# SUSTAINING THE NOTE OF HOPE

Report from the 'Music & Dementia' seminar, 18 November 2013 hosted by The Rayne Foundation and National Alliance for Arts Health & Wellbeing

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Music, dementia and meaningful lives

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## **Report at a glance**

## What is it for?

The report draws on the presentations, discussions and stories from a creative multidisciplinary seminar in order to:

- outline the emerging shape of dementia services in the UK, and the potential contribution of the arts, especially music, to dementia care.
- offer examples of current excellent practice in this area and provide a list of useful resources.
- provide an overview of the evidence underpinning music and dementia programmes and suggest constructive approaches to evaluation.
- explore the benefits of music and dementia programmes for different stakeholders in different settings, including people with dementia, management and staff of care and support organisations, musicians, commissioners of services and programmes.
- identify the key challenges that need to be met in order for music and dementia activity to grow, along with potential responses to these challenges.
- propose ways of continuing, sharing and expanding the learning from the seminar.

## Where did it come from?

The Rayne Foundation and the National Alliance for Arts, Health and Wellbeing both have a long-standing interest in the contribution that music can make to dementia care. The Rayne Foundation funds a range of projects in music and health and in dementia. In the autumn of 2013, the two organisations came together to plan and present a multidisciplinary seminar to address the aims outlined above. The seminar took place on 18 November, 2013.

Approximately 40 participants attended (see Annex), from a range of backgrounds, including providers of music and health services, researchers, third/private sector and statutory dementia services.

This report by Marsaili Cameron and Belinda Sosinowicz from PublicServiceWorks Associates draws on the presentations, discussions and stories from the seminar, and includes some developments of interest since that day.

## Who is it for?

The report will be of immediate interest to those who attended the 18 November seminar, along with those who heard about the event from colleagues or other sources.

The publication will be of particular interest to:

- Commissioners and providers of music and health services.
- Third/private sector dementia services.
- NHS and local authority dementia services.
- Evaluators and other researchers engaged in music and dementia, including dementia researchers and relevant music researchers.
- Charitable foundations interested in older people and in health.
- Policy makers and advocates for dementia.

Since concern about dementia stretches across the world, other readers will come from rather different backgrounds. The report aims to inform, stimulate and encourage all involved to work together.

## How can you use it?

- to understand the depth and breadth of the potential contribution of music to dementia care.
- to draw on work already done in the field and to make contact with those involved in this work.
- to create dialogue across artistic, academic, clinical and managerial groups about how music can be used effectively in different care settings for people with dementia.
- to develop evidence-based programmes.
- to make a case for funding music-based initiatives and research.

#### **Acknowledgements**

Grateful thanks to the speakers at the event who kindly shared material: Rachel Thompson, Dementia Project Lead for the Royal College of Nursing; Ursula Crickmay, Director of Learning, Wigmore Hall, London; Debra Fox, Vice Chair, Jewish Care; Charlotte Cunningham, Director of Turtle Key Arts; Dr Trish Vella-Burrows, from the Sidney De Haan Research Centre for Arts and Health, Canterbury Christ Church University.

Thanks too to the numerous other participants who responded generously to follow-up questions.

Wigmore Hall and Nina Large kindly granted permission to use the photograph on page 12.

# Section 1 The brief guide to making the most of music in dementia care

## Section 2 What is the place of music in dementia care today?

- Dementia is not a natural part of growing old; it is caused by diseases of the brain.
- There are over 800,000 people in the UK with dementia; and it is predicted that 1 in 3 people over 65 will develop the condition.
- Societal costs of dementia in the UK already far outstrip those of cancer, heart disease and stroke.
- In the most effective forms of dementia care, health and care professionals work with a model of person-centred or relationship-centred care.
- There is a role for creative engagement and support by musicians at all stages of dementia.
- Music and other arts can also constitute valuable teaching tools to support staff delivering care.

# Section 3 What kinds of musical engagement seem to work best?

- There are many variables to consider when setting up a music programme in the context of dementia care.
- Two very different case studies illustrate that there is no simple answer to the question, 'What is best practice?'.
- However, the unique contribution of arts professionals is to be able to offer artistic experience of high quality.
- It is often useful to think about the role of music in a wider artistic context.
- When working with people with dementia, it is crucial to focus on the individuals involved, responding not just to age but to culture and individual taste.
- There are significant benefits in practitioners from different backgrounds working together and with staff from the care setting.

## Section 4 Who benefits, how? Creating a virtuous circle

- Many different groups derive specific and significant benefits from the use of music in dementia care, including the individual and family; care and support staff and their employers; musicians.
- There is a complex, rich and mutually reinforcing relationship among the different elements involved in what is a typically 'win win' situation, activities tend to result in multiple benefits for a range of people and organisations.
- The concept of a 'virtuous circle' offers a potentially useful framework for advancing the work further.
- The starting point for the process may be 'arts push', 'health pull' or 'carer pull'.

# Section 5 What evidence can help us judge the quality of programmes?

- Both commissioners and providers of projects/programmes need to find a balance between effectiveness and cost-effectiveness and need to be able to demonstrate that the decisions they make about individual projects/programmes are soundly based.
- Music can be shown to stimulate multiple neural pathways, and different projects use that understanding to boost response in different ways.
- Commissioners need to be persuaded that investment in music will prove a more effective use of money than the current allocation of funds.

- Potential arts providers need to think carefully about the stage of dementia at which they believe their input would be most effective, identify the relevant funding streams and decision makers, and plan their approach.
- Monitoring and evaluation need to be thought about from the onset of a project or programme, not regarded as an add-on.
- There are many benefits in applying creative and systematic thinking to monitoring and evaluation.

## Section 6 Sharing learning and expanding the work

- A crucial area for learning during the day was how to set about moving music into the mainstream of dementia care.
- An important focus for future learning and action is the creation of a shared resource of information and analysis relating to music and dementia.
- A resource of this kind could make a significant contribution to the ability to design and deliver training programmes for musicians, practitioners, staff and volunteers.
- As quality of delivery is essential for real effectiveness, training, development and accreditation need to be given high priority.
- There could usefully be exploration of how to support more closely integrated working across the different partnerships, networks, relationships that currently sustain much of the work in music and dementia.

## Section 7 Further sources of information and support

 A selection of resources relevant to practitioners, commissioners, services and researchers.

# Section 2 What is the place of music in dementia care today?

## **Overview**

At the 18 November seminar, Rachel Thompson, Dementia Project Lead for the Royal College of Nursing, talked about the future of dementia care, highlighting particular challenges and potential solutions. Section 2 is based on this talk and on the lively discussion that followed it.

## **Defining dementia**

'The term dementia describes a set of symptoms including memory loss, mood changes, and problems with communication and reasoning. Dementia is not a natural part of growing old. It is caused by diseases of the brain, the most common being Alzheimer's.' (Alzheimer's Society, 2012)

## How many people are affected ...?

The following figures provide an estimate of the number of people with dementia in the UK, along with the settings in which they live. The figures do not include the large numbers of families and friends whose lives are also changed significantly when a diagnosis of dementia is made.

800,000 people in the UK with dementia

of whom 17,000 people under 65

54% remain undiagnosed (regional variations)

63.5% in community

36.5% in care homes (> 80% prevalence)

25% of people in hospital

1 in 3 people over 65 will develop dementia

It is predicted that the number of people in the UK with dementia will double in the next 40 years.

(Alzheimer's Society, 2012, 2013a, 2013b)

## ... and what is the cost to society?

The societal costs of dementia in the UK, direct and indirect, already far outstrip those of cancer, heart disease and stroke (Alzheimer's Disease International, 2011). Despite this, research into dementia is severely underfunded, receiving 12 times less than cancer research.

More recently, the Prime Minister's Challenge on Dementia (2012) has pledged to increase investement into dementia research (see below).

## Who is most at risk?

Different types of dementia have different causes; may be experienced in significantly different ways; and may call for rather different patterns of response.

Alzheimer's disease currently accounts for 62 per cent of dementia cases in the UK; but 17 per cent of cases are attributed to vascular dementia; and the numbers of people with alcohol-related dementia are rising fast.

Certain illnesses and conditions seem to increase the risk of developing dementia. Diabetes, for example, can double the risk; cardiovascular disease can increase the risk by about 30 per cent; and, with Parkinson's disease, more than 80 per cent of people have cognitive

## What strategies and frameworks are in place to combat the challenge of dementia?

There are dementia strategies/plans for England, Scotland, Wales and Northern Ireland. Key common themes include:

- Raising awareness and improving understanding.
- Earlier diagnosis and development of treatment/care pathways.
- Improving quality of care in all settings.

In 2012, the Prime Minister, David Cameron, launched the 'Dementia Challenge' for England. This is an ambitious programme of work designed to make a real difference to the lives of people with dementia and their families and carers, building on progress made through the National Dementia Strategy.

The annual report<sup>1</sup>, published in May 2013, sets out the achievements toward delivering major improvements in dementia care and research by 2015. Crucial areas for action include:

- Improvements in 'timely' diagnosis.
- Dementia friendly hospitals clinical leads, education and carer support.
- Improved awareness Dementia Friends and dementia friendly communities.
- Dementia Care and Support compact.
- Increased investment in research.

## What principles and values underpin effective care and support?

A person with a diagnosis of dementia comments:

'People can cope with this disease. But they need time.'

(Sterin, 2002, p9)

A carers' group explains:

'We need professionals to work with us, not exclude us, and realise we are often the key to understanding the person with dementia.'

(Uniting Carers, 2009)

Both quotes express in vivid form the desire for people with dementia to be seen as the individuals they are, with their own relationships, needs, preferences, likes, dislikes, fears, aspirations. In the most effective forms of dementia care, health and care professionals respond to this desire by working with a model of **person-centred care**, as illustrated in the diagram.

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/government/publications/the-prime-ministers-challenge-on-dementia-annual-report-of-progress

#### Figure 1 Person-centred care



#### Source: Kitwood (1997)

The 'social environment', of course, includes the important role to be played by family and friends in caring for, and supporting, the person with dementia. Coordination and collaboration are key principles in designing and delivering successful dementia care; and at the heart of this joint working are **relationships of trust between the person with dementia, professionals, and family carers**. Indeed, so important is the building of relationships that the term 'relationship-centred care'<sup>2</sup> is a term being increasingly used in this area of work.

In practical terms, what does person-centred care look like? The short answer is that it is care that is individualised and recognises the uniqueness of the person. It should be informed and guided by an individualised care plan which includes the perspective of the person and is based on their biography, personality, history and an assessment of their needs. It offers all those involved a guide on how best to promote and maintain well-being for the person living with dementia.

## Supporting people through all stages of dementia

People with dementia, along with their family and friends, need support throughout different stages of the condition, including pre-diagnosis; diagnosis; living with dementia; and end of life. Each of these stages brings its own challenges – but, along with these challenges, important opportunities for creative and constructive engagement.

## At what stage can artists, and musicians in particular, make their most important contribution?

There is arguably a role for creative enagagement and support at all stages of dementia.

Some people would claim that the 'living with dementia' stage offers most opportunities for creative engagement. After all, as one person put it, 'I am living with dementia ... not *dying* with dementia.' Or, expressed in clinical language, it is at this stage that people, along with their family and friends, might be seen as most open to, and appreciative of, psychosocial interventions and social engagement.

Others may suggest that music has an important role to play during the pre-diagnosis stage, when both the person being assessed and their family carers are likely to be experiencing heightened stress, anxiety and depression.

Music may have a particularly important therapeutic function at the end of life (see Section 5 for a brief exploration of the continuing capacity of music to communicate when words have lost their power).

<sup>&</sup>lt;sup>2</sup> <u>http://www.kingsfund.org.uk/sites/files/kf/mike-nolan-relationship-centred-care-improving-outcomes-for-patients-familes-carers-and-staff-nov12.pdf.pdf</u>

## Supporting staff delivering care

There is another important contribution that the arts can make to dementia care. This is as a **teaching tool to support staff delivering care**.

#### Example – Using the arts to improve basic care

The Age Exchange project RADIQL (see Section 7 for further details) is trying to embed a system of care delivery where staff are trained to engage more effectively during times of basic care and also during basic care itself. So, rather than simply brush someone's hair, staff are encouraged to try and engage the person in conversations about how they may have brushed a child's hair, or how their hair was brushed by their mother. Attending to personal hygiene presents another situation where the arts are likely to be useful. For instance, music or singing can play an important role in calming someone who may be distressed during bathing.

For a variety of reasons, care staff are increasingly task orientated and may forget to use basic care skills. These can be enhanced through the use of music, and through knowing what music may affect mood. So the RADIQL project seeks to understand the person through reminiscence and may be able to record music specific to that person's interest or cultural background that could help them become calm.

## Hot topics from Q&As

- It's often a **real challenge to ensure coordination of care and effective collaboration** with partners in care. For example, there can be a pretty much complete lack of dialogue between hospital and care home.
- **Confidentiality of patient information** is often cited as a reason not to collaborate in an active, constructive way. But the Mental Capacity Act, as clearly explained by organisations like the British Medical Association<sup>3</sup>, allows for the sharing of information in the kind of circumstances likely to emerge during dementia care. The 2013 Department of Health response to the Caldicott Review<sup>4</sup>, particularly in relation to Principle 7, provides further clarity on this issue.

<sup>&</sup>lt;sup>3</sup> http://bma.org.uk/practical-support-at-work/ethics/confidentiality-tool-kit

<sup>&</sup>lt;sup>4</sup> https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/251750/9731-2901141-TSO-Caldicott-Government\_Response\_ACCESSIBLE.PDF

# Section 3 What kinds of musical engagement seem to work best?

## **Overview**

This section is based on two case studies presented at the 18 November seminar, along with the discussion stimulated by them.

Ursula Crickmay, Director of Learning, Wigmore Hall, London, and Debra Fox, Vice Chair, Jewish Care, talked about '**Music for Life'**, a project that has run successfully for over twenty years.

Charlotte Cunningham, Director of **Turtle Key Arts** described the work of the company and, with her colleague, composer Jon Petter, engaged participants in a sample session.

## Case study 1: Music for Life

#### Purpose and nature

Music for Life is a music workshop project involving people living with dementia, the people who care for them, and professional musicians.

The aim of Music for Life is to enhance the well-being of all its participants, while raising awareness for staff of the emotional, social and physical potential of those living with dementia.



#### Photograph: Nina Large

The setting for the project may be either residential or day care. The numbers involved are carefully controlled: eight people living with dementia; five members of staff (which could be a mixure of care staff and other staff from the setting); three musicians; a specialist dementia practitioner; and a project coordinator.

Once a week for eight weeks, the participants get together for three hours. Each workshop is structured in the following way:

**Hour 1** – Preparing the circle, selecting instruments, considering each participant.

**Hour 2** – Opening tune; welcome song; improvised pieces with the group; closing tune. Quotes from people with dementia describing their experience include, 'You are making music from nowhere' and 'The place has come alive ... the world should always be like this'.

Hour 3 – The debrief. The dementia practitioner and the project coordinator facilitate a

feedback discusssion with the musicians and staff group (either as two groups or as one). This discussion aims to draw out conclusions/observations about what they have seen and felt. The idea for the staff group is to build on this understanding and to work towards how it affects/changes their care and working practices with the individuals concerned, and also more generally in the care setting.

#### **Benefits for Jewish Care**

Twenty years ago, when Music for Life was introduced, the norm in dementia care was to focus almost exclusively on the physical needs of people with dementia – and to make heavy use of the drugs trolley when behaviour was considered 'challenging'. Music for Life was an important part of a movement that opened up totally new opportunities for people to **communicate, contribute, engage, give, share and enjoy.** In short, a diagnosis of dementia was no longer seen as a bar to living a meaningful life.

The very positive experiences flowing from the programme have made a significant contribution to Jewish Care's understanding of how they work with people living with dementia. And important changes have been made to the culture of care within the organisation. In particular, reflective practice has been actively encouraged among staff, and person-centred approaches to care are now the norm. Staff mirror how musicians interact with residents, and find that they can develop much richer relationships as a result. Management and staff continue to learn, and to cascade the learning, the benefits and the understanding across the care setting.

#### Taking the work forward

What is the most effective way of taking this work forward? Jewish Care has found it important to build legacy for each care setting. After Music for Life has left the care setting, five reflective sessions are held for staff so that they can share, discuss and learn from what has happened. All types of staff are involved in these sessions, including those whose responsibilities are in catering and cleaning rather than direct care.

A buddying system has also been recently introduced where staff who participated in Music for Life are linked with staff who were not involved in the project, the aim being to cascade the learning and pass on/share best practice.

#### Hot topics from Q&As

- The release of staff for time-consuming involvement off the floor is always a challenge. One approach is to hold a pre-meeting to describe the programme and explain that staff will have to make a real commitment to it – including possibly attending sessions on days off.
- **Relatives** are not included in the Music for Life workshops. The belief is that the group needs to be contained.

## Case study 2: Turtle Key Arts

#### The approach

#### Who?

In partnership with English Touring Opera and the Royal College of Music, Turtle Key Arts runs projects for people with dementia all over England. In the towns to which the project travels, the three founder organisations create partnerships with other music and arts organisations – for example, with the Grand Theatre Wolverhampton. Partnerships are also formed with local music education institutions or universities, such as Reading University or Cambridge University, in order to recruit music students for the project.

Over 10 sessions, composer, director, pastoral team and music students work with a group of people with dementia, and some of their carers, to create a song cycle. Pastoral teams made up of volunteers and representatives from Turtle Key Arts, English Touring Opera and the Royal College of Music join the group to help facilitate and support the participants. Members of the pastoral team often travel with the participants on the buses or other transport provided.

#### Where?

The physical environment is important – when they meet, people need to feel relaxed, comfortable, ready to enjoy themselves. Arts organisations are usually able to offer the most suitable space – somewhere that is not institutional and that underpins the artistic quality of the project. Transport to and from the venue is a very necessary addition to making the project accessible for those who can no longer travel safely by themselves or for whom leaving their homes can be a stressful experience. As the project progresses, journeys can also offer an opportunity to revisit some of the music that has been created. It is important that all are involved in the project, including carers and even the minibus drivers.

#### How?

Everybody gathers in the space. After tea and coffee and a short physical and vocal warm up, the composer and director act as facilitators to create approximately one song per session. Keyboard and interactive screen are used to share the building of melody and lyrics, and the student musicians form an orchestra that accompanies the songs. Sometimes the group is divided up into smaller groups, facilitated by the music students to come up with ideas for specific themes or verses.

A starting point is found at the beginning of the cycle. In one case, for example, the main story of the Odyssey attracted people's interest and desire to explore the various themes that arise from the story – for example, a farewell song, obstacles on a journey

At the end of the 10 weeks, at a separate professional venue, the group mount a performance of their song cycle for friends and family and other interested individuals. This usually takes place in the morning during the same time that the project would have run and is informal but celebratory. Performances are often held in beautiful theatres such as Cadogan Hall in London or West Road Concert Hall in Cambridge.

Programmes are produced and the performance is filmed and recorded. The participants receive an edited DVD and a CD of the work after the end of the project.

#### Hot topics from Q&As

- It's important to **tap into the creative potential of everybody involved** including family carers
- The unique contribution of arts professionals is to be able to offer **artistic experience** of high quality.

## Lessons for good practice

As can be seen from the case studies above, there are many variables to consider when setting up a music programme in the context of dementia care. During the seminar, participants worked together to consider the role of music, to define what's meant by 'music', to agree the range of settings where music is suitable, and to discuss the appropriate use of the art form. The discussion is summarised below.

#### Why music?

Many participants wanted to think about the role of music in a wider artistic context. As one person put it:

'Why concentrate on music apart from other art forms? We know that they're all linked and can reinforce each other in a powerful way.'

Exploring this perspective led to some agreement that **a useful goal for further action would be to have an arts or activities coordinator in every care home** (see Section 6).

That said, there was general consensus that music is distinguished by the following features:

- it offers both individual and communal experience.
- it offers different associations to different generations and can act as a connector between generations.
- it can 'unlock' people who may be removed from the present through their illness
- it is one of the great art forms.
- it is inherent in our senses.

## What's meant by 'music' anyway?

Participants identified the following sources, types and dimensions of music with potential for use in dementia care.

- man-made/natural
- live/recorded
- performance
- visual/auditory
- passive listening/participatory
- instruments/singing
- genres
  - classical, rap, choral world music, jazz individual, duets, chamber music brass, military music and movement faith, musicals
- soundscapes
- background music
- ipod
- radio.

#### Which settings are suitable, and how should music be used?

Settings discussed included:

- day care, dementia care
- own home, bedroom, communal area
- GP waiting room
- gardens/courtyards

There was agreement that:

- common sense is essential in choosing the appropriate musical form for the particular setting.
- it is important to understand the power of silence, and to know when not to use music for example, when it can be distracting, as it sometimes is for people with special needs.
- the temptation to use bland, generic music should usually be avoided it is crucial to focus on the individuals involved, responding not just to age but to culture and individual taste.
- one-to-one work is likely to be beneficial where people are very frail, find groups difficult or can't leave their room.
- short-term projects may be beneficial, but longer term projects can deepen relationships and affect outcomes 8- 12 week projects are probably a good minimum length.

#### Who should be involved, why?

The case studies at the beginning of this section demonstrate the **value of engaging a range of staff** in music-based projects. There is increasing evidence that the involvement of staff can both help support sessions and significantly enhance the subsequent delivery of care.

The **practitioners facilitating sessions may come from a wide variety of backgrounds**, including musicians, specialist facilitators, dance therapists, occupational therapists and performers. Significant benefits are associated with practitioners from different backgrounds working together and with staff from the care setting. Such arrangements, of course, require considerable management support and commitment.

Section 4 discusses at more length the potential inter-linked benefits involved.

Sections 5 and 7 provide information on the evidence associated with the use of music in dementia care.

## Section 4 Who benefits, how? Creating a virtuous circle

## **Overview**

There is growing evidence that many different groups derive specific and significant benefits from the use of music in dementia care. The evidence is mounting too that there is a complex, rich and mutually reinforcing relationship among the different elements involved. The concept of a 'virtuous circle' offers a potentially useful framework for advancing the work further.

## Can dementia really be linked with creative outcomes?

The answer to this question seems to be a resounding 'Yes'.

Sharing their experience of embedding music in dementia care, participants in the seminar identified a range of potential benefits for many different people and organisations, including people with dementia, family carers, management and staff of care and support organisations, musicians, commissioners of services and programmes. So, what does music offer? Core benefits seen as cutting across the different groups included:

- both individual and communal experience
- different associations to different generations and cultures along with the opportunity to share experiences and memories across generations
- means of communication and connection

The following specific benefits have been associated with different groups.

#### Benefits for the individual and family – 'the past embedded in amber'

Discussions during the seminar revealed the same kind of insights expressed in a recently published memoir where the broadcaster Sally Magnusson writes about her mother's life and her journey through dementia (Magnusson, 2014). Music proved to be key to maintaining contact with her. During an interview with a journalist, Magnusson commented, 'I started writing it to keep hold of my mother [Mamie], because she was beginning to change and this is a book about memory and I wanted to remember her ... I didn't want it to come across as a misery memoir ... It's an affirmation of life and love and family and the continuing individuality of people with dementia.' (Christie, 2014)

The interviewer sums up the importance of music as dementia took hold, 'As the other elements of Mamie's life faded and the words became harder for her to find, the tunes and singing continued. For Magnusson, music is the one thing dementia cannot destroy – "the past embedded in amber", as she puts it.'

Magnusson is quoted talking eloquently about what she saw happening when her mother sang with members of the family:

'It wasn't that one day we woke up and thought we must start singing with my mother: she was always singing. But we gradually realised that as her grip on a lot of things loosened, her connection to songs was as strong as ever. When words became difficult and she was finding it hard to express herself, singing engaged her. Then the words would rise unbidden and there was this sense that she had these abilities still to do something better than anyone else.

'Also, there was clearly something neurological going on, because after singing for a while she was much more alert. It was taking her back to a place of familiarity and belonging, achievement and good memories. So we would strike up a song and sing them over and over, to the point where I thought if I have to sing White Cliffs Of Dover one more time I'm going to scream! I'm not proud of my own impatience now. Why couldn't I sing it one more time?'

### Benefits for care and support staff

Participants at the seminar addressed the question, 'What does music offer staff?'. There was agreement on the following conclusions.

#### Supportive framework

Encourages reflection Offers supportive, valuing and nurturing framework Ensures engagement and communication Enables experiential learning Promotes development of staff – accreditation (this is further discussed in Section 6)?

#### Means of communication and connection

Connects musician, staff, service user, family Creative organic process.

#### **Person-centred focus**

Enables/demonstrates valuing and nurturing Demonstrates commitment.

#### Benefits for musicians

In the course of the seminar, several musicians stressed that working with people with dementia made a significant contribution to their own development. The organisation Live Music Now later elaborated on these comments.

'A few thoughts about benefits for the musicians we work with:

**Professional Experience**: planning, performing, programming; developing their repertoire and the range of music they perform, stimulated by the need to have a broad range of music to call upon, to respond to the participants' requests and preferences in the moment

**Development of communication skills:** working outside the concert hall, and making a connection with people, who might otherwise find communication very difficult, drawing them into a shared experience – an understanding of how they can make connections through performance, repertoire and body-language to connect with the participants

**Personal Experience**: meeting a wide variety of people in different settings which develops their personal awareness and the confidence to cope in any situation

An understanding of the potential of their creative practice to have an impact over and above enjoyment and musical appreciation, particularly through benefits to the wellbeing of participants

**Development of a reflective approach** to their performance and creative process.

The feedback from the musicians that we work with is that this is invaluable in their work with Live Music Now, and that it enhances and develops them in all areas of their professional practice.'

<code>`LMN</code> teaches you skills to enhance your performance that you didn't even know you needed.'

Helen Paskins, clarinet

'There is no space for egos but there is a limitless capacity for development as a reflective musician.'

Gustavo Marques, guitar'

What emerges clearly from even a cursory look at the benefits associated with the use of music in dementia care is that there is a complex, rich and mutually reinforcing relationship among the different elements involved. In other words, in what is a typically 'win win' situation, activities tend to result in multiple benefits for a range of people and organisations. In this kind of situation, it may be useful to build on the concept of a 'virtuous circle', a framework that has proved valuable in helping create positive change in many different contexts.

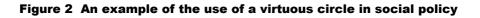
### Creating a virtuous circle

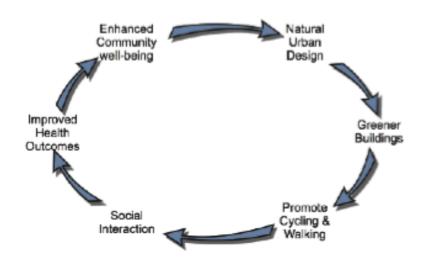
#### What is a virtuous circle?

A virtuous circle, like the vicious variety, is a term taken from economics but now used much more widely. It refers to a recurring cycle of events, the result of each event being to increase the beneficial effect of the next. Two examples may help to clarify what is meant by the term.

#### Example – Promoting natural urban design

Introducing environmental sustainability into urban design can help economic, environmental and social benefits flow from each other to improve quality of life now and in the future.

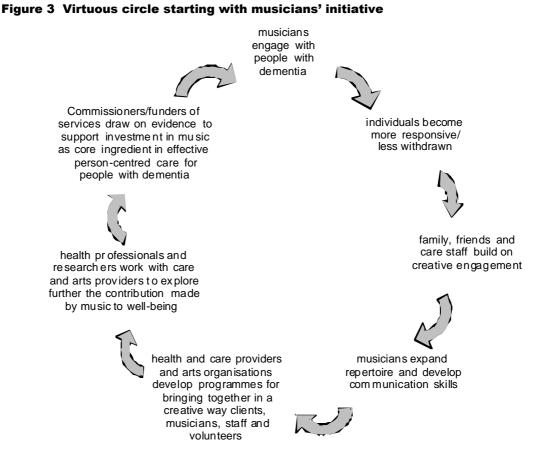




Source: London Sustainable Development Commission (2008)

#### Music and dementia - some potential virtuous circles

The following diagram shows one particular form that a virtuous circle might take:

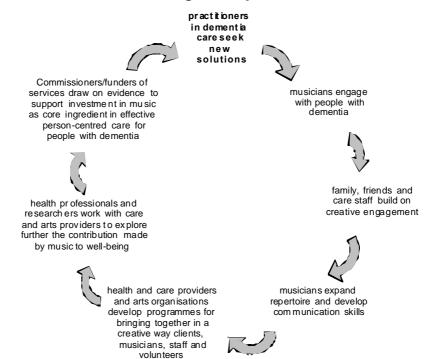


An interesting question presents itself: where does the circle start? In the case above, the starting point for the process is shown as the initiative of the musicians – the arts side of the picture. This could be called 'arts push', where the incentive and initial thrust comes from arts organisations.

However, as shown in the second diagram, the circle could instead demonstrate 'health pull' where those working in dementia care are seeking a new approach to address unmet needs/challenges. At the moment, for example, Skills for Care are showing interest in the potential contribution of the arts to the fields of work of interest to them<sup>5</sup>.

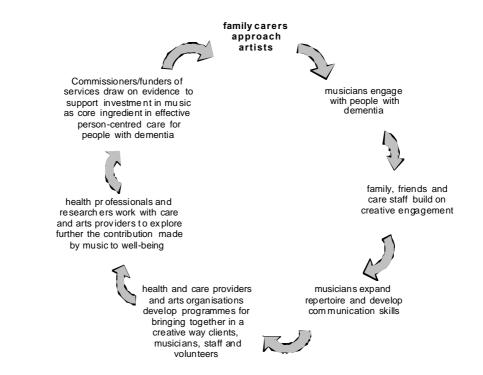
 $<sup>\</sup>label{eq:started_st$ 

Figure 4 Virtuous circle demonstrating 'health pull'



There is a third possible starting point, demonstrated in the third diagram. This could be called 'carer pull', where carers with family knowledge about personal interests ask arts organisations to work with their family member.

Figure 5 Virtuous circle demonstrating 'carer pull'



# Section 5 What evidence can help us judge the quality of programmes?

## **Overview**

This section looks at the evidence underpinning music and dementia programmes. It outlines key aspects of research evidence and other kinds of information that commissioners and funders are looking for. The material is mainly drawn from a talk by Dr Trish Vella-Burrows from the Sidney De Haan Research Centre for Arts and Health, Canterbury Christ Church University, and from the plenary discussion that followed the talk.

## Effective and cost-effective – both needed for 'quality'

Both commissioners and providers of projects/programmes need to find a balance between effectiveness and cost-effectiveness – and need to be able to demonstrate that the decisions they make about individual projects/programmes are soundly based.

### The hypothesis and the research evidence

What does it mean to say that the use of music is an effective element in dementia care? The underlying hypothesis can be expressed as follows:

- Music can positively affect the lives of people living with dementia. In particular, it can:
- Support physical, mental, emotional and psychosocial well-being
- Support cognitive function
- Enhance inter-relationships and spritual connections
- Support the well-being of carers and care staff
- Provide support alongside, or potentially as an alternative to, psychotropic drug therapy.

What science underpins this hypothesis? Music can be shown to stimulate multiple neural pathways. It used to be thought that only the right brain was involved in processing music, but this has been proved not to be the case. The experience of language and of melody and harmony results in complex interactions within the brain. Importantly, the limbic system is involved: this is a set of evolutionarily primitive brain structures located on top of the brainstem and buried under the cortex. Limbic system structures are involved in many of our emotions and motivations, and are linked too with memory. A small part of the pre-frontal cortex, which is stimulated by musical memories, is the last to be affected by the disease process characteristic of Alzheimer's; and this may explain why music still affects people even when they are at a late stage of the condition.

One research study (Janata et al, 2007) used MRI scanning to look at what happens within the brain of a listener to music. Different parts of the brain were shown to be associated with:

- Familiar tunes
- Enjoyable unfamiliar tunes
- Autobiographical musical memories and recall
- Emotional responses.

Using knowledge of this kind, researchers at Plymouth University's Interdisciplinary Centre for Computer Music Research<sup>6</sup> have started to work with patients with early dementia in order to develop rhythm, tunes and lyrics that enable them to boost their everyday memory in constructive ways.

Physiological responses to music have been shown to involve many of the main bodily systems (for example, Bartlett, 1966; Juslin and Sloboda, 2001; Hodges, 2009). Respiration has been affected; also gastric motility, skin temperature, blood pressure and heart rate.

Musician Martyn Ware recently developed a 3D sound installation, Recapture, an immersive reflection of memory and Alzheimer's. In an interview with a journalist, he describes

<sup>6</sup> http://cmr.soc.plymouth.ac.uk/

something of the experience he believes is associated with his work:

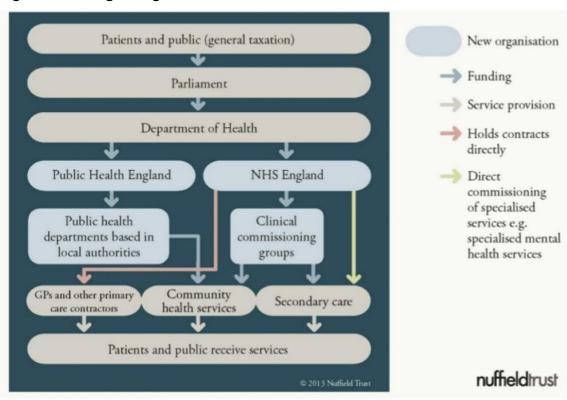
'Sounds fly around the listener and are able, he says, to awaken dormant primal impulses. "Ancestrally, we had to engage with the sound world in a much more spatial way for survival, from birds sweeping down behind you to the weather approaching from a distance. If you take a high-timbre piece of sound and move it over the listener's head from behind, it gives them a frisson, like some vestigial flight-or-flight response thing."

(Beaumont-Thomas, 2014)

#### It may work – but is it worth it?

If the arts are to be introduced into mainstream activities, commissioning bodies need to be thoroughly on-side. **They need to be convinced that the use of music will improve dementia care in significant ways, and that investment in music will prove a more effective use of public money than the current allocation of funds**. As things stand at present, there is no clear pathway for funding the arts in dementia care. Furthermore, current funding streams are mainly directed towards supporting new projects, so that it can be very difficult for arts organisations and practitioners to build on past success.

The diagram below illustrates the funding arrangements in England as from April 2013.



#### Figure 6 Funding arrangements

Source: Nuffield Trust (2013)

It is a useful exercise for potential arts providers to think carefully about where they believe that their input would be most effective. For example, would it be after diagnosis of dementia and mainly within secondary care? In which case, which commissioners are going to be most relevant/influential locally? Or is there a strong case to be made for addressing public health people, now based in local authorities? After all, local authorities have a long tradition of involvement in cultural activities, and also host the influential Health and Wellbeing Boards? At first glance, GPs may seem a less relevant audience – but it is worth bearing in mind that there is growing interest across the country in Arts on Prescription schemes.

Whatever the focus of attention and whichever commissioner is considered most relevant, it is important for the arts provider to **speak the language of commisioners**. As outlined below, that language tends to be shared across all funders.

#### A robust evidence base

Identify key priorities (National Dementia Strategy; Prime Minister's Challenge on Dementia; QUALYs; living independently for longer)

Well designed evaluation (RCTs – Särkämo *et al.*, 2013; Guetin *et al.*, 2009; Raglio *et al.*, 2008; Hokkanen *et al.*, 2008; Van de Winckel *et al.*, 2004)

Measuring tools understood by health professionals (see Moniz-Cook *et al.*, 2008) Larger samples (e.g Särkämo *et al.* 2013; Tadaka and Kanagawa, 2007) Longitudinal studies (e.g. Särkämo *et al.* 2013)

#### Sound health economics

- Cost-Benefit Analysis measuring cost benefits (for example, reduction in drugs; reduction in staff sick days; retention of staff)
- Social Return on Investment calculating the monetary equivalent of impact (for example, 'A spring in your step') (Nicholls *et al.*, 2009).
- Sustainability investing in the future? (inter-professional sharing knowledge/skills)

#### **Reputable service providers**

Build organisational reputation:

- National Alliance for Arts, Health & Wellbeing; local consortia of arts professionals with health-centralised agenda to drive good practice/evaluation
- Professionalisation/Continuing Professional Development/Knowledge Exchange (partnerships). Many funders like to see organisations working in collaboration – as with, for example, OPAN Older People's Art Network which is funded to provide a series of seminars to link arts and dementia practitioners. Described further in Section 7, OPAN is a collaboration between Age Exchange, Entelechy Arts, Trinity Laban and others.

In practical terms, how might arts providers make progress in these three areas? One means of bringing them together in a dynamic way is through **applying creative and systematic thinking to monitoring and evaluation**.

## Monitoring and evaluation

Monitoring and evaluation need to be thought about from the onset of a project or programme, not regarded as an add-on. The arts provider needs to think about what they would like to investigate, along with the values and ethics that would be an integral part of such an investigation, and then build the evaluation and project strategy around this core. One starting point would be to identify gaps in the evidence that a project could be developed around. For example, participatory art is an under-researched field of practice, though the research that exists suggests that there is great value in terms of improving wellbeing.

At the same time as the arts provider is devising their project, they are likely to find it helpful to develop **an evaluation framework** that measures the proposed process and outcomes. Steps to take here are to:

- List your aims, objectives and impacts for the project
- Outline how you are going to measure these and what indicators you will use to gauge success
- Identify who you will be measuring and describe any special support that will be needed for these people
- Consider the evidence base for the project. Has it been done before? Can you repeat the project but with your own ideas or different people? Are there any tools that were used that you could look at? This stage is often seen as costly and complicated, but could reap financial benefits as part of a funding proposal.

Because there are many tools, options and measures available (see Section 7), as well as many different sources of evidence, some arts providers find it worthwhile to employ an external adviser to support them in developing their framework and gathering evidence to support their investigation. One clear advantage of doing this is that it avoids a situation where arts facilitators, overwhelmed by the demands of delivery, find it difficult to maintain positive relationships with participants when also asking them questions about their engagement.

#### Designing the evaluation

Arts providers can gather simple data about numbers attending and demographics through short questions about involvement and observations from facilitators. More complex information can be acquired through validated questionnaires describing, for example, changes of self-esteem before and after the project. A comparison or `control' group may be necessary to ascertain that the particular project was likely to have been the cause of the change.

Additional funding would give rise to all sorts of further exciting possibilities, such as Randomised Control Trial (RCT) research and in-depth qualitative evaluation, including participatory action research, participative appraisal, and phenomenological research (again, see Section 7). Other research in the arts is moving away from the 'impact study' model and looking at practices and responses of session participants themselves. Research can be conducted through an extended period of participant observation and ethnographic documentation alongside interviews and discussion groups, and through the introduction of more exploratory kinaesthetic research approaches including dance and visual arts. (See, in Section 7, Age Exchange's RADIQL for its arts-based practice research and Trinity Laban's Transformation, Memory and Actualized Selves study.)

## Hot topics from Q&As

- **Outcome-based commissioning** often boils down to, 'How many people can we keep out of hospitals and care homes?'
- Arts people often feel that 'evaluation is not what we do best' but there really are
  opportunities for creative thinking and action here, especially in relation to
  wellbeing
- **Mixed funding**, from a range of statutory and not-for-profit bodies, has much to offer resource-intensive projects like Music for Life
- Randomised Control Trials are important but they usually take a very long time to complete. In the meantime, local projects and partnerships are crucial
- Every opportunity should be taken to **customise tools and frameworks** in order to maximise their relevance to arts and health
- It takes a comparatively large organisation/partnership to commission effectively, and this is being done in the area of music and dementia. **But what about smaller care homes?** How can skills/knowledge be shared most effectively? One answer is to use consortia to train staff
- Another setting of concern: **sheltered housing** this is currently neglected, although most people with dementia live in the community
- Music helps people **discover the selves they thought they'd lost**: are dementia cafés something to be worked towards?

# Section 6 Sharing learning and expanding the work

## **Overview**

The seminar facilitated much immediate learning and exchange, particularly in relation to getting music taken seriously in dementia care. Work during the day also signposted key areas for learning and action in the future – including a concerted effort to develop high quality training and accreditation.

## How best to get music taken seriously?

There was consensus during the day that the seminar was an important milestone in a learning journey that most people would like to see continue. A great deal had been learned during the day itself, both through presentations and through individual and group discussion. A crucial area for learning was **how to set about moving music into the mainstream of dementia care**, where it would be recognised as a key 'enabler' rather than just a pleasant add-on to core services.

It was agreed that funders, commissioners, health and care professionals, and artists/practitioners all need to be helped to understand the potential contribution of music – and that there is a powerful story to be shared with a receptive wider public, as demonstrated, for example, by the intense media interest shown in Sally Magnusson's memoir of her mother and her subsequent setting up of the Playlist for Life charity which aims to offer those with dementia their own bespoke playlist (Magnusson, 2014; Christie, 2014).

### Tailoring the messages

**Different audiences will be interested in rather different aspects of the use of music in dementia care**, and therefore are likely to respond to different messages or emphases. Section 5 stressed the importance of using the right language for the different organisational cultures involved and of presenting evidence of effectiveness in a way that really makes sense to the particular audience. The effort put into this kind of tailoring was summed up by one participant as 'packaging music'. She went on to say:

'Both commissioners and providers of services will want to grasp what is the unique selling point of what's being offered; and they're both likely to want to know more about how the use of music contributes to staff retention and a culture of care. But local authorities and GPs will really pay attention when they hear that music and dementia programmes can help keep participants in their own homes for longer or ease transition between hospital and home.'

Actual and potential **policy/advocacy champions** were identified as a further grouping needing careful attention and clear communications. Examples of these organisations include Alzheimer's Society, Age UK, Royal Colleges, Skills for Care, central government, local authorities, the Arts Council (see Section 7 for further details and more examples).

## What else might we learn from each other?

Participants were keen to see a move towards building up a shared resource of information and analysis relating to music and dementia. Such a resource could make a significant contribution to the ability of arts and other organisations to **design and deliver training programmes** for musicians, practitioners, staff and volunteers. There was general agreement that, as quality of delivery is essential for real effectivenesss in this field, training and development need to take a high priority. One participant commented:

'Music delivery organisations really need to provide training and support and possibly specialised training in music. Although there are practitioners who are using music and not musically trained, I think an emphasis on good quality is really important – I hate seeing maracas being brought out by a visual artist! The best practitioners are those with specialist music training/ or masses of experience – who are good at playing/singing or composing, coupled with skills in engaging people. Not everyone has skill in both!'

Accreditation for training and a quality guarantee/artsmark were agreed to be important related issues, and ones to be pursued further. One discrete, and relatively manageable, focus for early work could be training for arts/activities coordinators in care homes – at present, unqualified positions. Increasing the profile of this position might also make a significant contribution towards another **useful goal for further action, which** would be to have an arts or activities coordinator in every care home

One of the things that emerged clearly from the seminar was that a great deal of innovative practice is taking place across the UK but that few people have a clear idea of what is happening, where. Accordingly, there was a **desire to see more closely integrated working across the different partnerships, networks, relationships that currently sustain much of the work in music and dementia** (see Section 7 for further information on these). The 'virtuous circle' framework described in Section 4 could form a starting point for mapping out how integration of activity might add value to current work.

# Section 7 Further sources of information and support

## **Overview**

The following is a selection of resources relevant to practitioners, commissioners, services and researchers.

The list is not exhaustive, but aims to provide a breadth of resources that encompasses a wide range of interests. Each group, organisation or research project listed may have a substantial resource list of its own that may provide further information, particularly in specialist areas. It was not possible to include all of this information here due to space restriction.

We would also want to encourage readers to get their own research underway where possible. So, building on the guidance on monitoring, evaluation and research in Section 5, we give details here of organisations that could support and fund activity of this kind and potential places and journals where outcomes could be published.

Organisations are listed as those offering a specialist music and dementia mission or project and those offering dementia services.

We hope that this resource section will provide useful pathways into an exciting field.

## **Organisations: Music/arts and Older People**

## Age Exchange

Leading UK reminiscence and arts charity. Works with older people to improve their quality of life by valuing their reminiscences and giving them opportunities to express themselves through:

- visual, performance arts and conversational expression, music, drama, song, dance, craft, handling objects
- intergenerational projects
- exhibitions
- publications
- documentary films
- performances
- social events
- participatory arts
- research.

Age Exchange also provides:

- staff training and service user consultation
- training and support for artists/practitioners to ensure well-being and good practice
- improvement to person-centred care delivery
- international work.

Age Exchange was founded in 1983 in the context of an emerging awareness of the value of reminiscence work, especially in care settings for older people. For 30 years Age Exchange has developed new models of work, offering participants a wide range of reminiscence-based creative activities and arts products.

Recognised nationally and internationally by many providers of services in the statutory and voluntary sectors as being the leading practitioners, consultants and sources of information about reminiscence work. Works in all settings including home, community care, hospitals, hospices, schools, cultural and community venues and in its own unique studios and theatre spaces.

## Age of Creativity

An online platform to share, celebrate and inspire work in the field of arts and older people.

Everyone has an inner artist, whatever their age. Sometimes this will be about continuing a lifelong interest in or even career in the arts; for others older age may represent the first opportunity to develop creative pursuits. Passionate about the impact that involvement and participation in the arts can have on improving well-being and physical health and reducing social isolation.

Aims to foster collaboration and discussion between practitioners, facilitators, artists and organisations through showcasing pioneering work and providing a shared space to exchange ideas, opportunities and resources.

## **Arts & Health South West**

Arts & Health South West is an information, support and advocacy organisation for people who believe in the value of creativity in enhancing people's health and well-being. Its aim is to encourage the development of the arts and health sectors across the region. It supports good practice through providing high-quality resources, information and support.

Arts & Health South West:

- encourages meaningful and productive partnerships between the health and arts sectors
- supports the professional development of people working in arts and health

http://www.ageofcreativity.co.uk

http://www.ahsw.org.uk

- - Its aims are:
  - to improve older people's access to the arts
  - to help combat the isolation of older people through participatory arts projects
  - to work with partners to raise the status of the field
  - to support and train artists to ensure good practice.

- facilitates access to current arts and health research and encourages robust evaluation practice
- raises the profile of arts and health in the region
- provides a voice for arts and health practitioners at a strategic level.

## Arts 4 Dementia

http://www.arts4dementia.org.uk

'Empowering people with memory loss through artistic stimulation.'

Arts 4 Dementia's mission is to inspire and re-energise people with dementia, to bring fulfilment to their lives and provide opportunities for quality time with their carers and loved ones through engagement with their chosen art form.

Activities to realise this mission include:

- Arts 4 Dementia Best Practice Conference 2011
- organising weekly arts events for person and carer at arts venues, covering art and design, music and dance, poetry and drama, film and photography, gardens and heritage, initially around London
- signposting arts activities for person and carer nationwide
- campaigning and raising awareness of the benefits of artistic stimulation
- providing opportunities to volunteer for Arts 4 Dementia and get involved
- providing information on the care pathway, memory aids, resources, the latest news and developments in arts and dementia.

#### **Collective Encounters**

http://collective-encounters.org.uk

http://www.entelechyarts.org

Collective Encounters is a professional arts organisation specialising in theatre for social change through collaborative practice. It uses theatre to engage those on the margins of society, telling untold stories and tackling the local, national and international concerns of our time.

## **Entelechy Arts**

Entelechy has been making great art for 21 years and continues to develop and manage programmes of work that promote cultural and social cohesion. Every year the company produces numerous high-quality arts activities and large-scale performance events. Entelechy is particularly skilled in creating work that builds bridges between groups of people and individuals who lead parallel and unconnected lives, often in the same neighbourhoods. This includes older people from diverse communities, young people, people with learning disabilities and people from different cultural and social backgrounds.

Entelechy develops sustained creative programmes working with individuals and groups over long periods of their lives, often through periods of transition and change. The work places people's current and lifelong experiences, gifts and needs at the heart of the practice, creating art works that build shared meaning and community.

## **Equal Arts**

Equal Arts is a registered charity with 25 years' experience in delivering arts and older people's projects. Its mission is to improve the quality of people's lives by helping older people participate in high-guality arts activity.

It achieves this by working with professional artists in partnership with residential care homes, sheltered accommodation schemes, GPs and hospitals, community venues, arts and cultural venues, local authorities and a range of older people's organisations.

http://www.equalarts.org.uk

In response to a recent groundswell of interest and increasing levels of activity in arts and dementia, Equal Arts has developed the Arts & Dementia Network to champion the role of the arts in dementia care and to support artists and health and social care professionals working in the field.

#### Hoot Creative Arts: Breathing Space

Creative time for older people living with dementia and their partner/carer.

#### Jacqueline du Pré Music Building, Oxford

http://www.sthildas.ox.ac.uk/jdp-music-building

Concerts especially for people with dementia and their family, friends and carers.

#### Ladder to the Moon

Ladder to the Moon provides workforce and service development that enables health and care organisations to develop active, creative, vibrant care services. It uses approaches that incorporate creativity and the arts, and involve staff, older people living with dementia and other long-term conditions, and the wider community.

By working with Ladder to the Moon, organisations improve activity culture and quality of life outcomes, achieve high levels of staff engagement and differentiate themselves in the marketplace.

### Live Music Now

Live Music Now works with a very diverse range of people who rarely, if ever, have the opportunity to experience live music – some of whom are very disadvantaged. They often face difficulties in communicating, cut off from the joy and pleasures of participating and sharing with others. Live Music Now's approach to overcoming these barriers is through the quality of musicians and delivery of music.

The organisation has been working over the years to bring joy to older people through unique music sessions. It strives so that older people accessing care services should live their lives as fully and creatively as possible.

## Lost Chord

Lost Chord was founded by its Chief Executive Helena Muller in 1999. From its earliest beginnings with 11 residential homes in Rotherham, Lost Chord has expanded into many parts of South Yorkshire, North Nottinghamshire and Derbyshire, with satellite schemes in London and Wales. It now also has schemes in Coventry, Cardiff, London, Bury St Edmunds and Ipswich.

Lost Chord produces more than 1300 interactive musical sessions a year in 130 homes, designed to stimulate responses from people with dementia through the media of music, song and dance.

## Magic Me

Magic Me is an arts charity that brings the generations together to build a stronger, safer community.

Its projects often link unlikely partners. Young people aged 8+ and adults aged 60+ team up through shared, creative activity. Intergenerational groups meet on a weekly basis in schools, museums, older people's clubs, care homes, and community and cultural organisations.

Projects are led by a team of freelance creative artists: musicians, dancers, photographers, printmakers, writers and drama specialists. They design activities to stimulate conversation

http://www.livemusicnow.org.uk

http://www.laddertothemoon.co.uk

http://www.hootcreativearts.co.uk

http://lost-chord.org.uk

http://www.magicme.co.uk

and an exchange of ideas. Participants are often diverse in culture and faith as well as age group.

Magic Me's annual programme combines tried and tested models with trialling new ideas and projects.

## Manchester Camerata

After 40 years of performing around the globe, Manchester Camerata is acknowledged as one of the UK's leading chamber orchestras. With a reputation for bringing audiences first-class performances that are bursting with vitality, Camerata is truly a product of its creative environment – a 21st-century orchestra in one of the most exciting cities in the world.

A central part of Manchester Camerata's work is an innovative, vibrant and award-winning Learning and Participation programme. Often inspired by the orchestra's work on the stage, the off-stage work uses music to empower positive change and personal social development across four main strands: children and young people in schools, early years and families, health and well-being, and a youth programme. Manchester Camerata's creative programme of Learning and Participation work reaches over 10,000 people each year.

## Music in Hospitals

Music in Hospitals is a charity whose mission is to improve the quality of life for adults and children with all kinds of illness and disability through the joy and therapeutic benefits of professionally performed live music, in hospitals, hospices, day care centres, special schools, and nursing and residential homes.

At Music in Hospitals concerts, memories are revived and all kinds of emotions are released, thus allowing staff to gain fresh insights into older people's individual backgrounds and tastes.

## Nordoff Robbins

Nordoff Robbins is a national music charity dedicated to transforming the lives of vulnerable children and adults across the UK.

They use music therapy and other music services to help people with a range of challenges such as autism, dementia, mental health problems, stroke, brain injury, depression and life-threatening or terminal illnesses, such as cancer. All of the people have one uniting factor: music dramatically improves their quality of life.

## Playlist for Life

A charity founded in 2013 by author and broadcaster Sally Magnusson, Playlist for Life encourages families and caregivers of a person with dementia to create a playlist of uniquely meaningful music on an iPod and offer it at any time of the day or night. It is effective both at home and in residential care, at an early stage of the condition and later on.

The benefits of this approach extend much further than one person. Family members, either looking after someone at home or visiting them in residential care, find that sharing this kind of music can help recover the closeness of a relationship and bring structure to what is often a long day or a difficult visit.

## Sage Gateshead: Silver Lining

http://www.sagegateshead.com/join-in/music-for-adults/music-for-silvers/silver-lining

Silver Lining, delivered by Sage Gateshead's Silver Programme, provides fun, accessible and confidence-building ukulele-supported singing sessions that aim to promote health and well-being for people in care settings.

http://www.playlistforlife.org.uk

http://www.music-in-hospitals.org.uk

http://www.nordoff-robbins.org.uk

http://www.manchestercamerata.co.uk

#### Sustaining the Note of Hope

#### Sing For Your Life

Silver song clubs are regular sessions of singing and music making for older people and, where appropriate, their carers. Over 1500 older people attend a Silver Song Club.

### Singing for the Brain

Singing for the Brain is a service provided by Alzheimer's Society which uses singing to bring people together in a friendly and stimulating social environment.

#### Sound Sense

UK professional association promoting community music and supporting community musicians.

## Spare Tyre Theatre Company

Spare Tyre is one of the UK's leading participatory arts companies, with over 35 years of experience of creating theatre with voiceless communities. It works with people aged 60+, adults with learning disabilities, and women who have experienced violence.

Spare Tyre enables creativity, sharing and risk-taking in supportive workshop environments. It develops new models of working with communities with changing needs. It challenges prejudice with bold and powerful shows. It uses a multi-sensory, multi-artform approach across all of its work.

The company disseminates its learning and practice to promote change in the creative sector, social sector and wider community. This includes artists, admin staff, volunteers, care staff, and partners such as day centres and residential homes.

## Suffolk Arts Link

'Inspiring creativity for people and their communities.'

Suffolk Artlink is a participatory arts charity delivering high-guality creative activities to a range of people including young people, people with learning disabilities, children in hospitals and older people. Suffolk Artlink also plays a developmental role in the county by creating partnerships with other organisations in order to deliver innovative projects.

## Trinity Laban

Trinity Laban's ever-evolving Degree and Masters programmes are designed to meet the needs of contemporary dance professionals and artists, deepen their understanding of contemporary dance, extend their technical abilities and increase their creative skills to succeed in the competitive world of dance.

Research into Trinity Laban's older people's outreach programme is currently investigating the processes and possibilities of transformation through dance and music, as initiated by the 'Retired not Tired' programme. This research is exploring the means by which performance may 'actualise' potential memories in older participants, examining how and why this kind of expressive activity animates the idea of virtual, 'possible' selves among participants with such intensity.

## **Turtle Key Arts**

Turtle Key Arts' main objective is participation in the arts for all with an emphasis on disabled, disadvantaged or socially excluded people.

Turtle Key Arts has played a committed and innovative role in advancing disability arts, and is widely recognised as a leader in this field.

#### http://www.singforyourlife.org.uk

http://www.soundsense.org

http://www.suffolkartlink.org.uk

http://www.trinitylaban.ac.uk

http://www.turtlekeyarts.org.uk

http://alzheimers.org.uk

Turtle Key Arts pioneers arts participation projects that identify and fill the gaps in education provision, often charting new territories.

## Wigmore Hall Learning: Music for Life

http://www.wigmore-hall.org.uk/musicforlife

Interactive music workshop for older people living with dementia.

## **Voluntary Organisations**

## Age Cymru

Age Cymru works to improve the lives of older people. The organisation celebrates ageing and believes it presents unprecedented opportunities and challenges at home and abroad. It challenges ageist prejudice in society.

Age Cymru helps people enjoy a better later life by providing life-enhancing services and vital support.

Its practical services help people stay independent at home and carry on doing the things they love most. It also works to tackle isolation and sustain good health.

## Age UK

Age Concern and Help the Aged are now Age UK. 'We believe in a world where everyone can love later life. Age UK is here to inspire, enable and support older people to help people make the most of later life.'

## Alzheimer's Society

A membership organisation which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland.

E- journals

http://www.alzheimers.org.uk/site/scripts/download info.php?fileID=1001

## **Dementia UK**

http://www.dementiauk.org

http://www.alzheimers.org.uk

http://www.ageuk.org.uk

The mission of Dementia UK is to improve quality of life for all people affected by dementia.

Objectives:

- Promote and develop Admiral Nursing a specialist nursing intervention focused on meeting the needs of carers and families of people with dementia.
- Empower carers to have a voice through Uniting Carers, a national network of family carers.
- Promote good practice in dementia care.
- Work in partnership with the NHS, social services, other voluntary groups, carers and people with dementia.
- Contribute to national policy on dementia, older people and carers' issues.
- Influence practice and policy development.

## Healthy, Social, Creative

http://www.healthysocialcreative.org.uk

If you're a health professional working with people with long-term conditions, the Healthy, Social, Creative website will help you to find out about the profound affect that creative activities can have on people's well-being as well as, in some cases, their condition and its symptoms

http://www.ageuk.org.uk/cymru

#### http://www.mentalhealth.org.uk

## **Mental Health Foundation**

The Mental Health Foundation is committed to reducing the suffering caused by mental ill health and to helping everyone lead mentally healthier lives.

The Foundation helps people to survive, recover from and prevent mental health problems, by:

- carrying out research and evaluation
- developing practical solutions for better mental health services
- campaigning to reduce stigma and discrimination
- promoting better mental health for us all
- arts.

## Young Dementia UK

http://www.youngdementiauk.org

Award-winning organisation for young people with dementia in Oxfordshire.

### Department of Culture, Media and Sports, DCMS

https://www.gov.uk/government/organisations/department-for-culture-media-sport

The Department for Culture, Media & Sport (DCMS) aims to help make Britain the world's most creative and exciting place to live, visit and do business. Its remit is to protect and promote Britain's cultural and artistic heritage and help businesses and communities to grow by investing in innovation and highlighting Britain as a fantastic place to visit. Alongside this, it protects deeply held beliefs in freedom and equality and helps to give the UK a unique advantage in the global race for economic success.

#### **Department of Health**

Improving care for people with dementia

https://www.gov.uk/government/policies/improving-care-for-people-with-dementia#issue
The Dementia Challenge
http://dementiachallenge.dh.gov.uk

The dementia challenge was launched in March 2012 by Prime Minister David Cameron to tackle one of the most important issues we face as the population ages.

The dementia challenge is an ambitious programme of work designed to make a real difference to the lives of people with dementia and their families and carers, building on progress made through the National Dementia Strategy.

## NHS England

The main aim of NHS England is to improve health outcomes for people in England.

NHS England believes the new approach it is taking will really make a difference and deliver the improved health outcomes we all want to see.

Central to its ambition is to place the patients and the public at the heart of everything it does. 'We are what we want the NHS to be – open, evidence-based and inclusive, to be transparent about the decisions we make, the way we operate and the impact we have.'

#### NICE

http://www.nice.org.uk

http://www.england.nhs.uk

'Providing guidance to ensure quality and value for money.'

NICE guidance supports healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.

NICE provides independent, authoritative and evidence-based guidance on the most effective ways to prevent, diagnose and treat disease and ill health, reducing inequalities and variation.

Its guidance is for the NHS, local authorities, charities, and anyone with a responsibility for commissioning or providing healthcare, public health or social care services. It also supports these groups in putting its guidance into practice.

## **Royal College of Nursing**

https://www.rcn.org.uk/ Rachel.Thompson@ydh.nhs.uk

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies. It also has a role as a creative producer in relation to innovative dementia care.

### South London and Maudsley NHS Foundation Trust

http://www.slam.nhs.uk/about-us/art-and-history/slam-arts

The Trust provides NHS care and treatment for people with mental health problems. It also provides services for people who are addicted to drugs or alcohol. As well as serving the communities of South London, it provides specialist services for people from across the UK and beyond.

SLaM Arts' objectives are:

- to support and develop SLaM's high-quality arts provision and collective intelligence
- to improve patient experience through engagement in the arts
- to reduce 'revolving door care' by sustaining people's well-being and recovery
- to encourage a culture of innovation that will attract a range of funding and partners
- to support service user involvement and peer learning
- to further SLaM's reputation as leaders in arts and health.

### The Extra Care Charitable Trust

The Extra Care Charitable Trust enables older people to enjoy a healthier, active and more independent lifestyle in a network of inspirational communities that represent a modern alternative to the traditional care or nursing home. The charity operates 14 retirement villages and 17 smaller housing developments across the Midlands and the North.

Each Extra Care resident can expect a safe, secure future, renting or buying a spacious and affordable home with award-winning care and a wide range of social opportunities to enjoy.

### Jewish Care

Jewish Care is the largest health and social care organisation serving the Jewish community in London and the south-east of England.

It runs over 70 centres and services, caring for more than 7000 people every week.

The organisation believes that Jewish people should have access to specialist services that are designed to meet their needs. This is reflected in the care it provides, which recognises traditions, beliefs and cultures which are frequently shared by Jewish people.

Clients' emotional needs are just as important as their physical requirements and providing for their day-to-day needs is just the beginning.

### MHA Live at Home

Supporting independence for Older People

Methodist Homes (MHA) is a charity providing care, accommodation and support services for older people throughout Britain. Well-established care providers in the sector, providing services to older people for over 70 years, and amongst the largest charities in Britain.

### Nightingale Hammerson

The charity's origins can be traced back to 1840. The three original homes were called the Hand in Hand Asylum, the Widows' Home Asylum and the Jewish Workhouse, also known as the Jewish Home. They were established in the old Jewish quarter in London's East End to cater for the needs of poor Jewish people.

In 1894 the institutions amalgamated to become the Home for the Aged Jews. In 1904, the Home moved to its current site on Nightingale Lane in Clapham, south-west London, following a gift of the house known as 'Ferndale' and grounds by Lord Wandsworth, the Viscount de Stern. Lord Wandsworth opened Nightingale House in 1910.

In the 1970s The Home for the Aged Jews officially became known as Nightingale House.

### Prama

Prama supports disabled and older people across East Dorset, Christchurch, Bournemouth, Poole, Purbeck and North Dorset.

The core business of Prama is providing support to people within their own homes; this can range from personal care, domestic support or enabling people to access the resources of their local community. Prama is registered with the Care Quality Commission for the provision of personal care services.

Prama runs Carers Groups for family members who care and need support themselves. The number of groups grew during 2013.

Prama also runs a Prama Club in Wimborne on Saturdays and operates charity shops in Parkstone, Tuckton, West Moors and Kinson.

http://www.extracare.org.uk

http://www.jewishcare.org

www.mha.org.uk

http://www.nightingalehammerson.org

http://www.pramacare.co.uk

### British Association of Art Therapists, BAAT\_\_\_\_

http://www.baat.org

The British Association of Art Therapists (BAAT) is the professional organisation for art therapists in the UK and has its own Code of Ethics of Professional Practice. Comprising 20 regional groups, a European section and an international section, it maintains a comprehensive directory of qualified art therapists and works to promote art therapy in the UK.

### British Association of Music Therapy, BMAT\_\_\_\_\_

http://www.bamt.org

BAMT, the British Association for Music Therapy, replaced the Association of Professional Music Therapists and the British Society for Music Therapy in April 2011. BAMT has an office base in Islington, London and is run by a capable administrative team who ensure the smooth running of the organisation and respond to public and member enquiries.

It acts as a central point for information about music therapy, the health benefits experienced by people, young and old, who have music therapy, and the latest research, books, videos and events. It offers help to students interested in a career in music therapy and Associate Membership provides a chance to `put something back' and get involved.

The association acts as a national voice for the music therapy profession and provides support and guidance for members, whether training or in practice, including:

- web-based resources and a monthly e-bulletin
- regionally based Area Groups which provide support, companionship and training for music therapists across the UK
- BAMT Networks, where music therapists can share experience and develop new skills in specialised areas of work
- Three experiential student days every academic year to support music therapy trainees.

### **Global Alliance for Arts & Health**

http://www.thesah.org

The Global Alliance for Arts & Health (formerly Society for the Arts in Healthcare) is a nonprofit 501(c)3 corporation in Washington, DC. Founded in 1991, the Global Alliance for Arts & Health is dedicated to advancing arts as integral to healthcare by:

- demonstrating the valuable roles the arts can play in enhancing the healing process
- advocating for the integration of the arts into the environment and delivery of care within healthcare facilities
- assisting in the professional development and management of arts programming for healthcare populations
- providing resources and education to healthcare and arts professionals
- encouraging and supporting research and investigation into the beneficial effects of the arts in healthcare.

# National Alliance Arts Health and Wellbeing

http://www.artshealthandwellbeing.org.uk

The National Alliance launched in autumn 2012 and aims to provide a clear and focused voice to articulate the role creativity can play in health and well-being. Over the past 40 years, a huge range of arts and health work has developed in the UK; the National Alliance seeks to represent this work, to advocate on its behalf, to encourage the use of the arts by health and social care providers and to raise standards in this sector.

The Alliance's website provides a range of resources and examples showing the ways in which creative activity can benefit the health and well-being of individuals and communities.

### **Centre 4 Creative Collaboration (C4CC)**

The Centre for Creative Collaboration is an initiative of the University of London, working in collaboration with the Royal Central School of Speech and Drama, Goldsmiths, University of London, and Royal Holloway, University of London.

C4CC supports new types of collaboration using the principles of open innovation. This is a groundbreaking project for London, delivering collaborative projects and multidisciplinary ways of working in an attractive and flexible space.

C4CC is a partner in the London Creative and Digital Fusion project.

Funded in part by the European Regional Development Fund, London Creative and Digital Fusion are focused on job creation and new revenue opportunities for SMEs. It is a collaboration involving C4CC, the Council for Industry and Higher Education, Lancaster University, the Royal College of Art, Queen Mary, University of London, and the Work Foundation.

### **Creative Dementia Arts Network (CDAN)**

http://www.creativedementia.org

At the forefront of new opportunities, challenges and possibilities connecting artists, arts organisations and cultural institutions with commissioners of creative arts for dementia.

CDAN believes that participation in music, singing, theatre, drama, dance, visual arts, crafts and other creative arts is beneficial for people with dementia. Its mission is to promote the use of creative arts as a means of improving the health and well-being of individuals living with dementia, their families and communities, through providing artists, arts organisations and educators with information and resources for their work and facilitating the sharing and exchange of best practice. The Network connects creative arts providers with commissioners working across cultural, health, social care, housing and business sectors to raise awareness of the value of creative arts for dementia.

### London Arts in Health Forum (LAHF)

http://www.lahf.org.uk

London Arts in Health Forum is a membership organisation which aims to develop the role of culture in well-being and to promote and support arts in health activity across London and nationally.

The organisation is free to join and offers events, a regular newsletter, training sessions, advice and support for artists, architects, clinical staff and service users – basically anyone with an interest in arts in health. LAHF currently has nearly 3000 members from London and further afield.

On the website you will find information and updates about arts and well-being activity in London and nationally, as well as information about arts in health work overseas and research highlighting the value of creativity and culture in well-being.

### Natural Voice Practitioner's Network

Natural Voice Practitioner's Network is a network of people who share a common philosophy in relation to singing and group work. Most members are based in the UK but there is a steadily growing international membership. Natural Voice has been a constituted group since 2000. Its working methods and philosophy emerged out of the pioneering work of Frankie Armstrong who began leading voice workshops in the early 1970s.

http://www.naturalvoice.net

http://creative-collaboration.net

The Older People's Arts Network (OPAN) http://www.trinitylaban.ac.uk/schools-community/for-adults/retired-not-tired-over-60s-dance-and-music/older-people-arts-network

OPAN is a network of older people's arts providers within the borough of Lewisham, which includes Age Exchange, Entelechy Arts, Montage Theatre Arts, The Albany, The Horniman Museum and Trinity Laban Conservatoire of Music and Dance. The aim is to help find a way to articulate the local arts/culture/participatory offer for older people and improve the coherence of what is provided, sharing expertise, practice, research and training.

### **Research, Researchers and Consultants**

### Age Exchange: RADIQL <u>http://www.age-exchange.org.uk/news\_events/index.html#top</u>

#### Pioneering an initiative that will model future provision of Reminiscence Arts in Care

Reminiscence Arts and Dementia – Impact on Quality of Life (RADIQL), is a 3-year research programme which aims to provide a model of excellence in the provision of person-centered creative care for older people in south London. It seeks to improve the quality of life and well-being for the older people who participate in the programme, specifically those with dementia.

The initiative has been funded with a grant of £595,500 from <u>Guy's and St Thomas' Charity</u> in line with their ambitions to support innovation in health which will improve the health and well-being of the population of the two London Boroughs of Lambeth and Southwark, but which may influence changes in policy and practice more widely.

RADIQL aims to identify and develop a new form of reminiscence and arts practice, to be piloted in end-of-life care, in care settings and the community in Southwark and Lambeth. It will enable participants to engage in therapeutic reminiscence arts activity, as well as increasing their social interaction. The aim of the intervention is to improve mood and selfesteem and reduce levels of isolation, unhappiness and depression. RADIQL will also provide activity in Healthy Ageing Cafés, a support group for carers, and ongoing mentoring and training for staff and carers in reminiscence and arts-based methodology in daily care. It also has an artist's/practitioner's resilience and training programme supporting them throughout.

The programme is being delivered by teams of Age Exchange practitioners, through both group work and the provision of one-to-one sessions for those benefiting from focused individual support. They are working closely with professionals and family carers to ensure that the new model of care is informed by their shared expertise and experience.

The intervention is being evaluated by Royal Holloway, University of London, using Dementia Care Mapping<sup>™</sup> ethnographical arts-based methods, also measuring staff impact, carer and practitioner impact on well-being and some cost-benefit valuations. Following the initial 2 years of practice, and informed by the evaluation, Age Exchange will create two new professional full-time roles of Reminiscence and Creative Carer as part of its plan to embed the new approach across south-east London and more widely.

Seminars on 4 April, in June and October 2014 and in May 2015 will disseminate the outcomes.

Reminiscence Arts and Dementia – Impact on Quality of Life is a partnership programme between: Age Exchange, Alzheimer's Lambeth and Southwark, Guy's and St Thomas' NHS Foundation Trust, and South London and Maudsley NHS Foundation Trust.

### **Bangor University**

http://www.bangor.ac.uk/imscar/dsdc/projects.php.en?menu=1&catid=4347&subid=0

Bangor University's Dementia Services Development Centre received £1.2 million to lead a project with other universities researching how taking part in visual arts can contribute to the health and well-being of people with dementia. The Dementia Services Development Centre at Bangor University has expertise in developing and researching the effectiveness of psychosocial interventions for people with dementia and their carers, interventions that improve the health and well-being of older people, and delivering specialised training in dementia care.

This new research explores how dementia-supportive communities might benefit from creative activities.

#### Sustaining the Note of Hope

### Consilium

http://www.skillsforcare.org.uk/NMDS-SC-intelligence-research-and-innovation/Research/Research-reports/What-do-we-know-about-the-role-of-arts-in-social-care.aspx

Skills for Care in partnership with Skills for Care and Development (SfCD) and Creative & Cultural Skills (CCS) commissioned Consilium Research and Consultancy to undertake an evidence review and activity mapping study to inform future thinking around the role of arts in the delivery of adult social care and in particular the implications for workforce development.

The briefing paper *What do we Know about the Role of Arts in the Delivery of Social Care?* pulls together the main findings from these two pieces of research, the employer workshop that fed into the work, and research themes that emerged from the work.

### Dementia Research

http://www.nihr.ac.uk/research/Pages/Dementia.aspx

During early 2011, the NIHR issued a call for research on dementia. This call extended across the translational pathway, covering the fields of cause, cure and care, including prevention. Seven of the NIHR research programmes participated.

Funding On 21 December 2012, the Health Secretary Jeremy Hunt announced £22 million of NIHR funding, for twenty one successful research projects that will pioneer dementia diagnosis and ground breaking treatments.

A full list of funded projects and other information on this site

### Professor Susan Hallam

Professor of Education and Music Psychology, Institute of Education, University of London

Susan Hallam has research interests in disaffection from school (behaviour, attendance, exclusion), learning and understanding (studying, homework, practising, the role of feedback), ability grouping, music psychology and music education.

Research: Promoting social engagement and well-being in older people through communitysupported participation in musical activities. ESRC/AHRC New Dynamics of Ageing Programme, Greater London Authority Music Education Audit (2011–2012).

### Methodist Homes for the Aged

Music Therapy in Methodist Homes: a cluster randomised controlled trial including mixed methods analysis investigating the efficacy of the impact of a music therapy programme on caring for people with dementia who have behavioural symptoms

The study is a cluster randomised controlled trial, which aims to investigate the effectiveness of music therapy in minimising behavioural and psychological symptoms of dementia (BPSD) in older adults with dementia. In particular, the study aims to identify the main components of music therapy that are key in achieving this. The study will also explore carers' perceptions of music therapy and investigate whether carers become more attentive to patients' needs and more able to manage patients' BPSD as a result of the music therapy programme.

Primary outcome measures:

- Neuropsychiatric inventory (NPI) (Time frame: at baseline in the 2 weeks prior to the music therapy intervention, then at weeks 11–12, weeks 21–22 and as a follow-up at weeks 27–28.) Designated as safety issue: No.
- The NPI assesses the neuropsychiatric symptoms and pathology of patients with Alzheimer's disease and other neurodegenerative disorders.
- 10 behavioural areas (delusions, hallucinations, agitation/aggressions, depression/dysphonia, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability and aberrant motor behaviour) and 2 neuro-vegetative areas (sleep and night-time behaviour disorders, and appetite and eating disorders) are assessed.

http://www.ioe.ac.uk/staff/ffps\_17.html

http://clinicaltrials.gov/show/NCT01744600

Changes in these areas of behaviour over the 2 weeks prior to interview will be investigated. This project will employ the version of the NPI which has been developed for use within institutional settings (NPI-NH). The interviews will be conducted with an informed professional caregiver.

Secondary outcome measures:

Dementia Care Mapping (Time frame: at baseline in the 2 weeks prior to the start of the music therapy intervention, then at weeks 11–12, weeks 21–22 and as a follow-up at weeks 27–28.] Designated as safety issue: No.

### **Participation Agency**

http://participationagency.com

Public Service Works (PSW) joins with its partners Amazon PR and TAP Arts to form the Participation Agency, specialists in engagement and participation.

The Agency offers a tailored approach using tried and tested tools, techniques and science to involve, engage and enable action in communities, organisations and partnerships.

The Agency brings people together who may not usually meet and supports them to work out together their own issues, plans, priorities and solutions. It offers expertise in communications, strategy, creative/arts engagement, research and evaluation, events and publications.

### Sidney de Haan Research Centre for Arts & Health

www.canterbury.ac.uk/research/centres/SDHR Trish.vella-burrows@canterbury.ac.uk http://www.canterbury.ac.uk/Research/Centres/SDHR/Home.aspx

'Researching the value of music and the arts for well-being and health'

The Sidney De Haan Research Centre for Arts and Health is committed to researching the potential value of music, and other participative arts activities, in the promotion of well-being and health of individuals and communities, and continues to build the case for Singing on Prescription.

The Centre has shown that group singing has positive benefits for people with enduring mental health issues and people with COPD.

It has conducted the world's first randomised controlled trial on community singing with older adults, showing improvements in mental well-being.

The Centre is researching the role of art galleries and museums in promoting well-being, the value of drama workshops for children with communication difficulties and the benefits of dance for people with dementia.

### **Professor John Sloboda**

http://www.gsmd.ac.uk/about\_the\_school/research/research\_staff/department/37-research-and-knowledge-exchange-staff/1032-professor-john-sloboda

Research Professor at the Guildhall School, where he directs its Understanding Audiences research programme. He is also Emeritus Professor at Keele and was a staff member of the School of Psychology at Keele from 1974 to 2008, where he was Director of its Unit for the Study of Musical Skill and Development, founded in 1991.

John is internationally known for his work on the psychology of music. He is a Fellow of the British Psychological Society and has been President of both the Psychology and General Sections of the British Association for the Advancement of Science, as well as President of the European Society for the Cognitive Sciences of Music, where he has served on the editorial board of its journal *Musicae Scientiae*. He is a committee member of the Society for Education and Music Psychology Research, and was Editor-in-Chief of its journal *Psychology of Music* from 1985 to 1989.

He was the recipient of the 1998 British Psychological Society's Presidents Award for Distinguished Contributions to Psychological Knowledge, and in 2004 was elected to Fellowship of the British Academy.

John is Honorary Consultant to the AHRC Centre for Music Performance as Creative Practice; a network participant in Theatrum Mundi and a contributing researcher to the AHRC Knowledge Exchange Hub Creative Works London. He is also a member of the Senior Management Group of the think-tank Oxford Research Group and co-founder of the Iraq Body Count Project.

### **TAP Arts Project**

http://www.tapartsproject.co.uk

An independent consultancy specialising in arts and well-being, using positive psychology, underpinned with robust evidence. TAP works with communities, business and health partners, with outstanding creative associates and with people who may be marginalised through poor health.

TAP primarily provides innovative services, through which people can develop, flourish, build psychological resilience and improve mental well-being; develop and promote artists' and staff well-being and engagement; and collaborate with local communities.

TAP combines arts and positive psychology to devise innovative programmes where evidence and theory are brought to life for people in practical, accessible, creative and fun ways, designing or using existing evidence and interventions. TAP is committed to the use of research and evaluation. It also provides innovative training for artists and staff, well-being, accredited occupational and careers coaching for individuals and groups through its partner agencies.

'Through client/relationship-centred, co-productive engagement and participatory methodologies, we place the people we work with at the centre of everything we do.'

### Willis Newson

http://www.willisnewson.co.uk

Willis Newson is an independent arts consultancy working with health, community and education partners in public spaces, specialising in the field of arts and health.

It aims to improve the experience of patients and healthcare staff, both day to day and in the longer term. It works to create excellent environments, promote mental well-being, tackle key public health priorities, boost staff morale and involve local communities. Passionate about the capacity of the arts to achieve these things, Willis Newson is also committed to the use of research and evaluation to demonstrate, measure and improve the effectiveness of our work.

'We like to actively engage all the individuals and communities involved in both the process and the outcome of our projects. We know that this is the best way to create sustainable legacies, forge lasting partnerships and embed learning.'

### **Reports and Publications**

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- Beard, R.L. (2011) Art Therapies and Dementia Care: A systematic review. Newcastle upon Tyne: Sage. doi 10.1177/1471301211421090. rbeard@holycross.edu
- Dartington, T. (2007) *Managing Vulnerability: The underlying dynamics of systems of care*, The Tavistock Clinic Series. London: Karnac Books.

Tim describes research over 40 years in thinking why institutional and community care are both subject to processes of denial and fear of dependency. His examples include children in hospital, people with disabilities living in the community, and the care of older people and those with dementia. He asks why there has been such splitting between health and social care and what underlying purpose this split may have in a societal response to vulnerability and long-term dependency.

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## **Research: Suggested**

Psychoanalytical studies into organisational defence mechanisms in nursing homes.

### **Environmental Design**

### Kings Fund: Enhancing the Healing Environment

http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-in-dementia-care

The Department of Health commissioned The King's Fund to develop a number of specific programmes to enhance the environment of care as part of its work to improve the patient experience. The latest of these is a programme to improve the care environment for people with dementia to support the implementation of the national dementia strategy. They have produced resources to enable hospitals to become more dementia-friendly.

### Tools

### Age Exchange

http://www.age-exchange.org.uk/our\_work/publications

A selection of books, handbooks, tools, manuals and posters with and for older people. Includes:

Bruce, E., Hodgson, S. and Schweitzer, P. (1999) *Reminiscing with People with Dementia*. London: Age Exchange

### **Mental Health Foundation**

http://www.mhf.org.uk

Resource pack facilitating groups for people living with dementia in sheltered housing (in press).

### **Monitoring and Evaluation**

Some examples of monitoring and evaluation measures are listed below. You would require the appropriate questionnaire for the investigation underway and may require special license from the publishers.

### CASP-19

CASP-19 is a theory-based quality-of-life measure comprising four domains ('control', 'autonomy', 'pleasure' and 'self-realisation'). It was developed under the UK's Economic and Social Research Council's Growing Older Programme (2000–2003), by David Blane, Paul Higgs, Martin Hyde and Dick Wiggins.

### Dementia Care Mapping<sup>™</sup> (DCM)

http://www.brad.ac.uk/health/career-areas/bradford-dementia-group/short-courses/dementia-care-mapping

DCM been recommended by the National Institute for Health and Clinical Excellence, the Social Care Institute for Excellence, the Audit Commission and the Commission for Health Improvement as a method for improving care practice for people with dementia. Although care mapping is a tool that could be transferred to many clinical areas, it was developed specifically for people with dementia and dementia-like illnesses.

It involves sitting at the side of the care area, usually for 6 hours, observing a patient's behaviour, well-being or ill-being and any positive or negative events. Mappers may notice how busy nurses inadvertently upset patients by failing to greet them properly or by talking over their heads. Results are uploaded onto specially designed sheets, can be transferred to SPSS-type data analytical systems, and analysed to assess statistical outcomes. Simple analysis can be made there and then following the mapping, to give staff an indication of service delivery and client well-being.

Dementia Care Mapping (DCM) is an observational tool used within institutional settings which aims to provide information on residents' well-being and the quality of care delivered by staff. During a mapping session, the mapper records residents' behaviours, mood, engagement and interactions with staff over a defined time period, within a communal area. For the purposes of this study, participants will be observed for 2 consecutive hours beginning from 1 hour prior to lunch.

Each construct of behaviour, mood and engagement is systematically coded within 5-minute time frames, and the resulting dataset is then analysed to give an overall 'well-being' level. Staff-resident interactions are recorded as and when they occur, according to type and potential for well-being, and are named as 'personal detractors' or 'personal enhancers'. These aim to give an overall picture of the level and quality of person-centred care being delivered.

Mappers may be sourced from the Bradford site given, or individuals can attend an intensive course to train as a mapper.

It is currently being used by Age Exchange to measure the impact reminiscence arts has on the well-being of people living with dementia in care homes (RADIQL).

After analysis, the observations are fed back to the teams and used to improve the processes of patient care.

### Mental Wellbeing Impact Assessment

http://www.apho.org.uk/resource/item.aspx?RID=95836

For an accredited practitioner of MWIA: <a href="mailto:info@tapartsproject.co.uk">info@tapartsproject.co.uk</a>

The MWIA toolkit for well-being provides an evidence-based framework for improving wellbeing through commissioning processes, project and service design and delivery, community engagement and impact assessment.

It enables people and organisations to assess and improve a policy, programme, service or project to ensure it has a maximum equitable impact on people's mental well-being, and to identify ways to measure those impacts.

Used to develop creative arts services for SLaM dementia projects and Emergence CiC Arts Social Network.

### Older People's Quality of Life Questionnaire (OPQOL-35)

Brief questionnaire at:

http://www.newdynamics.group.shef.ac.uk/assets/files/Bowling%20et%20al%202012%20A GG%200PQoL-brief%20%282%29.pdf

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### The SROI Network

http://www.thesroinetwork.org

SROI is a framework based on social generally accepted accounting principles (SGAAP) that can be used to help manage and understand the social, economic and environmental outcomes created by your activity or organisation.

'Social Return on Investment (SROI) aims to increase social equality, environmental sustainability and well-being. Our vision is for a world in which decisions take account of social and environmental returns as well as financial returns.

We believe that current approaches contribute to social inequality and environmental degradation. It will not be enough to create new approaches that sit alongside current practice. We need mainstream approaches to include a wider sense of value and to give a voice to those that are affected. For this to happen we need to show that value is missing from many or even most decisions about policy and practice. And that it is possible to show what is missing and value it, in a way that is clearly viable and reasonable.'

# The Warwick–Edinburgh Mental Well-being Scale (WEMWBS) http://www.healthscotland.com/documents/1467.aspx

Newly developed scale for assessing positive mental health (mental well-being). A positively worded item scale with five response categories. It covers most aspects of positive mental health (positive thoughts and feelings) currently in the literature, including both hedonic and eudemonic perspectives. However, it should not be used to give individual change, but is a good tool to compare population change against national averages.

### Arts & Health

http://www.tandfonline.com/loi/rahe20#.UuuDXSjRcR4

An international journal of research, policy and practice co-edited by Professor Stephen Clift and Professor Paul Camic of Canterbury Christ Church University and Professor Norma Daykin of the University of the West of England. *Arts & Health* is the official journal of the Society for Arts in Healthcare and is published by Routledge.

### Arts Journal

http://www.artsjournal.com

*ArtsJournal* was founded September 13, 1999 in the heady days of the dotcom boom. The site is a digest of some of the best arts and cultural journalism in the English-speaking world. Each day *ArtsJournal* features links to stories culled from around the internet, including blogs and more than 200 English-language newspapers, magazines and publications featuring writing about arts and culture. Stories from sites that charge for access have generally been excluded.

The current *AJ* site is the fifth design. In 2003 blogs were added and the site now features more than 60 prominent writers on culture. Further additions are expected, with individuals', group and limited-time group debate blogs.

*AJ*'s editor is Douglas McLennan, formerly an arts columnist and arts reporter with the Seattle Post-Intelligencer and the Seattle Weekly. Doug writes the diacritical blog on ArtsJournal, tweets as @AJDoug and for a number of publications. He also teaches at the Annenberg School for Communication and Journalism at USC and is a much-in-demand speaker on issues of arts, culture, journalism and how the digital revolution is changing culture.

AJ's assistant editors are Matthew Westphal and Suzi Steffen.

### **Arts Professional**

http://www.artsprofessional.co.uk

Keeping up to date with important issues and vital information can sometimes feel a bit like trying to fill a cup from a waterfall. *Arts Professional* tries to make this task just a little easier by creating and curating the most relevant content for those with a professional interest in the arts sector, with the aim of delivering a quality news and information service that will help readers to get the most out of their professional practice. *Arts Professional*:

- covers news stories that are too specialist for the national newspapers, but are important to those working in the arts
- investigates what's really going on in the sector, holding public bodies to account when necessary
- keeps the sector up to date with changes in areas such as the law and technology, and policies that may affect them
- shares good practice by giving arts organisations and practitioners a platform to write about their successes and tell others about their experiences
- provides a forum in which those with something say can pass comment on key issues or topical subjects.

### **Journal of Applied Arts & Health**

http://www.intellectbooks.co.uk/journals/view-Journal,id=169/

The *Journal of Applied Arts & Health* serves a wide community of artists, researchers, practitioners and policymakers evidencing the effectiveness of the interdisciplinary use of arts in health and arts for health. It provides a forum for the publication and debate within an interdisciplinary field of arts in healthcare and health promotion. The journal defines 'health' broadly which includes physical, mental, emotional, spiritual, occupational, social and community health.

### Films (music and dementia)

Gladys Wilson and Naomi Feil

http://www.youtube.com/watch?v=CrZXz10FcVM

Old Man In Nursing Home Reacts To Hearing Music From His Era http://www.youtube.com/watch?v=NKDXuCE7LeQ

The Dementia Research Funding Portal is a partnership project between DeNDRoN,

### Funding

For participatory work, it is recommended that arts organisations liaise with providers of dementia services to develop partnerships, providing potential avenues of funding. Local authorities, the NHS, older people's cafes, council arts and community services are also potential sources. You may need to be creative when seeking funding. For example, a creative reminiscence project based on nature could be funded though the local council 'green' funding streams. Libraries also provide excellent sources of funding information. Some funders may require you to be a not-for profit, community interest company or a charity. A few will allow individuals to apply.

For research funding, you should collaborate with an experienced researcher in designing your research project and application for funding.

Here are some more suggestions.

### Arts and Humanities Research Council (AHRC)

http://www.ahrc.ac.uk/Funding-Opportunities/Pages/Research-Grants---Standard-Route.aspx

The Research Grants Schemes are intended to support well-defined research projects enabling individual researchers to collaborate with, and bring benefits to, other individuals and organisations through the conduct of research. This scheme is not intended to support individual scholarship.

### Arts Council England

Arts Council England champions, develops and invests in artistic and cultural experiences that enrich people's lives, supporting a range of activities across the arts, museums and libraries – from theatre to digital art, reading to dance, music to literature, and crafts to collections.

Great art and culture inspires us, brings us together and teaches us about ourselves and the world around us. In short, it makes life better.

Between 2011 and 2015, we will invest £1.4 billion of public money from government and an estimated £1 billion from the National Lottery to help create these experiences for as many people as possible across the country. Government funding is received from the Department for Culture, Media and Sport and requirements are laid out in our funding agreement with them.

### The Concertina Charitable Trust

Concertina makes grants to charitable bodies which provide musical entertainment and related activities for older people. This not only brightens up their lives, but also provides a therapeutic benefit to their health and well-being. Concertina is keen to support smaller organisations which might otherwise find it difficult to gain funding. Since its inception in 2004, it has made grants to a wide range of charitable organisations nationwide in England and Wales. These include funds to many care homes for older people, to provide musical entertainment for their residents.

### **Dementia Research Funding**

The Dementia Research Funding Portal brings together funding opportunities from all the main UK research funders to provide a one stop shop for dementia researchers. The portal makes it easy for researchers to access the latest grant rounds, as well as news on relevant events, conferences and useful links. Dementia research is one of the UK's scientific priorities, and the portal will provide the very best support to the field in the search for breakthroughs.

Alzheimer's Research UK and Alzheimer's Society. The Dementia Research Portal was a recommended outcome from the 2011 Ministerial Advisory Group on Dementia Research

http://www.artscouncil.org.uk

http://www.concertinamusic.org.uk

http://dementiaresearchfunding.org.uk

### The Leverhulme Trust

http://www.leverhulme.ac.uk/funding/RPG/RPG.cfm

Offers up to  $\pm 500,000$  over 5 years for research on a topic of the applicant's choice. Grants cover salary and research costs directly associated with the project. Submit a first-stage outline application at any time.

The aim of these awards is to provide financial support for innovative and original research projects of high quality and potential, the choice of theme and the design of the research lying entirely with the applicant (the Principal Investigator). The grants provide support for the salaries of research staff engaged on the project, plus associated costs directly related to the research proposed, and the award is paid directly to the institution at which the applicant is employed.

### National Institute for Health Research (NIHR)

#### http://www.nihr.ac.uk/research/Pages/Dementia.aspx

NIHR's main priority is to make sure that funding for research is focused where it is needed and provides quality outputs and value for money through a totally transparent and accountable system.

Programme Grants for Applied Research (PGfAR) are prestigious awards directed towards leading researchers who can demonstrate an impressive track record of achievement in applied health research. Each programme funds a series of related projects, which form a coherent theme in an area of priority or need for the NHS. The amount awarded and the length of the funding period will depend on the nature of the proposed work, in particular whether or not the proposal includes a substantial powered trial. Although, funding in excess of  $\pounds 2.5$  million over more than 6 years will be unusual.

Nested within the PGfAR programme is the Programme Development Grants scheme. This initiative offers investigators the opportunity to undertake preparatory research that will position them to submit a competitive Programme Grant for Applied Research application.

Other schemes include:

- Research for Patient Benefit (RfPB) programme
- Invention for Innovation (i4i) programme
- Health Technology Assessment (HT A) programme
- Public Health Research (PHR) programme
- The Health Services and Delivery Research programme
- Efficacy and Mechanism Evaluation (EME) programme.

### The Wellcome Trust

The Trust's funding supports the brightest minds in biomedical research and the medical humanities, with the aim of improving human and animal health. It offers a wide variety of funding schemes, including Investigator Awards, fellowships and Strategic Awards, and also supports several major initiatives.

http://www.wellcome.ac.uk

# Annex List of participants

Name	Title	Organisation
Alastair Addison	Head of Activities	Nightingale Hammerson
Lorraine Axford	Dementia Development	Prama
Fionnuala Baiden	Dementia Development Specialist	Jewish Care
Danielle Battigelli	Trustee	Creative Dementia Arts Network
Marsaili Cameron	Director	PublicServiceWorks Associates
Paul Cann	Chief Executive	Age UK Oxfordshire
Alexandra Casey	Co-Director	Suffolk Artlink
Nuala Conlon	Involvement & Participation Lead MHOAD	South London & Maudsley NHS Foundation Trust
Alexandra Coulter	Director	Arts & Health South West
Ursula Crickmay	Director of Learning	Wigmore Hall
Charlotte Cunningham	Director	Turtle Key Arts
Prof Norma Daykin	Professor of Arts in Health	University of the West of England
Jo Davies	One-to-one support worker	Young Dementia UK
Evan Dawson	Executive Director	Live Music Now
Liz Dennis	PhD Researcher	University of Exeter
Jenny Edwards	Chief Executive Officer	Mental Health Foundation
Debbie Fox	Vice Chair	Jewish Care
Veronica Franklin Gould	Chief Executive	Arts 4 Dementia, Ltd
Cindy Glover	Group Facilitator	Mental Health Foundation
Hilda Hayo	Chief Admiral Nurse / CEO	Dementia UK
Damian Hebron	Director	London Arts Health Forum
Gemma Jolly	Information Office (Health & Wellbeing)	Alzheimer's Society
Jane Lloyd	PhD candidate	Royal Holloway, University of London
Adam Kent	Innovation Manager	Sage Gateshead
Mrs Orii McDermott	PhD candidate	Mental Health Sciences Unit, Univ. College London
Rosie Mead	Music Coordinator	Yeovil District Hospital NHS Foundation Trust
Helena Muller	Chief Executive	Lost Chord
Douglas Noble	Strategic Director: Wellbeing	Live Music Now
Jon Petter	Composer	Turtle Key Arts
Arti Prashar	Artistic Director and Chief Executive	Spare Tyre Theatre Company
Nicky Rushton	Freelance Musician	Equal Arts
Helen Sheam	Head of Arts Strategy	South London & Maudsley NHS Foundation Trust
Wendy Smith	Mental Health Older Adults and Dementia	Sage Gateshead
Belinda Sosinowicz	Consultant	Arts, Wellbeing and Positive Psychology
Michael Spellman	EOP Services Coordinator	The ExtraCare Charitable Trust
Les Sudron	Head of Fundraising	Methodist Homes (MHA)
Rebecca Swift	Creative Producer	Entelechy Arts
Rachel Thompson	Dementia Project Lead	Royal College of Nursing
Janine Valentine	Nurse Consultant in Dementia	Yeovil District Hospital NHS Foundation Trust
Dr Trish Vella-Burrows	Assistant Director	Sidney de Haan Research Centre for Arts & Health
Moira Wade	Project Co-ordinator	Hoot Creative Arts

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