackenzie**, Arts Manager & Green Health Programme Manager, Edinburgh & Lothians Health Foundation.

NORTHERN IRELAND

Professor Louise Dubras, Dean of the School of Medicine, Ulster University

Leanne McBrearty, Co-Chair Regional Manager, SPRING SP.

Lorraine Calderwood, Arts Council of Northern Ireland.

Dr Jenny Elliott, Chief Executive, Arts Care

#### **ACCESS**

Chair: **Professor Chris Fox**, Professor of Clinical Psychiatry, Norwich Medical School, University of East Anglia.

**Dr Alison Dawson**, Co-Leader, Dementia & Ageing Research, University of Stirling, 'Technology & Social Connectedness: implications for social prescription'.

**Zoe Rowe**, Social Innovation Consultant: Technology Guidance 'Remote engagement: Removing barriers to inclusion in the context of COVID-19'

**David Truswell**, Executive Director of the Dementia Alliance for Culture & Ethnicity, 'Undiagnosed Artists from Unknown Cultures'.

**Cailin Lynn**, Development Manager, Museums of Northern Ireland, 'Access for All at National Museums of Northern Ireland'.

Cicely Ryder-Belson, A4D SP Coordinator, 'ArtsPAL, the A4D cultural & creative befriender network'

Professor Chris Fox, Summary.

Nigel Franklin, A4D Chief Executive, A4D training & SP web directory of events.

#### A4D.4 Arts for Brain Health Conference Programme, Friday 21 May 2021

VFG, A4D President.

Hamaad Khan, neuroscience student, interviews Ron Bennett, fellow participant in A4D at Southwark Playhouse 'Muse of Fire'.

Bisakha Sarker, Artistic Director, Chaturangan South Asian Dance, 'Exchange'.

Chair: **Professor John Gallacher**, Professor of Cognitive Health, The University of Oxford, Director, Dementias Platform UK.

#### PREVENT WELL - Creative Ageing

**Professor Sir Muir Gray**, Value Based Healthcare, Nuffield Department of Primary Care, The University of Oxford.

Christopher Bailey, Arts & Health Lead, World Health Organisation.

**Dominic Campbell**, Artistic Director, Creative Aging International 'Celebration as Strategy – Hope & Creative Aging'

## Arts for Brain Health – SP as Peri-Diagnostic Practice for Dementia

**Professor Brian Lawlor**, Deputy Executive Director, Global Brain Health Institute. Professor of Old Age Psychiatry, Trinity College Dublin 'Arts & culture as part of a framework of hope for dementia'.

**Dr Michael Dixon GP, LVO, OBE**, National Clinical Lead for Social Prescription, NHSE&I, Chair, College of Medicine, Co-Chair, International SP Network.

#### PLENARY DEBATE:

#### 'How to Achieve SP at the Onset of Symptoms'

Neil Fullerton, Project & Communications Lead, Brain Health Scotland.

Kate Duncan, Programme Director, Wellbeing, Nottingham City Arts.

Professor Martin Marshall CBE, Chair, Royal College of General Practitioners.

Dr Charles Alessi, Senior Advisor, Public Health England.

Ian McCreath, Policy Manager, Personalisation & Integration, Alzheimer's Society.

Jo Ward, Co-Chair, North-West SP Network.

#### Arts & Health – Social Change

**Dr John Zeisel,** Founder & Emeritus Board Member, I'm Still Here Foundation, 'The Arts, Brain Health, & Social Change'.

**Veronica Franklin Gould** & Art Activist **Jane Frere**, 'D-IAGNOSIS: From Despair to Desire: The Transformative Power of Arts for Wellbeing'

#### Cross-Sector Partnerships for Sustainable Arts Prescriptions

Chair: Alyson McGregor, National Director, Altogether Better.

**Adele Dunn**, Senior Health Improvement, HSC Public Health Agency, 'Building Cross Sector Partnerships for Sustainable Arts Programmes'.

**Nesta Lloyd-Jones**, Assistant Director, Welsh NHS Confederation, 'How the arts are supporting health & wellbeing in Wales'.

Julie Hammon, Arts Development Company & Stepping into Nature, Thriving Communities Dorset 'Nature Buddies: re-connecting to nature through activity'.

#### A4D.4 Arts for Brain Health Conference Programme, Friday 21 May 2021

#### REGIONAL.

Chair: Victoria Hume, Director, Culture Health & Wellbeing Alliance OXFORD

Dr Stephanie Tierney, University of Oxford, 'SP for people living with (MCI'.

Beth McDougall, Community Engagement Officer, GLAM, University of Oxford.

Stephen Chandler, Head Adult Services Oxfordshire CCC & CCG, President, ADASS.

Helen Fountain, Age-Friendly Creative Network, Age UK Oxford.

HAMPSHIRE & ISLE OF WIGHT

Julie Kalsi, Partnership Support Officer - Health. Crawley Borough Council

Dr Michele Legg, GP, Clinical Lead Dementia, NHS Isle of Wight CGG

Angela Gill, SP Network, Hampshire & Isle of Wight, 'Hants & IoW SP Update'.

Hannah Griffiths, Community Engagement Manager, Independent Arts, 'Inclusivity & open to all Independent Arts work on the Isle of Wight.'

DEVON

Dr Daisy Robinson GP, College Surgery Partnership, Cullompton SPT.

Ruth Tucker, Health Facilitator, Culm Valley, Cullompton SPT.

Gail Mistlin, Wellbeing Exeter Coordinator, 'The Wellbeing Exeter Programme.'

Hannah Reynolds, Chair, Exeter Community Centre Trust, 'All's Well Heritage with Health Benefits'

#### REGIONAL

Chair: Dr Mohan Sekeram GP, SP Clinical Lead, NHS Merton CCG.

LONDON

Concia Albert, Head of SP, One Westminster.

VFG & Cicely Ryder-Belson, A4D Dance & Drama Prescriptions in Southwark.

Jenny Marshall, Head of Member Experience, Open Age.

Khadeja Chowdhury, Bromley by Bow Centre, 'Space to Connect'.

**MIDLANDS** 

Amanda Spruyt, Head of Learning, Nottingham Contemporary.

**Dr Sonia Asraf** GP, Dementia Lead, Governing Body, NHS Birmingham & Solihull CCG, 'Speaking with your GP about a diagnosis of Dementia & what happens next.'

Jennifer Luisada, SPLW, NHS Birmingham. & Solihull CCG.

Gordon Strachan, Commissioning Manager, Adult Social Care, Birmingham City Council.

YORKSHIRE

Geraldine Montgomerie, Leeds Arts Health Wellbeing Network.

**Dr Sara Humphrey**, GP Advisor, Clinical Lead OPMH & Dementia, NHS Yorkshire & Humber Clinical Network.

Ripaljeet Kaur, Coordinator BME Dementia Service Touchstone, 'Ethnic Diversity in Dementia'.

Tim Sanders, Community Prog Lead, Dementia, NHS Leeds CCG/CC.

#### A4D.4 Arts for Brain Health Conference Programme, Friday 21 May 2021

#### HERITAGE & NATURAL ENVIRONMENT.

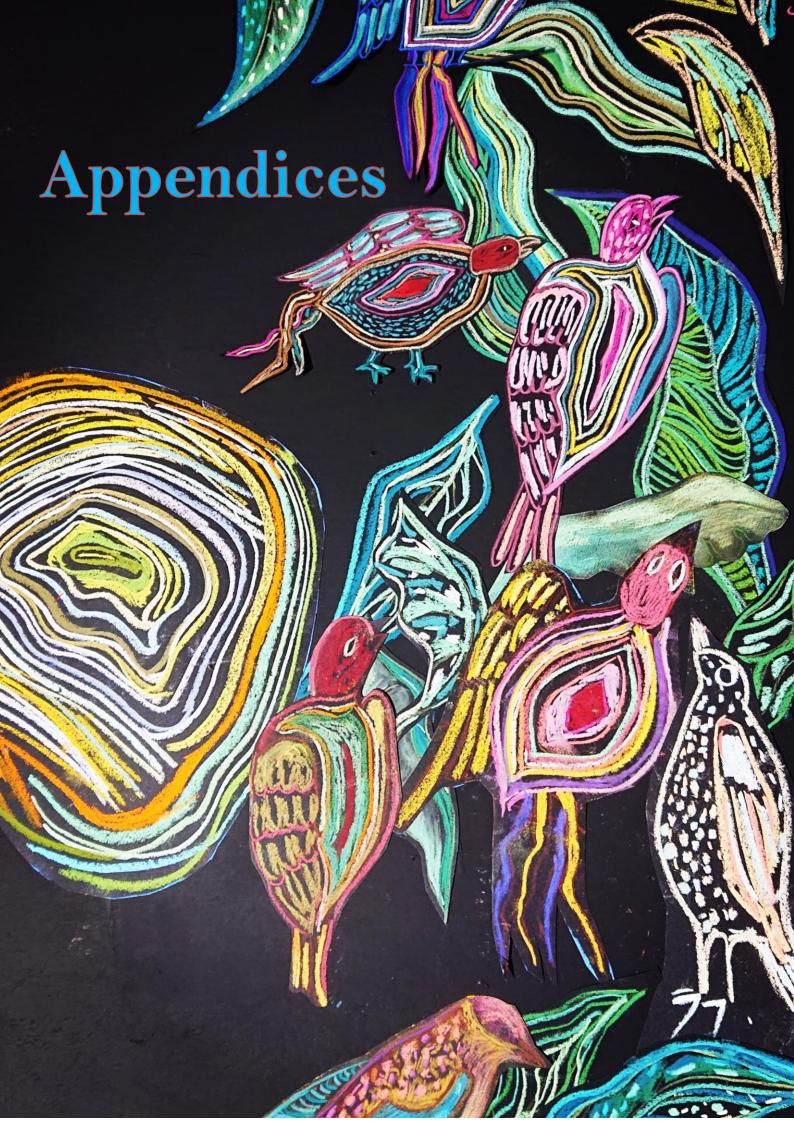
Chair: Craig Lister, Wellbeing Lead, East of England, Public Health England.

**Dr Desi Gradinarova**, Senior Policy Advisor, Wellbeing & Inclusion, Historic England; National Historic Environment Lead, NASP, 'May the force of the past be with you: why heritage is good for the human mind & soul'.

Elizabeth Galvin, Head of Learning & Digital, Victoria & Albert Museum.

Tom Mack, Programmes Manager, Active Devon, 'Connecting Actively to Nature'.

Sir Tim Smit, Co-Founder, The Eden Project: 'Making Natural History'.



#### A.1 – A4D MCI and Early-Stage Dementia Awareness Training for A.R.T.S. teams, arts, medical and neuroscience students and SPLW

#### Summary

This interactive awareness training is designed to help A.R.T.S. organisations make weekly programmes for older people accessible for people experiencing mild cognitive impairment and early-stage dementia, for SPLW to have a greater understanding of their needs, and for arts and medical students, learning together, to benefit their careers and help spread the practice

#### Suitable for

Arts teams, workshop leaders, animateurs, artist, musicians, dancers, actors, museum guides, front of house, learning, community and access teams, audience development, SPLW, community developers, GPs, medical and neuroscience students.

#### Aims of the day

- To give insight into the challenges people face as symptoms of cognitive decline or dementia arise, their existing skills and how best to access these, and awareness of their need to continue resilient life and interests in the community i.e., A.R.T.S. workshops for older people, to preserve brain health, rather than brand programmes for dementia, but with communication guidance to make A.R.T.S. programmes accessible to them.
- To increase skills and confidence in communicating and working creatively with people experiencing symptoms of MCI or early-stage dementia, and their companions.
- To inform SPLW and community developers, and to help arts organisations work towards reaching new audiences, in collaboration with SPLW, making their institutions more inclusive and increasing their impact in the community

#### Programme

Includes, Ageing and Dementia, MCI and Dementia sub-types, young onset dementia, early diagnosis and feelings about being diagnosed, person-centred care, components of communication, skills, challenges, analysis, understanding behaviours and participants' changing needs. Re-energising approach to override symptoms Delivering effective virtual programmes, sharing examples of good practice. A4D workshop model. Funding. SP referral. A4D website.

#### Learning outcomes

Delegates will be able to demonstrate understanding of MCI and dementia subtypes and how these impact on participants, explain key communication approaches, including use of virtual delivery, describe with confidence the value of arts-based approaches for people at the onset of dementia, explain the impact of A4D's re-energising approach to engage and encourage them to participate and develop new creative skills.

# A.2 – Remote access guidance for digital A.R.T.S. workshops

By Cicely Ryder-Belson, A4D Social Prescribing Coordinator

#### **Preparation for Zoom:**

#### **Digital Access:**

- Check participants have access to a device a laptop, desktop, tablet, or mobile phone.
  - o If they do not have access to these devices, councils, libraries and third sector organisations may be able to provide these.
- Check for stable internet and reception, using either Wi-Fi or mobile phone data.
- Send a physical guide to each participant, for reference in advance and throughout workshops, with joining instructions tailored to their device/s.

#### **Training and Support:**

- Dedicate one person to provide digital support throughout the programme. Provide participants with their name and phone number, to be available throughout the workshops.
- Provide a one-to-one training session for each participant a week in advance to familiarise them with using the technology in private and ahead of time.

#### **Plan Delivery**:

- Arrange any accompanying postal kits or materials needed to facilitate practical creative activities.
- Devise clear communications, establish how facilitators can cue in participant contributions and use audio controls to avoid audio interference.
- Dedicate a host who can facilitate breakout rooms for smaller group activities.
- Decide if you wish participants to use Gallery or Speaker View.
   Considering how the camera allows for a person-centred approach, where one facilitator can be making direct eye contact with a whole group.
- Consider how to use the camera or screen as a creative device.

#### **Delivery:**

- Open each workshop 15 minutes early, before delivery, so that each participant is comfortable with their device.
- Remind participants of their device settings. Test audio and video controls.
  - If comfortable, encourage participants to have their video on to facilitate interaction and engagement.

#### A.2 - Remote access: Zoom Guide

#### Opening Zoom:

On a Computer or Laptop, click on your Zoom Invitation Link **to** open your internet browser.

- If you have not used Zoom before, clicking the link will automatically download Zoom.
- If you have used Zoom, you will be automatically connected.

On a Tablet, iPad or Smartphone, download Zoom Cloud Meetings app.

- Go to the App Store (for iPhones and iPads) or Google Play (for Android phones and tablets).
- Click the Zoom Invitation Link, to be automatically connected.



#### **Zoom Controls:**

On a computer or laptop screen: these icons are in the bottom left corner On a tablet, iPad or smartphone, they are in the top right corner:

- **Audio:** The microphone icon controls the sound of your voice.
  - Mute (red line appears on microphone) means your voice cannot be heard.
  - Unmute (no red line showing) enables your voice to be heard.
- Video:
  - O Start Video is next to the audio icon.
  - o 'Stop Video' if you need to be unseen.

It is recommended to **Unmute** for the welcome at the start, for discussion and interactive exercises which requires you to contribute. You may be advised to **Mute** to ensure there is no background noise for everyone else.



#### Gallery View and Speaker View

These icons allow you to change how you view the other participants. On a computer or laptop screen, they are in the upper right corner.. On a tablet, iPad or smartphone: swipe left or right to switch between

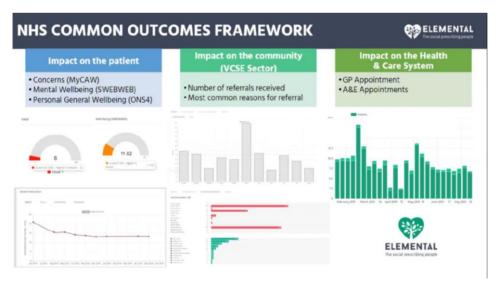
- Gallery View Every participant is visible, in rectangles of equal size. and
- Speaker View. The current speaker's video fills most of the screen, while other participants are seen in small rectangles at the top of the screen.

#### A.3 Data reporting Elemental Software Jennifer Neff, (Northern Ireland, A4D Mar 21)

The SP platform <u>Elemental Software</u> was launched in 2017. with measuring tools that enable health and social care professionals to track patient referrals to health and wellbeing activities and monitor their uptake and progress. Their award-winning technology enables health teams to evaluate the impact of prescribing non-clinical activity to improve their patients' health and wellbeing. Elemental Software, now widely used around the UK in association with clinical systems, EMIS Web, SystmOne and Vision, enables GPs to make and manage referrals to SPLW within three clicks. Elemental's co-founder and CEO explained the process at A4D's Northern Ireland SP meeting:

Elemental has a core platform used primarily by SPLW. They receive referrals electronically from GPs, social workers, OTs, hospitals, community paramedics, pharmacists and other VCSEs. SPLW can manage their case load through the platform, measure progress and do some wellbeing scores. There is a live and interactive database of services which people can access in the community.

We have a two-way integration with GP systems too. GPs said we're not going to log out of our system and into yours, make this seamless and make this easy. We have done that. Nearly 10,000 GPs, social workers and MDTs make referrals through their clinical systems straight into Elemental. The SPLW can access it anywhere in the community - they don't have to come into practice. We have also developed a self-refer button so carers and individuals can self-refer into SP.

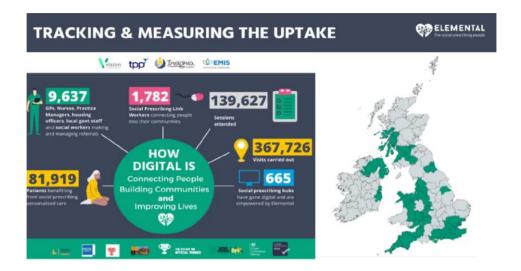


The NHS Common Outcomes Framework measuring the impact of SP on the

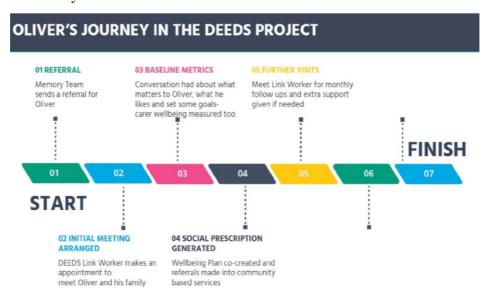
- Patient
- Community
- Health and social care system

can be demonstrated through Elemental, which can also show where the gaps are in the service delivery. There might be a particular neighbourhood that has a lot of issues around anxiety - are there enough services and support available

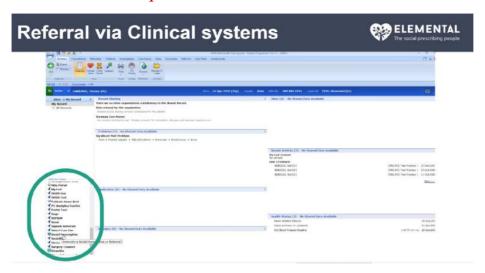
there in that neighbourhood? As a result of all this great work that everyone is doing, is there is a reduction in GP appointments, in A&E appointments, the waiting lists for services? Is there an increased demand for something else?



We have quite a large spread across Northern Ireland (NI), where we are based, and the UK. SPRING SP in NI and Scotland use Elemental. It can track and measure all the different aspects of the journey for the patient. Elemental refers participants to <u>DEEDS</u> (Dementia Engaged and Empowered Derry and Strabane) - a programme rooted in the Creggan community of Derry/Londonderry and beyond, for people with early-stage dementia and carers. Referrals from memory teams, GPs, VCSEs and self-referrals go through to the DEEDS team. They do the assessment and have a chat with the person and the carer and be able to connect them A.R.T.S. activities of their choice. Reducing carer fatigue and increasing wellbeing for those involved with family members.



#### How GPs refer patients to SP.



#### Click on Elemental SPX via EMIS



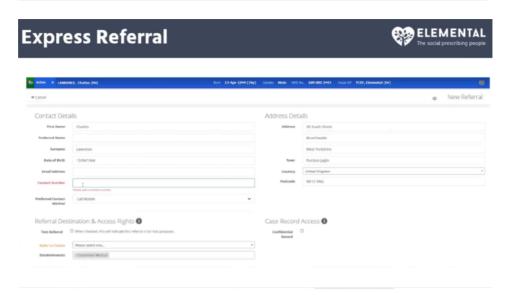


#### New Express Referral

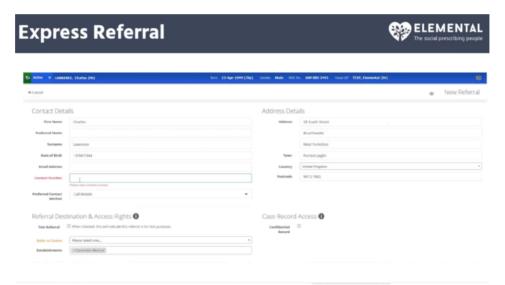




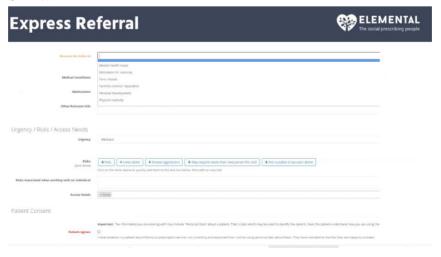
An SP button pulls up a referral form for them. It prepopulates the referral, bringing across their demographic data. The GP or referrer is asked the reason for referral.

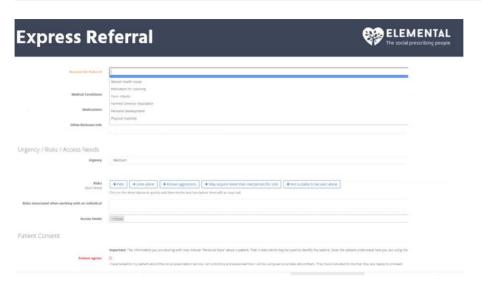


An SP button pulls up a referral form for them. It prepopulates the referral, bringing across their demographic data. The GP or referrer is asked the reason for referral.:

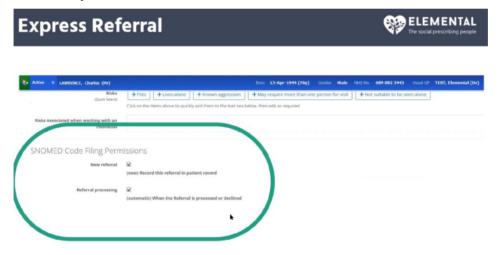


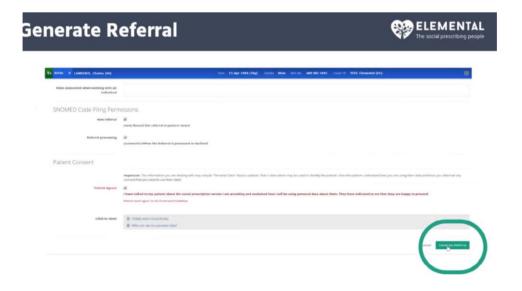
Urgency risks and access needs, as safeguarding information for the SPLW:



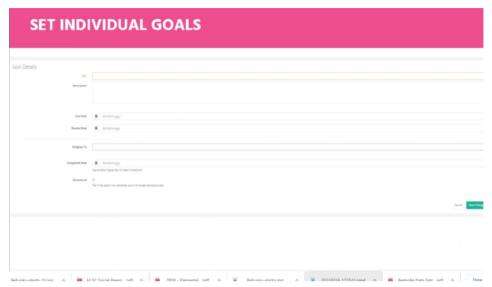


Using <u>SNOMED CT Codes</u> associated with SP to help everyone report more easily.





The platform lets people set individual goals which the SPLW would work through.



They gather baseline information using the <u>Short Warwick Edinburgh Mental Wellbeing Scale</u>..



MyCog is a tool that measures people's concerns and gives the patient view of how they feel hat day and over time, how their wellbeing increased or how their anxiety has decreased.



The database of services brings up all the different things available in the community and enables the SPLW to connect the person into services appropriate to them.

# Results Filters Comains Commains Commains

#### SPLW can identify

- Where their referrals are coming from
  - o which GP practice
  - social worker
  - o community pharmacist.
- Their team, who is managing the most referrals, so as to ensure there is no burn out in the team.
- Percentage uptake of referrals offered
- Which tools are being used, according to need.
- Reason for referrals.
- Activities people are engaging in, such as Men's Sheds, DEEDS or the Connect programme.
- Demand vs gaps.
- Age groups, gender

SPLW can set peri-diagnostic cohort groups pre-, post- or on diagnosis.

#### A.4 Data Reporting

#### Gloucestershire Creative Health Consortium

By Heike Fanelsa, Project Manager, Self-Care and Prevention Team, NHS Gloucestershire CCG

#### Background & context

A new delivery consortium of arts-based providers has followed extensive work since 2015 between the Clinical Commissioning Group (CCG) and local VCSE arts providers. The Gloucestershire Creative Health Consortium provides a mechanism for commissioning and delivery of creative health offers for the Gloucestershire population, enabling providers to work collaboratively to develop innovative delivery models. The Consortium currently has five local VCSE provider members and it is anticipated this will grow over time. It will provide an opportunity for growth and expansion of the VCSE creative health sector in Gloucestershire and enable more grass-roots organisations and individuals to contribute to high quality place-based health and wellbeing provision. The Consortium will enable the CCG to commission a diverse and rich portfolio of programmes to meet population needs; to improve efficiency of commissioning processes and to increase the likelihood of high-quality outcomes for individuals and communities.

As a non-constituted organisation, members have agreed to a lead provider model of commissioning for the Consortium, with Art Shape Ltd being this lead provider. Delegated governance and accountability for creative health activity commissioned by the CCG is therefore with Art Shape Ltd; and the provider members retain delegated responsibility for delivery.

#### Why data reporting is important

The Consortium delivers programmes that encompass a targeted SP offer known locally as 'Social Prescribing Plus', which focuses on offering personalised and time-bound social prescriptions for people living with a range of physical and/or mental health conditions. Therefore, the aim is to explore how non-medical arts prescriptions can support self-management of physical, mental and social outcomes for people living with diagnosed health conditions.

A novel and trailblazing way of working with Arts on Prescription and creative health providers, the Consortium is currently delivered on a test-and-learn basis. To date, through qualitative measures, we have found that the programmes within the Consortium have significant benefits for people and show extreme promise going forward. However, we are now expanding our knowledge on the impact the programmes are having by including quantitative measures. This will ensure that we have a more robust and informative evaluation going forward with the ultimate aim of embedding SP Plus programmes within clinical pathways to contribute to meeting health and wellbeing outcomes across the life course.

In summary, good quality data is essential as it can be used for decision making, evaluation and development of future creative health offers.

#### A.4 Creative Health Consortium

#### How to do it

Provider members of the consortium worked collaboratively with the CCG to ensure that robust data reporting processes were implemented, prior to any data submission. This was to ensure that the appropriate data protection policies were adhered to. Our data protection lead at the CCG was involved throughout for guidance and signed off the finalised data submission process. The data protection process required all providers to complete the <a href="NHS Data">NHS Data</a> & Security Protection Toolkit. Referral forms were standardised to include all relevant participant data to be captured (see below for details) and GDPR consent statements were added, explaining to referrers and participants how their data was going to be used.

A Minimum Data Set (MDS) reporting template was designed by our CCG Business Intelligence Analyst and sent to all providers in the consortium. This included, for example, the collection of NHS numbers, whether someone is a carer and the number of sessions the person attended. CCG Commissioners and providers met a number of times to discuss and resolve any queries. On a quarterly basis each provider securely sends their completed MDS template to the Consortium Coordinator, who then carries out a data quality check and uploads the data to NHS Digital. The Consortium coordinator acts as a centralised point so that data is submitted in a more streamlined way. All data is then processed by the Data Services Team at NHS Digital and is pseudonymised, as CCG Commissioners are not permitted to access any participant identifiable data. After the data has been processed, the CCG Business Intelligence team are then able to perform any analysis required and turn the data into a format which can be shared and easily understood.

#### What we collect and what the data tell us

By collecting participant NHS numbers, we are able to track a person's healthcare journey including their number of GP appointments and attendances and admissions to the Emergency Department. The data enables us to track healthcare usage over time, before and after an intervention, and to understand how many sessions / courses of an arts intervention it takes to bring about change for someone. We also understand that some people will only join the programmes if their carer or a member of their family can accompany them. Our MDS allows us to capture this, so that we can see how many places carers/family members take up on the programmes and to determine whether the programmes also have an impact on the health and wellbeing of the carer/family member.

We are currently exploring whether we can link our data to other health and social care services (such as IAPT) and as every programme uses bespoke Outcome Measures (such as the Office of National Statistics Loneliness measures), a further MDS reporting template is being developed to capture this information on a regular basis, which will also go through NHS Digital as detailed above. We hope to identify gaps in the existing provision and demonstrate the impact that Creative Health programmes offer not only for the individuals but also for the wider healthcare system.

# A.5 – Dementia friendly internal environment guidance

Many low cost and small-scale changes around your premises can have a major impact on improving accessibility for people with dementia, e.g.:

#### Lighting

- Entrances should be well lit and make as much use of natural light as possible.
- Pools of bright light and deep shadow should be avoided.

#### **Flooring**

- Avoid highly reflective and slippery-looking floor surfaces
- Changes in floor finish should be flush against each other
- Where possible avoid highly patterned carpets and floor coverings, or sharp contrasts, e.g. black and white tiles where the black tiles can be mistaken for holes in the floor.

#### Seating

- Provide seating areas where possible if people will be waiting.
- Use traditional-looking seating that can easily be recognised as such, e.g., a wooden bench rather than an abstract metal Z-shaped bench.
- Try to ensure a contrast between the colour of the seating and the surrounding environment, e.g., floor, wall, etc.

#### Navigation

- Research shows that people with dementia use 'landmarks' to navigate their way around, visually stimulating objects, a painting, sculpture or plant.
- Try to avoid changing layouts where possible, to promote accessibility and the maintenance of recognised routes.

#### Signage

- Signs should be clear, with contrast between text and background.
- Ensure contrast between the sign and the surface it is mounted on.
- Fix signs to the door to which they refer (e.g., toilet or exit).
- Signs should be at eye level and well lit
- Consider using simple pictures as well as words, but avoid highly stylised or abstract images.
- Think about placing signs at key decision points for someone trying to navigate your venue for the first time.
- Ensure that glass doors are clearly marked.

To become a member of your local Dementia Action Alliance, with your organisation's page on the DAA website, and for further heritage guidance, contact your local DAA representative and complete an action plan, which you can download, with guidance notes, at dementiaaction.org.uk.

#### Aim:

- To establish the SP referral pathway from GP and SPLW to A.R.T.S. programme for people experiencing early symptoms of dementia and their partners.
- To provide two weekly ongoing drama and dance programme to reenergise and inspire participants.
- To engage participants to override symptoms through collaborative creative endeavour
- Arts and medical students to interact with participants to inform their future careers.

#### Summary:

- Two-year weekly A.R.T.S prescriptions programmes (January –
  December 2020) in partnership with Siobhan Davies Studios and
  Southwark Playhouse to re-energise and inspire local participants with
  early symptoms of a dementia and partners.
- Three eight-week terms per year, second year continues without A4D.
- Self-referral and referral through GPs, SPLW and memory services –
  offered as diagnostic practice for dementia and to preserve brain
  health.
- A4D first contact with surgeries and SPLW, May 2019
- Programme launched introducing all stakeholders, October 2019
- A4D early-stage dementia training for drama and dance teams and SPLW, January 2020.
- Three drama students and five dance students and 15 medical students attended for weekly learning and to spread best practice.
- Term one began in situ at the studio and theatre, due to COVID19 restrictions the second and third terms were held on Zoom.
- After A4D's first year, Siobhan Davies and Southwark Playhouse continues the programmes independently.

#### A4D Training for all stakeholders. 9 January 2020,

- Dementia Pathfinders trainer gives insight into the various challenges
  participants may face as MCI or dementia subtypes set in, their
  existing skills and how best to access these.
- A4D presents arts workshop guidance for early-stage dementia.
- Alzheimer's Society Southwark guides dementia friendly venues.

#### SP Referrals:

Each week our SP Coordinator liaised with Southwark's GPs, memory services and SPLW, inviting them to refer patients from the onset of memory concerns, or on referral to memory assessment. As SPLW teams were established within the PCNs, A4D presented programmes in their meetings. For a referral, the SPLW or the patient called to discuss the programme and were registered over the phone. Seven SP referrals were received across the two programmes, one from south-east London GP Champion for SP, two from a Mental Health Practice Nurse and four from the newly in place SPLW.

# A.6 – A4D SP pilots in Southwark 'Dance for the Brain', Siobhan Davies Studios

It is a feeling of lightness. I could be a bird when I make this sort of movement.

Joy! It keeps you healthy. It gets your muscles going.

It helps your brain and body to function.

I always enjoy movement. I just go with it. I do not think when I dance. It's a release. I go with the flow.

We are lucky to have someone inspire us with music. That's so important to have.

It's good for the body, makes you happy and it is refreshing. I enjoy every bit of it. I like the exercise.

My mind was flowing, it was swimming.

There was something new about tis class, but just as inspiring. I enjoyed it.

I found the class very liberating!

Free, weekly creative dance classes for adults with early symptoms of dementia to engage the body and brain through movement and co-created choreography. Led by a professional dance expert, participants were encouraged to develop body awareness, coordination and balance, alongside opportunities to make creative choices, create movement and have agency., connecting with the potential of their bodies and the capacity of their minds, renewing and developing a love of moving in a social environment.

Each class began with full body, rhythm and stretch warm-ups, followed by creative tasks, encouraging individual and interactive choreography, participants co-creating routines, which they performed at the end of the session.

After lockdown a different dance artist led the classes on Zoom each more inventive than the last. Musical accompaniment ranged from Shikoku *Black Chicken37* to Rene Aubry, *Salento*, to Bach, *Cello Suite No 1*, to Max Richter, *The Departure* and Nina Simone, *Feeling Good*. Philip Glass, *In the Upper Room*. Visually exciting and dynamic to observe, flowing, it was as if participants were creating a dance film. Learning Outcomes different each week,, involved co-creating choreography, exploring transitions, patterns and structures in nature, hand movements, combining elements of movement, dynamics and choreography into refined performances and how everyday movements can inspire movement.

#### Participants:

- A former actuary, aged 69, recently diagnosed with AD and his wife, a solicitor.
- A former fine art valuer, diagnosed with young onset FTD three years earlier, and his wife, an archaeological conservator
- A French former language tutor, aged 80, who had danced all her life, AD diagnosed three years earlier.
- A former dustman diagnosed with VD in 2010, his wife, with undiagnosed symptoms of a potential dementia, and their daughter
- A former dietician, aged 81, with suspected VD, undiagnosed

#### Students: (For reports, see pages 233-52)

- Five dance students, from the University of Roehampton and Trinity Laban Conservatoire of Music and Dance.
- Four biomedical or neuroscience students, including one logging on from Abu Dhabi, another from Greece

Siobhan Davies dance artist. A4D Veronica and Cicely.

#### A.6 – A4D SP pilots in Southwark 'Muse of Fire', Southwark Playhouse

Drama workshops led by David Workman, Youth and Community Dance Director and two drama workshop leaders. Participants met in the theatre bar and rehearsed in an informal space, starting with full body stretch and vocal warm-ups, followed by a series of improvisatory and development exercises, instinctive reactions, individual scenarios and group exercises, using objects, newspapers headline to trigger scenarios. With a drama or medical student joining each group gave an



intergenerational dynamism to the drama. In lockdown, acting across screens, encouraged heightened humour. Although the plan was to work towards a performance, each workshop was fulfilling in itself different each time, was the highlight of the week for participants. Zoom suited those with early symptoms, but a couple less recently diagnosed it was too challenging and they took up other arts. A participant who lived alone and had no access to the internet gave up but is returning to the Playhouse after lockdown. Engaging in the drama re-activated one participant's memory and reading ability and her diagnosis is put down to restored stroke damage, no longer VD.

#### Participants:

- French polisher, 65, pre-diagnosis
- A former actuary, 69, recently diagnosed with AD and his wife, a solicitor
- A food hygienist, aged 73, diagnosed with VD in 2017 and her friend.
- A former analytical planner, age 74, diagnosed with AD in 2018, and his wife, an arts event manager.
- A former vicar, aged 77, diagnosed with LBD in 2016 and his wife
- A hospital administrator, aged 69, diagnosed with familial AD in 2019.

Students: (For reports, see pages 233 ff)

- Four applied drama students from London South Bank University
- Five medical and neuroscience students from Kings College London,
   Queen Mary College, UL

**Southwark Playhouse** dance artist. **A4D** Veronica and Cicely Detailed evaluation records were kept for learning purposes.

Being amongst you lot makes me happy. I cannot wait to get back to the theatre.

It gets your mind think a hundred miles an hour. It was challenging but fun.

The best thing was connecting, connecting with everybody (carer)

You become a team.

Every week is different. We had our own little plays and parts to put into it.

It gives you the freedom to develop.

I like that you learned something new with each exercise, like using your body to communicate.

Performing to the group makes me nervous, but it was good to get out of the comfort zone.

I am developing skills. I can't wait for the next session, to see what's going up.

They accepted us and brought us in. I cannot wait for when we are back together in the theatre.

I really enjoyed engaging my creative

#### A.6 – A4D SP pilots in Southwark

#### Students:

- Neuroscience and Biomedical Science students from King's College London, Biomedical Science and Chemistry students from Queen Mary University of London, and a Medical Sciences and Engineering student from University College London all joined through the National Social Prescribing Student Champion Scheme.
- Applied Drama students from London South Bank University, Community Dance and Creative Practice students from Trinity Laban Conservatoire of Music and Dance, and a Dance student from University of Surrey.
- Secondary students from Lycée Franco-Hellénique Eugène Delacroix, Athens, and Brighton College, Abu Dhabi.

#### Content

- Co-production: Participant contributions were used to direct the choreography or dramatic scenes, allowing them to express their creative agency and individual taste. Guided improvisation created an organic model of working that was participant led. Tasks between sessions allowed for longer engagement and observation periods, so participants were prepared for meaningful exchanges in the session.
- Working cross medium: Participants were encouraged to use other art forms as a stimulus. In both workshops' poetry, paintings and photography were used to inspire new ideas and challenge the mind.
- Embracing the screen: The camera and screen were used innovatively as a creative tool; in the dance workshops, participants were encouraged to offer movements through the screen, and use the camera to experiment with distance and perspective. In drama, the screen was used to frame scenes, as participants could explore moving in and out of shot and perform a monologue directly into the camera.

#### **Impact**

- Participants and carers derived transformative benefit from the dance classes, restoring wellbeing and relief from isolation through the flow of dance exercise, stretch and improvisatory movement, heightened by imaginative involvement of decorative objects, poetry and visual arts. SDD's immediate willingness to override coronavirus restrictions through video and zoom ensured special enduring impact.
- Participants and carers were lifted through the camaraderie of the drama classes, restoring confidence in group activities, cultural interests through Shakespeare, and taking inspiration from the student involvement. All loved escaping from isolation in the warm atmosphere of the Playhouse.
- Medical student reports evidence bi-directional learning model, endorsing programmes both for participant benefit, and to inform their medical career.

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## A.6 - Student reports on participating in A4D SP dance and drama pilots in Southwark.

Inspired by hearing Bogdan Chiva Giurca, founder of the National Social Prescribing Student Champion Scheme, speak at the 2018 King's Fund conference, A4D invited medical, neuroscience students – our future doctors – as well as arts students to join participants with early symptoms of dementia and their companions in our Southwark SP programmes (see pages 228–32). Southwark Playhouse ('Muse of Fire' drama) and Siobhan Davies Dance ('Dance for the Brain'), in partnership with A4D, provided a year's weekly programme, coinciding with university terms. Dr Chiva Giurca highlighted at A4D Conference 2021, the value for students, through this weekly interaction, was both in understanding challenges and existing skills in early-stage dementia and in arts and medical students working together at the start of their careers.

#### A.6.1 Medical and neuroscience student reports

Medical students each participated in one of the three eight-week terms. Two school students who are aiming for medical careers joined from Athens and Abu-Dhabi.

#### Andreea Cuciuc, BSc in Medical Sciences and Engineering, University College London. (Southwark Playhouse, January - March 2020).

I am writing this report to summarise my volunteering experience and personal insights at the Southwark Playhouse as part of the A4D programme. I wholeheartedly say it been the most fulfilling and rewarding volunteering experience I have ever participated in!

Firstly, I truly believe in the impact this project has on people affected by dementia and during the eight weeks of the programme I have witnessed how the participants have been transformed by the power of artistic and creative activities. For example, I have observed how some of the shy participants were able, by the end of the session, to be more confident in expressing their ideas and become more eager in participating in the creative process. Moreover, I was very happy to hear when a participant told me that this is the highlight of their week, and they always look forward to coming back the following week. One participant, although very nervous when he first came to the drama classes, mentioned in the last one that he had cancelled a doctor's appointment so that he would not miss our session on Friday, which further highlights the positive impact this project has on the participants. He also mentioned how one of his friends has noticed how changed he is and how much happier he seems since he started going to the drama classes.

It was insightful to see participants both in very early stages of, and before, their diagnosis, as well as a participant in a later stage. I could see how the sessions were tailored so that both groups were able to benefit from the artistic activities. For example, one participant said that doctors talk to her too simplistically and she really valued the respect shown for her ideas and that she can express herself freely through these sessions. Or, for a late-stage participant, it was inspiring to see how, despite the illness, the positive and

### A.8.1 Andreea Cuciuc Medical student, UCL.

funny side of his personality remained intact and how it came out even more in creative exercises.

However, I strongly believe that creative activities are of utmost importance in early-stage dementia in order to slow the progress of the illness and to preserve their personality as much as possible. I have also noticed how these sessions were beneficial not only to the participants suffering from the effects of dementia but also to the carers accompanying them. Caring for someone with such a dreadful disease can be tough and isolating. It was lovely to see carers being able to enjoy creative activities with their partners, and also to be able to interact and share thoughts with other carers.

As I am currently in the process of applying to medical school, my passion for mental health has been one of the reasons that has motivated me to volunteer in this project. I have volunteered before in the past, but I didn't know what to expect as this was quite a unique project for me. However, the first thing that amazed me was how much we, as volunteers, were involved in the project and this made me feel that our contributions really were important and that we had a real positive impact. Moreover, I was pleasantly surprised by the sense of community built into this project: no matter if we were volunteers, participants, carers or coordinators, during the activities we were all equal, included and felt part of the team.

Secondly, I believe this project has provided me with more than just theoretical knowledge of what dementia is. It was a very humbling experience to be able to see the multi-dimensional layers of this illness and how it affects the patient and their family. By being able to communicate with someone living with dementia not in a clinical setting as a patient, but in an environment where I was able to get to know them as friends, I became more aware of the effects of this illness and how important it is to keep their personality alive with creative activities they enjoy.

Because we, as humans, are inherently complex, I believe that an illness such as dementia has the same level of complexity in the sense that it cannot be considered only from a biological standpoint: the biopsychosocial is just as relevant and vital in one's wellbeing. Interacting with participants with different stages of dementia has greatly improved my understanding and awareness of this disease and has improved my communication skills. I believe the insights I have gathered in this project cannot be learned in a textbook – communicating with the patient themselves, getting to know them and how it affects them is a type of knowledge that is vital for any future doctor. I believe this experience is very impactful in my journey towards becoming a doctor as it has made me more empathetic, aware and I can sincerely say that it is vital to any prospective doctor to see the effects of SP by participating in projects such as A4D.

#### A.6.1 Hamaad Khan - BSc in Neuroscience, King's College London (KCL) (Southwark Playhouse, January - March 2020)

As a Neuroscience undergraduate, my interest in dementia was solely rooted in the molecular and cellular basis of neurodegenerative diseases - how we diagnose them and seek to treat them. It was my passion to apply for Medicine that introduced me to SP, upon which I desired to know the patient to a personal degree. This report contains my own reflections on what I have observed, but it stems from my study in Neuroscience and prospective Medicine application. That I, as an inexperienced student can vouch for this SP programme should serve as evidence that SP (and A4D in particular) is unambiguous in its efficacy — be it marked upon cognitive exercise or social skills, I have seen improvements on both counts in all participants.

It is my view that this programme was doubly beneficial. It has helped me in equal measure as it has to the participants. As such, my reflections will be outlined by (1) how I feel the programme was effective for its participants, and (2) how I feel the programme helped me personally.

#### Social prescribing helping the participants

Forming lasting, healthy, social relationships: Unsurprisingly, the main outcome observed between the participants were the strong relationships fostered by all. Sue and Lynn, both best friends, were among the first participants in the programme (see page 34). Their friend S, who joined later on, lived alone and was more reserved at first. They started to meet up for breakfast before the workshops. SP is about creating a space that cultures healthy social attitudes that extend beyond the confines of the workshops — in this example, SP strengthened social contacts between three people. They now all go to pottery classes together. This is not an isolated example. The workshops were consciously designed to increase social contact between everyone. One participant R whose partner has later-stage dementia, decided to share her social media with a few of us students. Even though this was a virtual connection, it provided opportunities to talk about the activities during the week. She reciprocated, appreciating a fellow student's Instagram post. These pocketed amicable interactions are not transitory, they will outlast the duration of the programme and serve as a support system.

#### Shakespeare as a remedy - lost identities, new acceptance, shared existence.

I imagined dementia to be known by the slow death of one's identity until nothing more than a shell remains – the brain atrophied, the speech slurred and nonsensical. A4D taught me otherwise. As R observed, dementia opens up another path for you to become more of yourself. Her husband had not always been as exuberant with his wardrobe style, but his sartorial flair had become more pronounced after his dementia diagnosis.

Lynn too reported a change in her friend Sue's identity. I noted that Sue was always on the ball with her quips and comedic timing, to which Lynn said she wasn't always like this. I guess, ever since she was diagnosed.

#### A.6.1 Hamaad Khan – Neuroscience, KCL.

I soon realised that the A4D programme shelters you from the shock of the changes you may experience in dementia. The workshops provided an avenue, an outlet to exercise these changes in an unapologetic manner, and in doing so, reconciled people to themselves. It became apparent when talking to D, recently been diagnosed with early-stage dementia, that he was frustrated by the disease. He mentioned how he could not remember yesterday or this morning, but random childhood memories would suddenly arise out of nowhere. Having studied Mathematics at Oxford, he confided in me that as a man of logic, this programme was a bit too whimsical for him to get used to. However, by the last week of the programme, he was wholly immersed in the exercises – even falling to the floor at one point rather dramatically.

I noted that in the beginning that D was more on the fringes during the workshops, at moments visibly dejected. In the last few classes, he entered as he left, smiling. These personality changes that I witnessed arose, I believe, because the workshops provided a shared existence of dementia in a non-patronising way. The participants knew that everyone entered the programme because of a dementia diagnosis, but no word of dementia was explicitly spoken of. Instead, a safe space was given to them once a week to escape and explore.

Speaking to D's wife also made me realise that the struggle with dementia diffuses across relationships. She was struggling other family health issues and her husband's diagnosis worsened the situation for her. 'At times I feel like running away just to escape', she observed. I believe her coming to these workshops alongside her husband was just that, a form of much needed escapism.

This to me highlights the necessity of SP and the effectiveness of the A4D programme. It offers help that no pill can. It offers company and support - and these are not flimsy terms, they have actionable consequences. Another participant who joined before pre-diagnosis, though he joined the programme some weeks in, the positive impact on him was so great that he decided to cancel a medical appointment he now deems unnecessary. SP is a tangible remedy for both the participants and the NHS crisis.

#### How SP has helped me

As mentioned, I am a university student currently studying Neuroscience and applying for Medicine in the next academic year. Throughout my studies, I was given the doom and gloom of dementia and its unfortunate effects on patients. My time at A4D has removed this fatalistic misconception around the disease – there is so much vibrancy in these patients even after their diagnosis – in spite of their debilitations.

This experience has provided a personal dimension to my neuroscientific learning that would not have been afforded to me in my studies. It has also enabled me to exercise certain core skills that are directly relevant for my prospective role as a doctor. Firstly, I had to make myself aware of why I was attending the programme. My principal reason was to aid the workshop in helping the participants. The offshoot of this was empathy. I had to be empathetic towards every individual; I was cautioned against phrasing questions in a manner that would be stressful to certain participants' feeble memory, I had to ensure that questions in discussions were targeted to each individual by using their names directly, I had to be willing to participate but ensure that I was not dominating group discussions. This was a balance act that I believe I have honed over the past eight weeks.

#### A.6.1 Hamaad Khan - Neuroscience, KCL.

Not to mention my confidence skills were also put to the test. During my time at the programme, I was not an external studying the participants, I was amongst them. Performing with my body and speech was a task I learned to be comfortable with. Overcoming this enabled me to help other participants who were shy and uncomfortable too. I remember pairing up with S on the first day we welcomed her to the programme: she was very quiet and struggled with the idea of having to perform our piece in front of everyone, 'I don't mean to be churlish . . . I'm just not very good at this sort of thing,' she said. Immediately seeing my past self in her place, I put my hand on her shoulder and said 'Let's just go up and make an absolute fool of ourselves. We'll have a good laugh by the end of it together.' And we did. In fact, at the end of her first workshop, she thanked me profusely and said, 'You're definitely going in my journal tonight!'

#### **Conclusion**

I have only presented a cursory glance of my experience at the A4D programme, citing examples that glow above the rest. It was a deeply unifying, humbling and informative experience - one that I am proud to have taken part in, and thankful for being given the opportunity to do so.

It is my firm belief that if it were not for this programme, many of the participants would be made to suffer in silence, alone. I would argue that it is in the NHS's interest to continue funding such programmes, as it becomes a means of abating mental and physical health deteriorations that would arise from psychosomatic illnesses. It is not above exaggeration to state this. Much evidence shows that social isolation is a risk factor for worsening mental and physical health. And examples have been given above where the social relationships made extend beyond the programme. It undoubtedly has prevented the participants from going through dementia alone.

Each workshop would usually end with everyone going around and stating how they feel. I believe these words serve as enough encouragement to continue the funding: 'happy', 'energised', 'joyful', 'excited' and 'fulfilled'.

#### A.6.1 Gayathri Nantharatnam – BSc in Biomedicine, KCL (Southwark Playhouse, Jan - Mar 2020)

A4D has been a very rewarding experience for me, and I believe for the participants too. I was able to develop my communication skills with participants who had different types of dementias. I think this is important as I'm not sure how much exposure I will get to dementia when I am in Medical School, but even then, I believe it will be more focused on diagnoses and not interaction with the patient and their family.

Whilst attending these sessions you get to develop relationships between the participants which I think helps for participants to express their feelings and concerns and in general for them to feel they have a talking buddy.

There have been times where participants have rescheduled appointment times so that they don't miss a session, as that is how much they enjoy and find comfort in these sessions.

I really liked how students were involved during the sessions as that gave a variety of age groups present. You can't tell who has dementia in the group. There were no judgemental actions, putting participants at ease especially since these are weekly sessions.

On the whole, I believe SP is very important and that it should be done routinely. As this is not a physical disease, patients should be encouraged to go out often and do activities, yet often patients don't know about these groups or would not feel safe to go unless mentioned by a clinician. With these kinds of activity groups, patients would have a purpose to leave their homes and try out new activities – several participants have mentioned this.

I think that possible dementia patients or those with high risk should be encouraged to attend these sessions though early SP. Depending on the individual, offering activities after diagnosis might not be a good idea. After experiencing all the trauma post-diagnosis, patients might not want to attend anything which has 'dementia' labels. Whereas if they attend these sessions before diagnosis then they might be more at ease and have someone to talk to if they are worried. Overall, I think this will help with the mental health of dementia patients.

VFG adds: Among Gaya's suggestions for the ongoing programme were 'Maybe at the end of sessions before wrapping up, ask each individual if there are any drama activities they would like to try out or suggest something they find challenging and create an activity based on that, as a splendid means to involve participants in co-producing sessions.

# A.6.1 Anya Kaptilina – BSc in Biomedical Science, KCL (Siobhan Davies Dance, May – June 2020).

After joining three A4D workshops and their Oxford SP meeting, I have learned a lot about the condition itself, but moreover, had an opportunity to interact with the patients, which I can already tell is very rewarding. I have made some observations and would like to kindly share my experience at the charity as a student.

Having some background on the participants, I knew that they were all affected by early-stage dementia. However, not having any previous exposure to the condition, I was not able to tell straight away. Everybody was very welcoming and enthusiastic about dancing, inspiring others to enjoy themselves. Based on first impressions I realized how important fun and relaxing activities are during early stages; it directly helps the individuals to get their minds off the fact that they have dementia. The workshops truly allow them to feel healthy and active.

Many enjoy arts and dancing, others less, but what effectively unites the group is the aftermath of dancing – rise in positivity and self-confidence. As a student, it was very interesting to learn that during early stages only small parts of the brain are affected; but dancing helps to energize them, provoking intellectual stimulation and dopamine release. Personally, I was very inspired by the case of one participant, who shared that dancing was her hobby when she was younger, so I felt extremely grateful to be part of the group, which gives her the chance to enjoy dancing up to this day, even after dementia diagnosis.

In addition to that, being a part of A4D workshops allowed me to improve my understanding of health. I used to think that it is almost entirely dependent on science, but now I can reflect and tell that both medical and wellbeing aspects are crucial. They work in symbiosis to make the healthcare system more inclusive and advanced. Interactions with the programme participants through arts has given me an opportunity to learn things that the traditional medical degrees would not cover in such detail.

In conclusion, I would like to thank you and Bogdan for giving me this outstanding opportunity to be a part of A4D. It is incredible to observe how the activities give people sense of purpose, and possibly belonging in some cases - I can tell that they are excited to come back every week and boost their wellbeing through dance. It is my pleasure to participate, learn and provide youthful atmosphere to the older people, inspiring them to be more energetic and healthier, both mentally and physically.

[VFG adds: For summer and winter evaluations, we provided students with a questionnaire, for their reports. During the pandemic both programmes were delivered by Zoom]

# A.6.1 Komal Guirdar – BSc in Biomedical Sciences, Queen Mary University of London (QMUL) (Southwark Playhouse, May-July 2020)

#### What was the most valuable insight you gained through participating?

I learned how beneficial the arts are for not only individuals with dementia, but for students like myself. It gave me the opportunity to clear my mind and focus my attention on the present moment. I was also able to use the programme as a form of stress relief.

#### Were participants' responses as you expected?

The responses were very insightful, and the participants provided valuable and innovative contributions.

#### In what way did their responses surprise you?

I was intrigued by the participants' boisterous and sociable demeanour. The group was extremely warm and welcoming. I was inspired by their creativity and imaginative ideas which also encouraged me to think outside the box.

#### Behavioural differences you observed in participants:

#### • Increased engagement / or no change?

At the beginning of the programme I found that the early-stage dementia participants who were in pairs often chose to engage less and depend more on their partners. Nevertheless, over the weeks these participants were engaging much more and actively contributing to the activities.

#### • Increased confidence / or no change?

Participants were able to showcase their creativity and step outside their comfort zones when improvising and participating in character hot seating.

#### • Increased interactivity / or no change?

Participants were comfortable with sharing and suggesting ideas with each other. This opportunity also allowed everyone to learn from one another.

#### • Increased creativity / or no change?

Participants were able to reflect on their own thoughts and incorporate their ideas into their final performances. Some participants also built or used their own props, which showcased their creativity.

#### What were the disadvantages of Zoom?

There were issues with internet connectivity as sometimes it was difficult to hear or see other participants. It was also hard to make use of the space around you when performing as you have to be in frame with the webcam.

#### What were the advantages of Zoom?

It was convenient to be able to engage in activities in the comfort of your own home. Zoom was also very straightforward and easy to navigate. The breakout rooms were also helpful as it allowed you to work directly together with other group members.

#### Were you surprised how participants responded to the Zoom?

I was amazed by the participants as they were able to attend all of the sessions without any problems. It was also exciting to see the interactivity between the screens.

# A.6.1 Komal Guirdar – Biomedical Sciences, (QMUL)

How do you think participating may have helped inform your career? Working with A4D made me realise that all patients should be treated as individuals. Regardless of their diagnosis, these individuals are still able to engage in everyday activities and perform various tasks that are assigned to them. People often find it challenging to communicate with dementia patients however, this shouldn't be an issue, as they are still in need of friendship and support just like any other person.

#### What did you enjoy most?

I enjoyed how different personalities were able to interact and collaborate together. It was exciting to see different perspectives and learn more about each other every week. It was a pleasure to work with such a vibrant and enthusiastic group, who taught me a lot about the benefits of drama and enabled me to bridge the gap between medicine and the arts.

# A.6.1 Aisha Sharif – BSc in Chemistry, QMUL (Southwark Playhouse, May-July 2020)

#### What was the most valuable insight you gained through participating?

By participating, I got to see different people affected by dementia. I got to see their involvement and how even during lockdown; people were still engaging. I think seeing the power of art was amazing. It was inspirational, not only for me but the participants. For some, it may have even been a chance to empower themselves.

#### Were participants' responses as you expected?

Yes, definitely, everyone was interacting and engaging. I think that the sessions were planned in an amazing way which led them to feel more comfortable and talk and discuss more ideas within the group!

#### In what way did their responses surprise you?

Not in any particular way.

#### Behavioural differences you observed in participants:

#### • Increased engagement / or no change?

From the start, there was little engagement and interaction from everyone in my opinion. Lucy, the drama facilitator, would usually handle the activities which I thought were really helpful. I think that one of the main points where there was a change in engagement was when we had to pick a random object. This got participants talking to each other which I thought was brilliant.

#### • Increased confidence / or no change?

There was definitely an increase in confidence from everyone as though the weeks, we got to know each other more and I think the Breakout rooms really helped too.

#### • Increased interactivity / or no change?

Answered along with engagement.

#### • Increased creativity / or no change?

As the sessions went on, they became more and more creative as we would be doing mimes, performances, character developments and we even got a chance to choose our own moves for the warm-up activity!

#### What were the disadvantages of Zoom?

Sometimes, there could be technical difficulties. It could be hard to sometimes mute yourself or even realise you are on mute.

#### What were the advantages of Zoom?

Zoom makes it easy to communicate with a wide range of people who live in different parts of the country!

#### Were you surprised how participants responded to the Zoom?

I think everyone was really confident when it came to using Zoom and there weren't many struggles.

#### How do you think participating may have helped inform your career?

I worked for 11 months with patients living with dementia, and I think that this was really nice, seeing people getting involved and being active. It helped with communication, especially in the Breakout rooms, you get to know more about the individuals.

#### What did you enjoy most?

I think preparing for the performance was really pleasurable and engaging. We all embodied our roles well and it was great to see everyone perform. I also really enjoyed the warm-up activities. I think that they were a great way to get the session started and they were fun and interactive.

## A.6.1 Fatumah Jama – BSc in Neuroscience, KCL (Southwark Playhouse, May - July 2020).

What was the most valuable insight you gained through participating?

It was very inspiring to see how creative the participants were. I learned how important SP is and the positive impact it can have on the quality of life for people affected by dementia.

Were participants' responses as you expected? Not at all.

#### In what way did their responses surprise you?

I was surprised at how engaged they were.

#### Behavioural differences you observed in participants:

#### • Increased engagement/ or no change?

I observed an increase in engagement in the participants, especially as we worked on developing our scenes. They were talking more and making a lot more effort in joining in with group exercises, such as the warm-ups and miming exercises. There was a stark difference when compared to earlier workshops at the beginning of the term.

#### • Increased confidence/ or no change?

Their confidence increased as they became more familiar with the theme of the play.

#### • Increased interactivity / or no change?

Yes, there were increasing interactions between the participants and students. There were more opportunities to interact in the Breakout rooms on Zoom. Participants were talking a lot more and discussing day-to-day life as well.

#### • Increased creativity / or no change?

I was surprised at how the participants were really creative. They were very enthusiastic about their characters, inventing monologues to make the characters more relatable, preparing props to for their scenes and ways to use their home backgrounds to add to the story.

#### What were the disadvantages of Zoom?

Sometimes there were connectivity issues and using Zoom could be hard to navigate for some of the participants. Furthermore, we could not use props efficiently, i.e., it was not possible to pass props physically to each other, so instead we had to come up with creative solutions, such as 'passing' items through the screen.

#### What were the advantages of Zoom?

The Breakout rooms were a great feature of Zoom. It helped give us the time and space to develop our scenes and practise them, which greatly benefited the participants. The Chat option was also helpful for jotting down notes to remember ideas, and for getting information across.

#### Were you surprised how participants responded to the Zoom? Yes, they adapted to Zoom very quickly.

#### How do you think participating may have helped inform your career?

Having learnt about the mechanisms of Alzheimer's disease for my Neuroscience degree, it was hard to separate the disease from the person. Through joining the drama workshop, I have learnt how wonderfully creative those with dementia can be. I have also gained an insight into how art workshops can help people by engaging them and encouraging them to use their minds to create and increase their quality of life.

#### What did you enjoy most?

Watching the final play was great, seeing how everyone's hard work paid off. I had so much fun acting in the scene with participants - I will never forget it.

# A.6.1 Grace Matuta – BSc in Biomedical Sciences, KCL. (Siobhan Davies Dance, Oct – Nov 2020)

#### What was the most valuable insight you gained through participating?

The most valuable insight I gained is that true wellbeing and health of a person isn't just in what can be done medically. Although providing medical assistance is very important, the mental state of patients can be overlooked if the focus is just on treating them medically. I was amazed at how the dance instructor could just use an image and turn it into a creative dance that allowed the participants to use their imaginations, which considering the lockdown, must have been especially crucial for them as there were no opportunities for them to leave their house.

#### Were participants' responses as you expected?

I wasn't entirely sure what to expect. I had a general understanding that the arts help patients with dementia, but it definitely made the difference seeing it with my own eyes. The participants were actively engaged, and I could see the joy that they had participating.

#### In what way did their responses surprise you?

I think how well they had adjusted to the format of the lessons. They really made the best of every lesson and actively engaged in them.

#### Behavioural differences you observed in participants:

- Increased engagement/ or no change?
  - There definitely was increased engagement throughout the programme. As it continued, participants gave more contributions, sending in photos/ideas for lessons and suggesting dance moves.
- Increased confidence / or no change?
  I believe that the participants had grown in confidence through their increased engagement with the classes.
- Increased interactivity / or no change?
  - The more comfortable the participants got with using the platform and adjusting to the lessons' format, the more they were able to interact with the programme. They had given a lot of wonderful suggestions and truly used their imaginations to create different dances.
- Increased creativity / or no change?
  - I believe that the dance instructor was key in increasing the creativity of the participants and even myself as an observer! The dance facilitator had given a lot of useful prompts and guides to participants to expand their creativity and look at things in a different way. For example, in one class, the dance facilitator had turned a poem into a dance, which I found to be incredible.

How do you think participating may have helped inform your career? Through the programme I have understood the importance of taking a holistic approach concerning providing care to patients.

#### What did you enjoy most?

I enjoyed seeing how much joy and excitement this programme had brought to the participants faces, they were sad that the programme had come to an end. Considering the COVID-19 situation, a lot of them would have remained at home with little social interactions, so it was amazing seeing them engage with the instructor and everyone on the platform.

#### A.6.1 Rozet Balliou – Lycée Franco-Hellénique Eugène Delacroix, Athens. (Siobhan Davies Dance, Oct–Nov 2020)

#### What was the most valuable insight you gained through participating?

I believe the most valuable insight I gained through participating was an insight into the lives and actions of people with early-stage dementia and carers. Seeing their struggles and motivation was truly inspiring.

#### Were participants' responses as you expected?

My own grandfather having had dementia; I had a vague idea of what to expect. I was genuinely amazed at the involvement and commitment of some of the participants. Their responses were lively, interested and quite confident, and quite different from what I could have imagined.

#### In what way did their responses surprise you?

I think the liveliness and most of all the creativity of their responses surprised me. All the participants would follow the dance moves correctly, sometimes in perfect coordination with their partners and carers. When asked for a favourite movement, or an idea to add to choreography they would always have something to show or say to enrich the dance.

#### Behavioural differences you observed in participants:

#### • Increased engagement/ or no change?

As the sessions went by, I noticed that a few participants who might have been following the movements shyly or reluctantly were much more engaged and active towards the end. This engagement was highlighted when the participants were sending in pictures, poems and ideas beforehand in order to use them during the sessions.

#### • Increased confidence / or no change?

This can be linked to the increased engagement. Participants were more confident to dance freely as time went by.

#### • Increased interactivity / or no change?

Towards the final sessions, everyone seemed more comfortable to participate, discuss and give their opinions. When asked for feedback during the sessions, I noticed that a lot more participants were willing to interact after a couple of weeks had gone by.

#### • Increased creativity / or no change?

As the sessions went by, the choreographies got richer and more complex, and the participants would not hesitate to add their own movements to them.

#### How do you think participating may have helped inform your career?

Participating allowed me insight into the everyday life of people with dementia and the lives of people who care for them. I wish to follow a career in medicine, and therefore this insight is crucial as it illustrates the positive impact of SP and of a holistic approach to medicine.

#### What did you enjoy most?

I really enjoyed the fact that the sessions took place weekly and at the same time which allowed me to build a routine. I also loved how each week we would have a different theme around which we would build the choreography. Mixing dance with other arts such as music, painting, photography and writing also made the sessions much more interesting and thought-provoking.

#### A.6.1 Neiffer Sharif - Brighton College, Abu Dhabi. (Siobhan Davies Dance, Oct - Nov 2020)

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What was the most valuable insight you gained through participating? How there are alternative methods to helping those with chronic illness and how the right type of dance can benefit the human mind.

#### Were participants' responses as you expected?

I thought it would be more focused on an instructor telling participants what to do. Instead, it was more of a group collaboration.

#### In what way did their responses surprise you?

I was surprised at how they responded to images and came up with ideas.

#### Behavioural differences you observed in participants:

- Increased engagement/ or no change?

  There was increased engagement, many participated in group discussions.
- Increased confidence / or no change?

  No change, all participants seemed confident throughout.
- Increased interactivity / or no change?

  There was increased interactivity. Lots of participants got involved in group discussions.
- Increased creativity / or no change?
   There was increased creativity with new ideas on dance moves etc.

How do you think participating may have helped inform your career? It helped me see SP in action, which has increased my interest in wanting to study medicine in the future.

#### What did you enjoy most?

The creative freedom and how we all had to interpret things differently and see each other's thoughts and ideas.

#### Nieffer adds:

I just wanted to say that I really enjoyed attending the A4D sessions. It gave me an insight as to what SP is and what it looks like in action. You've inspired me so much that I've actually decided to write my extended project qualification on how long-term conditions can be treated with traditional and holistic approaches, such as A4D and other SP schemes.

I'm applying to university next year. I've been doing research in degrees in Medical Ethics / Medical Law and Bioethics which seem very interesting. I'll probably study Medicine and when I'm a Junior Doctor I'll probably do a part-time postgraduate degree, so I could work for organisations such as the General Medical Council or do research.

Thank you so much for the opportunity to participate in your wonderful sessions!

#### A.6.2 Drama students respond

Applied drama students from London South Bank University joined for the first two terms

#### Olivia Parker and Brent van der Merwe, BA, Drama, London South Bank University (Southwark Playhouse, January - July 2020).

I am so very honoured to have been chosen to take part in such an insightful and inspiring programme of workshops. Not only was it helpful for my studies as a drama student who hopefully will be venturing into a career of applied theatre, but also incredibly humbling in my personal life. After experiencing the loss of a family member due to dementia several years ago, I only had negative connotations associated with the disease, and whilst I can acknowledge that it is still something to be taken seriously, these workshops proved to me that not all hope is lost for those suffering with the condition. It was truly wonderful to see physical and cognitive improvements in the participants as the weeks progressed and see once shy and timid individuals become more vocal and creative that ever! A lovely network of people connected in a little theatre in Elephant and Castle.

Nikki and Lucy's workshop outlines were so well crafted and really bought out the best in everyone. Brent and I enjoyed ourselves and it was such a lovely way to end a potentially stressful week, with such positivity and friendship. I found this entire experience so useful for my future career as my knowledge of applied theatre had never really extended beyond children, so now I feel as though I have a whole new category of people under my belt for any future projects. Overall, a wonderful and heart-warming time!

VFG adds: We congratulate Olivia and Brent on achieving First-Class degrees.

#### A.6.3 Dance student reports

Dance students from the University of Surrey and Trinity Laban Conservatoire of Music and Dance joined the first and third terms:

#### Mary Adams – BA in Dance, University of Surrey (Siobhan Davies Dance, Feb – Apr 2020)

#### What was the most valuable insight you gained through participating?

How small actions can have a big impact. Taking time to just dance in a studio with other people to embrace your own creativity, exploration and expression, can drastically alter your mood and the way you communicate with other bodies and your surroundings.

#### Were participants' responses as you expected?

As I have never worked with people affected by dementia before I was not really sure what to expect from the participants or how much their dementia would affect their movements and engagement in class. During the term I was very pleasantly surprised by the their engagement and commitment to the sessions.

#### In what way did their responses surprise you?

I was surprised by how engaged the participants were in the sessions, all of them put so much effort into the tasks Marie, the dance facilitator, offered them; and they were not shy about moving. In general, most people become very reserved and hold back when trying something new (especially dance), but they all got involved straight away and they seemed really engaged and energised, which I was not expecting to see so early on. Over the course of the first term I was impressed to see how quickly the participants began to explore movement and stimuli for themselves more as they stopped looking to Marie for demonstrations or inspiration, they began to trust in their own interpretation of her words, allowing themselves to fully indulge in this newfound creative freedom and expression.

#### Behavioural differences you observed in participants:

#### • Increased engagement / or no change?

As soon as we had completed the warm-ups, moving on to more movement-based tasks, incorporating music and improvisatory explorations, the participants became so much more engaged. All of them became very focused in what they were doing, which was evident from the way they carried out certain tasks; thinking of ways to interpret the stimuli and trying out different movements. It was clear they were all very invested in the classes and wanted to be as involved as they could.

#### • Increased confidence / or no change?

In the initial sessions, the participants tended to have a lot more dependence on Marie, looking to her for inspiration and copying her movements, rather than finding their own. However, over the eightweek term, it was clear the participants who had been coming every week had grown a lot more confident and independent. They were all finding their own ways to interpret what Marie offered them, exploring how they naturally wanted to move and engage with the stimuli to find their own individual movement. It also began taking less time for the participants to begin moving and engaging in tasks as they all began to jump straight in and dance around the room, showing off their movements and interpretations.

#### A.6.3 Mary Adams – University of Surrey

#### • Increased interactivity / or no change?

At the end of the first session one participant's wife told me how her her husband did not really talk much at home and she was thrilled by the class and how it had made him so chatty, even after finishing the session. I was quite shocked to hear her say that he was usually quiet as he was the most talkative participant we had in the class and was always smiling and chatting, even joking around during and after the sessions. It was incredible to see how dance really did have this remarkable impact on him and his mood, as it did for all of the participants. They each became very lively and happily engaged in the sessions; smiling together, laughing together, discussing art. I believe that the fact we had such a small group of participants by chance, allowed this interactivity to increase between the participants as it did. It felt like we had established a temporary community of people just dancing together without judgement.

#### • Increased creativity / or no change?

As the term progressed, so did the difficulty and sophistication of the exercises and stimuli offered to the participants. Marie began the term working with the basic dance actions; action, space, dynamics and relationship, allowing the participants to explore and work with these principles of dance. After a few sessions the participants were given more opportunities to explore improvisation, interdisciplinary art and choreography. This method of delivering the sessions encouraged the participants to move in more abstract and creative ways. It was lovely to see their creativity and individualisation as people and movers grow so quickly. They were all so eager to move and to find new ways in which they could interact with their environment and each other.

#### How do you think participating may have helped inform your career?

Facilitating classes for people with dementia is definitely something I would like to do in future. I think it is so important and has such a remarkable impact on their lives and ability to express themselves in new ways, especially working with contemporary dance. This works so much more holistically, encouraging people to not just work with their body, but their mind and their surroundings connecting them all together. It allows full freedom of expression and exploration that can be so beneficial to people with dementia. There are few classes that incorporate contemporary dance, improvisation and multi-disciplinary art as a way to combat the progression of dementia. I would very much like to continue working in this area and fighting to increase opportunities for people with dementia to engage with these kinds of classes.

#### What did you enjoy most?

The highlight for me in participating in this programme was just to see the impact it had on participants and their companions. The classes were so lighthearted. Everyone was always smiling and so energised from being able to just dance in a studio. I also loved seeing how small changes in the environment could affect the energy of their movements so much. For one exercise we just walked around the room and explored space and directions whilst music played in the background, but whenever the music changed all of the participants' movements were affected. For instance, one participant literally jumped into action as some dramatic music played and when an upbeat, jovial song came on, all the participants subconsciously began this little shuffle across the room, all bouncing, with some even clicking their fingers and smiling. It was a real metaphor for the class how such a small action of just coming to one short session a week could have such a big impact on their mood and their lives.

#### A.6.3 Orlanda Otley – Postgraduate Diploma in Community Dance, Trinity Laban Conservatoire of Music and Dance (Siobhan Davies Dance, Oct – Nov 2020)

\_\_\_\_\_

What was the most valuable insight you gained through participating? The value of direct, personal communication with participants, including immense patience and recognition of specific individual needs.

#### Were participants' responses as you expected?

There was palpable pleasure in simple movement, which was a joy to witness. I did expect this, having worked in many different community settings and seeing what benefits dance can bring to everyone's wellbeing, but it's lovely to have that belief validated again and again. To some extent, every participant was able to follow and comprehend the different movement themes; to enjoy the feeling and freedom of their body's movement; and, by the end of the term, to offer their own ideas for movement and really make the dance their own.

#### In what way did their responses surprise you?

What I found interesting was how different each participant is, both in terms of personality and stage of dementia. Each participant brought this unique personality to their dance interactions: One was very focussed on the screen, mirroring the dance facilitator's movement very gracefully; Another came alive when he danced with his wife; Eugenie (see page 34) took the smallest of invitations to leap off into her rich imagination and dance freely, unhindered by the screen. I think that all people gained something and were able to engage with the classes, regardless of their difference. I was also surprised by the level of challenge involved in the classes, in terms of remembering a series of different movements, and how everybody seemed able to rise to this challenge.

#### Behavioural differences you observed in participants:

#### Increased engagement/ or no change?

Particularly with one participant, I saw how he became far more engaged through the term. He began being keen on just one kind of movement – patting his knees repeatedly – and finished the season actively dancing with his wife, exploring all kinds of different qualities of movement.

#### • Increased confidence / or no change?

I noticed how most participants became more confident with offering up their own ideas for movement as the term went on and they were invited to submit images, poems and words that were then translated into simple dances. I also noticed a small but significant change with one couple, who were often quiet and a little reticent with each other but by the last session did some beautiful dancing and hugging together. It seems like the dance classes increased their confidence in their relationship with each other.

#### • Increased interactivity / or no change?

This is a hard one to answer because of the nature of online teaching, with the necessity of muting participants and the presence of an invisible barrier between each other. I think people appreciated the times when we offered movements towards the screen and each other, and the parts of each session when we spoke and interacted, but this element would have been far stronger in a studio setting.

#### Increased creativity / or no change?

As participants' confidence increased, they became far more open to suggesting their own movement ideas, and to dancing in their own creative ways.

# A.6.3 Orlanda Otley - Trinity Laban Conservatoire

How do you think participating may have helped inform your career? It's helped me think of ways to facilitate dance using other artforms as springboards, and how to deliver personable, interactive sessions online.

# What did you enjoy most?

The moments of genuine interaction between us all – offering gestures towards one another screen; performing and sharing work with each other. This, for me, created a comfortable community amongst us, valuing all participants equally.

# A.6.3 Petra Jansson – BA in Contemporary Dance, Trinity Laban Conservatoire, (Siobhan Davies Dance, Oct – Nov 2020)

## What was the most valuable insight you gained through participating?

The most valuable insight for me was to see how much that was possible to do in a class, even if it was over Zoom. There is a lot you can draw inspiration from in classes and I really enjoyed how everyone was involved and were forming a class together.

### Were participants' responses as you expected?

I was not sure of how the class would be in advance, but I was very happy to see the participants responses to the classes. They all engaged and were willing to be involved in the process of creating.

# In what way did their responses surprise you?

I was surprised of how they all responded differently to the many themes we had during the classes. Some people really enjoyed the big movement we had from the fireworks lesson, while others really loved the movement from the idea of being outdoors and free.

# Behavioural differences you observed in participants:

### • Increased engagement/ or no change?

I thought most participants had an increased engagement in the classes depending on when there was maybe a theme or a particular music playing that they enjoyed a bit extra. They all engaged in different ways.

# • Increased confidence / or no change?

I think they were more confident after a few classes, just because the movement developed over time, with them giving more input of what it could be.

#### Increased interactivity / or no change

Throughout the classes the participants interacted both with the tasks given and with the people around them, both on the screen and in person.

#### • Increased creativity / or no change?

I think that the participants showed more and more creativity throughout the classes, giving ideas that we all could work with together.

### How do you think participating may have helped inform your career?

I have gained a new understanding of how dance classes for people with dementia can be structured and executed. I want to keep on learning about dance for people with dementia and partake in other opportunities where I can learn more about it. I really think this has been a great opportunity for me to see how dance can be used for a different purpose, which I really enjoyed.

### What did you enjoy most?

I enjoyed that I could be a part of the class and actually be able to dance with the others. It made me very happy to be able to participate in that way.

# A.7 – arts4dementia.org.uk UK social prescriber web directory

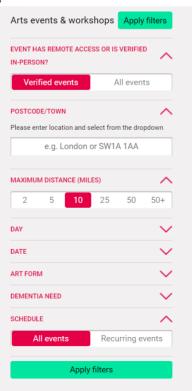
# A.9.1 Find a creative or cultural event for brain health.



- Click **Find events** at the top of every page.
- Select Verified events to view 'Remote access events' or

'Verified in-person events.' Select **All events** to view all events, including those ongoing posted prior to restrictions.

- Type in your **Postcode/Town**(on a tablet or smartphone use current location) and select the maximum distance in miles: 2, 5, 10, 25, 50 or 50+.
- Refine by:
  - o Day of the week, to select specific days.
  - **Date** to set a specific day or a range of dates.
  - O Art form, to select one, or any combination of: Crafts, Dance, Dance & Movement, Drama & Poetry, Film, Film & Photography, Heritage & Visual Arts, Music, Outdoor Arts, Reminiscence, Singing, Theatre, Visual Arts or Walking. Or 'Select all art forms.'
  - Dementia need to select one or more from:
     Arts 4 Brain Health, Dementia Friendly, Early stage,
     Moderate dementia and Young onset.
- Select Recurring events for on-going weekly, fortnightly, monthly events or All events which includes one off events too.
- Select Apply filters. A map will now show locations of all qualifying events within the specified distance, followed by a listing below including all the key details.
- Sort the list by **Date (soonest)** or **Distance (nearest)**.
- Click on any individual event for further information.
- Maps and listings can be printed out as a PDF, and we welcome SP services to print out listings appropriate for their patients.



# A.7.2 Posting your event on the A4D website

# arts4dementia.org.uk



- Click Post an event at the top of every page.
- Create a profile or Log-in to your existing profile. You can upload an organisation logo (minimum size, 205px wide x 64px high) to show by default on all your events.
- Insert the Event title.
- Select the Event date (or the next event if one of a series).
  - Choose when event repeats: Weekly, Fortnightly, First/Second/Third/Fourth/Last day of the month. Or select One-off event or See venue website.
  - Specify the number of weeks your event repeats for or select No set end date.
  - o Input 'Event time (from)' and 'Event time (to)'.
- Insert the **Venue name** where the event will take place.
- Add a **Location** by entering a postcode and selecting from a dropdown list.
  - Select if the Event has remote access or Event is verified in-person.
- Select Transport options and select one or more from Buses,
   Underground, Rail, Parking nearby, Disabled parking.
- Add your main event image and Choose a file from your computer. Image should be landscape image (jpg, png or jif), minimum size 710px wide x
   640px high.

  Choose a file from your compute
- Add your organisation logo. Either include the logo from your profile or 'Choose a file from your computer'. (Minimum size, 205px wide x 64px high).
- Enter the description About the event and add an Event website.
- Detail Cost and enter the 'Price per participant' and 'Carer price' or select that either or both can attend for free.
- Select one or more Art form from: Crafts, Dance, Dance & Movement, Drama & Poetry, Film, Film & Photography, Heritage & Visual Arts, Music, Outdoor Arts, Reminiscence, Singing, Theatre, Visual Arts or Walking.
- Select the **Dementia need** your event caters for: Arts 4 Brain Health, Dementia Friendly, Early stage, Moderate dementia, Young onset.
- Select Accessibility: Disabled access, Hearing aid loop, Disabled toilets, Dementia-friendly venue, Wheelchair access, Wheelchair facility.
- Enter Contact details to be shown on the listing: Name, Email and Phone number.
- Select Review and submit your

  event. Select 'Edit listing' or 'Confirm and post'. The Arts 4

  Dementia team will then review the details of the event.

  Note: You are able to copy an existing or past event.

# A.7.3 Listing your dementia-friendly arts or heritage venue.

# arts4dementia.org.uk

On the Home Page, click **Dementia Friendly Venues.** Select 'Submit dementia-friendly venue.'

Home Chatty Wednesdays Events & Workshops Social Prescribing Training Resources Dementia Friendly Venues About Us A4D Gallery My Profile Search Q

#### Venue submission:

- Insert the Venue title.
- Add a Venue location by entering a postcode and selecting from a dropdown list.
- Select Transport options and select one or more from Buses,
   Underground, Rail, Parking nearby, Disabled parking.
- Add Contact name.
- Add Email.
- Add Phone number.
- Add your main venue image. Image should be landscape image (jpg, png or jif), minimum size 710px wide x 640px high.
- Enter the **Venue description** and add **Venue website**.
- Dementia-Friendly Provision: Select if you have the following:
  - O Do you have a dementia friendly certificate?
  - o Has your staff had dementia training?
  - O Would you like your staff to have dementia training?
  - Does your venue/site provide a natural and stimulating welcome to people with dementia, through any of the following (Tick as appropriate): Talks, Guided tours, Free daytime recitals, Relaxed performances/screenings, Wellbeing walks, Workshops for dementia.
  - Does your venue have any of the following facilities/capabilities? (Tick as appropriate): Guide dog friendly, Hearing aid loop, Disabled toilets, Dementiafriendly venue, Wheelchair access, Wheelchair facility.
- When complete, select Submit venue for review.

Submit venue for review

# User input about DF Arts & Heritage venues and events

As A4D develops this website to meet arts, heritage and wellbeing needs for dementia in the community, we welcome input from our user community about DF arts and heritage venues and arts events.

On the Home Page, scroll down to:

- 'Tell us about events for families affected by dementia.'
- Tell us about a dementia-friendly venue near you.'

Suggest an event
Suggest a venue

Your contributions will enable A4D to offer an improving service for families living with dementia and those who care for them. The A4D website also includes sections on **Training**, **Resources**, **SP**, **Chatty Wednesdays**, **About Us**, **A4D Gallery** and **News**.

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#### Robbie McGhee, Chair, Arts, Culture Health and Wellbeing Scotland:

We are really interested in the whole conversation around social prescribing. Early intervention to access culture for people who have not had their dementia diagnosis and who are in the early stages, can have a really positive effect.

Christopher Bailey, Head of Arts, World Health Organisation: The arts have a key aspect to play in managing dementia, slowing its progression and most importantly, making sure that within this journey, that life is worth living.

Dr Kalpa Kharicha, Head of Research, Policy and Practice, Campaign to End Loneliness: There is increasing evidence on how loneliness can affect cognitive impairment, where having one increases the likelihood of the other and can set off a negative downward spiral that can really affect self-esteem and motivation. There is great potential for social prescribing to reduce loneliness and the stigma of dementia and really engage people, helping them to connect with tailored support that is meaningful to them.

#### Craig Lister, Wellbeing Lead, East of England, Public Health England:

From a health perspective we are all very concerned about deconditioning in older adults before diagnosis of dementia, getting people back into activities, heritage sites and green spaces is a prophylactic towards that.

**Sir Tim Smit, Co-Founder, The Eden Project**: For me the best part of social prescribing is kissing frogs, finding something which isn't in good heart and putting it into good shape, a damaged clay pot – or actually working with people, older people who believed that their best days were behind them and seeing the joy of finding their 19-year-old self, who they thought they had said goodbye to. Give them another adventure, another journey, another group of people. You will find this tremendously uplifting and life affirming energy coming out.

Professor Brian Lawlor, Executive Director, Global Brain Health Institute: It is impossible to overestimate the feeling of anxiety and fear around the time of disclosure for diagnosis. Hope being a powerful antidote to the fear and stigma around dementia. The arts offer opportunity for hope, can improve brain health, promote equity and inclusion, decrease anxiety and improve a sense of wellbeing and mood. There are many ways that can help turn the fear and stigma of dementia inside out. Science, arts and medicine need to work together, to transform perceptions, reduce stigma and create a much greater awareness about the value and benefits of arts to improve the lives of people living with dementia.

Professor Louise Dubras GP, Foundation Dean of the School of Medicine at Ulster University, Northern Ireland: 'It is really important for doctors to appreciate the value of arts-based approaches to care for their patients. Social prescribing is the perfect approach in those early stages of dementia because it is an opportunity to slow progress - or, if someone is awaiting assessment, it is an opportunity to engage and find support. Engaging in a range of physical and creative activities maintains and enhances brain health. In other words, it delays cognitive decline. Central to social prescribing is the value of joy, pleasure and fun.

Bisakha Sarker, Artistic Director of Chaturangan: When one waits for a diagnosis, time looms large, fills with anxiety. Waiting takes away our control. Art gives permission to enter a world of imagination where one can feel in control. Indian dance, with its rich vocabulary of hand gestures and storytelling offers scope to improvise. What art proposes may not be a cure, but it gives precious moments of happiness, a sense of regaining control, away from the grip of fear. In between treatments and diagnosis much autonomy is lost — a session of dance and movement can allow all to put aside sufferings, to enter another space.

Sir Muir Gray, Director of the Optimal Ageing Programme at The University of Oxford: We cannot prevent Alzheimer's at the moment, but we can reduce the risk of dementia. We know that a combination of stress and inactivity, and disrupted sleeping patterns increase the risk - in terms of pre-sleep rituals, music has a very important part to play. Keeping engaged, joining groups, painting, a choir, arts are playing a part in our programme to reduce the risk or delay the onset of dementia.

# Fergus Early, Founder and Artistic Director of Green Candle Dance:

Dance involves much brain power, memory, but in its improvisational form, it involves creativity, taking decisions, negotiating with others and calculating spatial relationships at speed. Emotionally, dance offers the opportunity to express yourself, and allow your feelings to emanate through your whole body. It offers older people a joyous route to health and wellbeing, slowing the symptoms of dementia.

