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'WHAT WOULD LIFE BE - WITHOUT A SONG OR A DANCE, WHAT ARE WE?'

A REPORT FROM THE COMMISSION ON DEMENTIA AND MUSIC

SALLY BOWELL SALLY MARIE BAMFORD



ABOUT ILC-UK

The International Longevity Centre - UK (ILC-UK) is an independent, non-partisan think tank dedicated to addressing issues of longevity, ageing and population change. It develops ideas, undertakes research and creates a forum for debate.

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In particular, we would like to thank the Commissioners for their advice, contributions and ongoing support¹:

- **Chair: Baroness Sally Greengross OBE**, cross-bench peer and Chief Executive of the International Longevity Centre - UK
- **Luciana Berger MP**, Labour and Co-operative Member of Parliament for Liverpool, Wavertree
- **Professor Alistair Burns CBE**, Professor of Old Age Psychiatry, University of Manchester and Honorary Consultant, Old Age Psychiatrist, Greater Manchester Mental Health NHS Foundation Trust
- **Professor Sebastian Crutch**, University College London
- **Councillor Christabel Flight**, Westminster City Council
- **Professor Martin Green OBE**, Chief Executive, Care England
- **Ming Hung Hsu**, Chief Music Therapist, MHA
- **Liz Jones**, Head of Policy and Research, MHA
- **Tim McLachlan**, Operations Director – Local Services, Alzheimer’s Society
- **Sarah Metcalfe**, Chief Executive, Playlist for Life
- **Professor Helen Odell-Miller OBE**, Anglia Ruskin University
- **Alexia Quin**, Director, Music as Therapy International

Alongside the final report, the Commission will be publishing the written evidence that was submitted to the Commission, excluding those submissions where the author(s) explicitly requested that their evidence not be included. We will also be publishing a separate, full list of all contributors to the Commission.

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FOREWORDS

Foreword by Baroness Sally Greengross

Dementia is one of the most pressing health issues facing the world, with the World Health Organisation estimating that there are currently 50 million people living with the disease globally. The number of cases of dementia is expected to triple to 152 million by 2050. In the UK alone, it is anticipated that there will be one million people living with dementia by 2025.

Whilst finding a cure or effective form of prevention is of course a major area of research, we concurrently need to explore opportunities for managing all forms of dementia, and ensuring the highest possible levels of wellbeing for the people affected. When delivered effectively, music gives carers and loved ones an avenue through which to sustain relationships and share experiences and can help to minimise the often-upsetting symptoms of dementia such as agitation, anxiety and depression. Moreover, it can help to improve a person's wellbeing and quality of life.

Through the Commission on Dementia and Music, we have engaged a wide group of stakeholders, as well as individuals new to the debate, in order to explore the value of music in dementia. As this report shows, this is a burgeoning area which deserves greater recognition and support moving forwards. This report adds valuable insight to the conversation by summarising a field of work which has historically been fragmented in nature, and by taking a holistic view of the provision currently being offered. The authors put forward recommendations which we believe, if taken, would considerably help the sector in growing, and in serving our communities.

As outlined in this report's recommendations, and building on the important improvements in care in the health and social care sector, we want to see recognition, backing and support from government, the music industry, academia, arts organisations, local communities and others to ensure that this issue reaches the top of the agenda. We want to see an Ambassador emerge to take forwards this field of work, with the support of a dedicated task force empowered with the necessary funding to take action. With combined efforts and collaboration, we are confident that we can improve the lives of people with dementia through the meaningful use of music.

We would like to thank the authors for developing this important call to action for professionals and the public alike: music can help people with dementia, so let us ensure that it is available to all.

Baroness Sally Greengross OBE, Chief Executive, ILC-UK.

Foreword by The Utley Foundation

The Utley Foundation is delighted to have been able to fund the establishment of a Commission on Dementia and Music and the publication of this report, in partnership with ILC-UK.

Exploring and advancing the positive impacts of music for people living with dementia has been a priority area of funding for The Utley Foundation since our inception in 2014. In the context of an ageing population, and with predictions that 1 in 3 people born in 2015 will get dementia, the powerful potential of music to reduce anxiety, agitation, isolation and depression - perhaps even delaying the onset of symptoms - while increasing communication and vitality, is so important.

This report brings together an impressive and wide-reaching selection of experts from across the fields of dementia, ageing, and music, each of whom has given valuable insight and contributions to the research. It represents a unique, ambitious and comprehensive piece of research that we hope will offer robust insight into the value of music in this context, with clear recommendations on how to advance the space. We hope that it will inspire tangible change through more awareness of the value of creative approaches, such as music, to help people living with and affected by dementia.

More than this, we see this report as critical in establishing a pathway for future action on the pressing issue of dementia and dementia care. We strongly support the report's recommendations, and call for backing from across the spectrum of music and dementia organisations, care homes, health and social care professionals, the music industry, funders, the general public and government. Together, we can make care for people living with dementia better and more meaningful. United in the understanding that music can enhance quality of life, we can be much more than the sum of our parts.

Finally, we would like to express our thanks not only to ILC-UK for their exceptional work, but also to the Commissioners as well as the wider selection of individuals who gave their time and contributions, in a multitude of ways, to the creation of this report. Our own commitment to the cause has been strengthened as a result of all of these efforts, and we hope that others will follow suit and commit ongoing energy and resources to this truly important cause.

EXECUTIVE SUMMARY AND RECOMMENDATIONS

This report examines the existing landscape and future potential of using therapeutic music with people with dementia, which forms one of the most pressing health concerns of our time. Adopting a holistic approach, this report is unique in providing an overview of current music-based provision for people with dementia, the scope of this work and the associated evidence base. This report has been guided and informed by the Commission on Dementia and Music, made up of experts in the field.

Ultimately, the report shows that music can provide a true lifeline for those both with and without dementia by promoting social connection, restoring a sense of self and bringing joy even in the most challenging of times. The ability to connect to music is an innate aspect of being human; having a diagnosis of dementia need not undermine this.

We believe that everyone has a right to meaningful music and that too many people with dementia are living a life in silence. We want to help bring people back into the present moment, using music as a tool to achieve this.

This report draws several conclusions about the field of music and dementia:

- The field is currently characterised by **devoted advocates operating in a complex and poorly coordinated ecosystem**. The dementia and music environment is supported by a dedicated network of individuals and organisations, looking to grow the sector and keen for pragmatic options and recommendations to take this field of work forwards. We need to improve local information and data collection to ensure that both the public and professionals have everything they need to ensure that music reaches people with dementia.
- The field is defined by **sporadic provision which is currently delivered only to the few**. Educated estimates suggest that very few people currently receive the full range of music options and support. This is likely due to multiple reasons, including a lack of public understanding about the benefits of music, the high cost (or perceived high cost) of some types of intervention and the lack of a centralised overview of current provision. Furthermore, it is difficult to know how many people with dementia currently have access to music, largely due to a lack of data. We want to see provision reaching all people with dementia, including the most vulnerable individuals who may not have family or friends to speak on their behalf.
- Fortunately, **the sector is supported by a promising evidence base which is quickly gaining traction**. A growing research base, spanning some twenty to thirty years, is beginning to demonstrate the range of benefits of music for people with dementia. Whilst there are areas in which the evidence can be improved and strengthened (as outlined in the full report), there is much to be celebrated in the existing literature, which shows that music can promote a range of hugely beneficial outcomes for people with dementia. Moreover, when used appropriately and in a meaningful way, the use of music has no known negative impacts.
- The sector would greatly benefit from **increased funding**. Further developing **cost-effectiveness research** would be a critical factor in boosting recognition and funding. Statutory budgets, both of central and local governments, are currently tightly restricted and are likely to continue to be closely monitored in the coming years. This is combined with health and social care pressures associated with an ageing population. In this light, those dedicated to dementia and music need first-and-foremost to focus on providing convincing cost-effectiveness evidence in order to be granted funding. Meanwhile, private sector and philanthropic organisations should recognise the importance and value of this field of work, and utilise their own resources and expertise to help grasp some of the opportunities available.
- **We need to raise public awareness** in order to maximise the potential of this field of work. As yet, the range of benefits that music can offer people with dementia appears to have not yet reached the general public. The value of music for people with dementia should be more clearly expressed in public-facing literature and a large-scale PR campaign would be highly valuable in raising awareness, winning over hearts-and-minds and ensuring an increased demand.

In order to achieve the goal of delivering meaningful music for all, this report makes the following recommendations:

Recommendation	Ask	Associated stakeholder(s)
Coordinate delivery and build intelligence	<p>An independent, non-political, high profile Ambassador for Dementia and Music needs to emerge as a leader in the field. Utilising a substantial budget, sourced from a mix of charitable, philanthropic and private funding, the Ambassador should lead a dedicated task force to deliver transformational change in music access for people with dementia and their carers. With an ambitious campaigning agenda to ensure the effective co-ordination of national and regional activities, co-opting the efforts of the music industry with the arts sector and new technologies.</p> <ul style="list-style-type: none"> • The Ambassador and task force should be able to speak for and to all strands of work across all sectors • The Ambassador and task force should work with various sectors, to ensure universal access to music for people with dementia, for example free or subsidised music downloads for people with dementia 	Music and dementia sector
	<p>We need clearer local offers of activities and interventions for people with dementia, including in residential settings</p> <ul style="list-style-type: none"> • To include music-based interventions • To follow a consistent format between local areas 	Local authorities
	<p>We need a national framework to collate information from local offers, generated into a centralised database summarising local provision for people with dementia</p> <ul style="list-style-type: none"> • This should include music-based provision • Data should be made publicly-available 	Local Government Association
	<p>In the meantime, all providers of music-based interventions should register their provision through the Alzheimer's Society's Dementia Connect tool</p>	Music and dementia sector
	<p>The dementia and music sector should work to coordinate, unifying and further develop tool kits and training guides to enable new practitioners to develop necessary skills. The resources should reflect and draw together best practice from a range of existing programmes, thereby acting as conclusive guides. Endorsement should be sought from recognised bodies (e.g. NHS England, CQC, Skills for Care, Skills for Health)</p>	Music and dementia sector

Develop the research base	NICE's upcoming review of the dementia care guidelines (2018) is imminent. It will not be feasible for researchers to produce a wealth of new evidence ahead of this review. Instead, researchers should focus efforts on proving the cost-effectiveness of music-based interventions. This will be crucial in the ongoing development of the field	Academics Music and dementia sector
	Other important areas in which to develop the research base are: <ul style="list-style-type: none"> Continuing to propose new research studies, using randomised control trials wherever practical and feasible Clearly voice the challenges inherent in undertaking RCTs with target cohorts, and propose studies which best suit the interventions in question, be that mixed-methods, non-randomised, qualitative etc 	Academics Music and dementia sector
	Meanwhile, we encourage NICE evidence reviewers to: <ul style="list-style-type: none"> Question the burden of proof, both considering challenges and feasibility of RCTs with target cohorts and the inherent costs involved in such studies Value the existing research base and reflect this in the new dementia care guidelines Continue to provide constructive advice to researchers in this field about building good-quality evidence in this sector 	Non-departmental public bodies (NICE)
Raise public awareness	All relevant organisations must ensure that public-facing advice and guidance clearly highlights the value of music for people with dementia	Central and local government Health & social care sector Government Voluntary organisations Care homes Arts organisations The music industry Any/all other relevant organisations

	<p>A national campaign should be launched to recognise the value of music for people with dementia, capitalising on recent media attention</p> <ul style="list-style-type: none"> • Engaging, approachable and informative mass media • Utilising varied platforms (e.g. television, social media, radio, public events, performances, festivals) 	<p>Voluntary organisations Care homes Professional bodies Philanthropic trusts and foundations The music industry Arts organisations Lobbyists Think tanks Health & social care sector Government Parliament Celebrities and high-profile figures Academics Music and arts festivals (e.g. the Proms, Glastonbury) Any/all other relevant organisations</p>
<p>Coordinate and grow funding</p>	<p>Philanthropic trusts and private sector organisations should leverage their collective networks and funding to pioneer work in this area; this topic provides an opportunity for philanthropists to make a tangible difference and develop new schemes of work</p>	<p>Philanthropic trusts and foundations Private sector organisations</p>
	<p>We propose the roll-out of integrated personal budgets to people with dementia</p>	<p>NHS</p>
	<p>We call for the recognition and promotion of music for people with dementia, including through personal health budgets and integrated personal budgets</p> <ul style="list-style-type: none"> • The therapeutic potential of music should be specifically recognised 	<p>NHS CCGs Local authorities</p>
	<p>Service commissioners must take music-based interventions for people with dementia seriously when planning both preventative and dementia care services</p> <ul style="list-style-type: none"> • This should be reflected in funding allocations 	<p>CCGs Local authorities</p>
	<p>Where directly funding provision is not possible or practical, we call on statutory services to play a role in better coordinating and supporting work in this sector, in order to support delivery by others</p> <ul style="list-style-type: none"> • This would include liaising with the proposed task force on dementia and music 	<p>Statutory services Voluntary sector</p>

Make the best use of technology	We need a consensus on the clear potential of digital interventions in this field and a celebration of their unique value, alongside the benefits brought by other forms of music-based interventions	Music and dementia sector
	Given the relative affordability of digital interventions, we want all people with dementia to be able to access interventions such as (but not limited to) Playlist for Life by 2020 <ul style="list-style-type: none"> It currently costs £250 in year one and £120 in subsequent years to provide a person with dementia with limitless music, through providing hardware and access to Playlist for Life and Spotify services If music publishers and streaming platforms could make music available for free or at a reduced price for people with dementia, this could help to considerably lessen the price and make music available for all 	Music and dementia sector Music industry
	We call for ongoing creativity in deciding how technology can support dementia and music. Urging engaged organisations and individuals to explore the value which can be derived from new and emerging technologies e.g. virtual reality and artificial intelligence	Music and dementia sector Technology companies of all sizes Music industry
	We want the dementia and music sector to build strong and mutually beneficial relationships with major technology companies and start-ups	Music and dementia sector Technology companies of all sizes The music industry Philanthropic trusts and foundations
Support individuals to find the right intervention at the right time	We want the proposed task force on dementia and music to create and roll-out a clear, public-facing tool or ‘roadmap’ designed to help explain which interventions might be more suitable for a person with dementia as the disease progresses <ul style="list-style-type: none"> This should be informed by the evidence base but easily understood by non-expert audiences It should include, where possible, different strands and emphases depending on variables such as type of dementia, age, ethnicity, comorbidities etc. 	Music and dementia sector Think tanks Academics Philanthropic trusts and foundations

CHAPTER 1: INTRODUCTION

Music is an undeniably significant part of being human. It spans different genres, cultures and eras, and it promotes bonding, communication and wellbeing.

For many, music is part of a daily routine. Breakfast radio shows ease lots of us into our days, whilst commuters use headphones to drown out train announcements or noisy fellow passengers. Digital platforms such as Spotify compile recommended playlists to match our moods, from 'concentration' or 'motivation' to 'that Friday feeling' and 'lazy Sunday afternoons'. Perhaps winding down at the end of the day, film scores tap into our emotions and transport us out of our living rooms into different eras, different parts of the world, even different planets.

In difficult times, music can soothe, comfort and help to rebuild a sense of self. From your first nursery rhyme to the first dance at your wedding, music accompanies us throughout our lives, cements our memories and helps us to define ourselves. Music is also important at the end of our lives, bringing us together with friends and family in times of celebration and of passing.

A life without music is unimaginable for many and yet for some people with dementia, opportunities to access music can be few and far between. This is despite emerging evidence, which shows a multitude of benefits associated with music for people with dementia.

ILC-UK has set up a Commission on Dementia and Music (hereafter 'the Commission') to ensure that everyone with dementia who could benefit from engaging with music is able to do so. The Commission has sought to understand what music means for people with dementia, and to explore the current and potential role of music-based interventions in the prevention, treatment, care of and quality of life for people with dementia.

The Commission's journey so far

The Commission has brought together experts in the field, both by training and by experience, to try to answer some of these questions and better understand the potential of music in helping us to tackle one of the most pressing questions facing society.

The Dementia 2020 challenge² calls on us all to help our country become the best in the world for dementia care, and for dementia research. The Commission aims to provide solutions and recommendations to help answer this call by drawing together information about the provision and value of music-based interventions.

Terms of the Commission

The terms of reference for the Commission are to generate greater political and public awareness, understanding and traction for this subject. The Commission has reviewed the current evidence base and critically explored the barriers to further take-up, aiming to set out a blueprint for future work in this area. Commissioners, drawn from a wide-range of different backgrounds and sectors, were asked to consider a number of critical questions during the gathering of oral and written evidence:

- What are the known benefits of dementia and music, and how established is this evidence base?
- What are the undefined or under-researched areas associated with this subject area and where is more research needed?
- How do we define 'music-based interventions', how do these vary, and what are the respective benefits and impacts of different types of intervention/ therapy?
- What influences the effectiveness of dementia and music?
- What are the emerging opportunities and current barriers and obstacles, which prevent further take-up and roll out?
- What are the current innovations in this field? Where is there potential for further innovation and what would be the enabling factors in this?
- What is the potential for growth?
- Who and what sectors of health and social care should be targeted to help raise awareness of dementia and promote music-based interventions and initiatives?

- How could we estimate and model any cost savings associated with music interventions for people with dementia?
- How do music interventions compare in terms of outcomes and potential value for money compared to other Arts therapies? How does this vary by type of music intervention?
- Is there any learning or best practice we can draw on from Europe or internationally?
- How do we embed dementia and music into the broader dementia agenda?

The activities of the Commission

In addressing the key questions, we draw on ideas, evidence and information from a variety of sources. All of these sources have helped to inform and guide the authors, and have been critical to the development of this report:

- **A desk-based literature review:** researchers utilised search engines and reviewed journals in order to collate and review the most relevant material. Advice and recommendations were also kindly provided by Commissioners and academics in the field.
- **Two ‘sold-out’ oral evidence sessions** with subject-matter experts, Commissioners and audience members in the House of Lords
- **A call for written evidence** was issued to ILC-UK’s network of over 6,000 individuals and organisations, as well as through Commissioners’ personal networks and to identified stakeholders. The call was also shared via social media. Over 50 submissions were received from individuals and organisations including academics, public sector organisations, the charity sector, practitioners and volunteers. Written evidence was also received from family members of people with dementia.
- **Three site visits** were organised to observe different forms of music-based interventions for people with dementia. One site showcased two music groups for people with dementia in a care home in South London. These sessions were delivered by a charity dedicated to dementia and music, and the sessions were facilitated by trained professional musicians. A second visit was to observe a music therapy group in a Continuing Care ward based on a hospital site in South-East England, run by a trained music therapist. A third visit was facilitated by a collaboration of musical organisations in central London and saw performances for people with dementia, from students undertaking a master’s in music.
- **A final report** was prepared by ILC-UK, bringing together the findings set out in the initial scoping paper, the collated evidence from the oral and written evidence submissions and a set of clear recommendations for future action and research.

About this report

This report is an integral part of the work of the Commission on Dementia and Music. It aims to inform the reader of the existing dementia and music landscape, outline the potential benefits of this kind of work and develop recommendations for next steps in the field, bearing in mind inherent challenges and opportunities.

To meet these aims, this report consists of nine chapters:

- **Chapter 2** frames the debate by defining key terms used in the report, and taking into account limitations
- **Chapter 3** pictorially reflects the current dementia and music landscape, showing the range and level of activity
- **Chapter 4** presents noteworthy statistics relating to current trends and activity
- **Chapter 5** summarises the evidenced benefits of dementia and music, bringing together research to highlight both what we know and what remains unknown
- **Chapter 6** draws attention to some of the challenges for this field of work
- **Chapter 7** discusses some of the areas of opportunity for dementia and music
- **Chapter 8** concludes the report and makes recommendations
- **Chapter 9** presents some ‘on-the-ground’ case study examples of practice in order to bring stories to light.

Methods and approach

The Commission found and received a range of different sources of evidence, which have been synthesised for the purpose of writing this report. ILC-UK has distilled key information and arguments from these sources of information in order to help inform the generation of recommendations. Below is a summary of the research methods utilised throughout the project in order to achieve this.

Literature review: The literature review aimed to draw together the main arguments and aspects of the debate around dementia and music, rather than to be fully exhaustive. ILC-UK were supported and guided in this process by Commissioners and those who submitted written and oral evidence. We also sought the advice of a current PhD student in the field, Biljana Vrancic-Coutinho, based at Anglia Ruskin University.

Site visits: Site visits were organised to permit ILC-UK researchers to observe a range of activities in practice, in order to enhance understanding. Commissioners joined to observe practice and to provide further insight during visits. Researchers decided upon the most appropriate sites to visit through the literature review and via recommendations from Commissioners. Three sites were chosen for visits, as we wanted to see a few different models of intervention.

Call for written evidence: ILC-UK designed a template for written evidence submissions, which included a range of key questions. These submissions were processed by pulling responses into an Excel framework, which allowed researchers to identify key themes and arguments. These themes and arguments have helped to guide the writing of this report. Where novel or innovative comments were made, we have directly cited these in the report.

Oral evidence sessions: Two evidence sessions were held in the House of Lords. We heard from four expert witnesses in the first session and seven in the second. The first session focussed on the current 'state of play' of music and dementia and we heard from those currently working in and engaged with the field. The second session was designed to help us to develop recommendations for the progression of this field of work. Seven speakers from a range of public organisations joined us to help reflect on these questions. Notes were taken by ILC-UK throughout.

CHAPTER 2: FRAMING THE DEBATE

Definitions and terminology

A definition of dementia

The Department of Health's National Dementia Strategy² provides a useful definition of dementia, which we have used to frame our own definitions and thoughts throughout this report:

"The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities.

Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.

The causes of these illnesses are not well understood to date but they all result in structural and chemical changes in the brain leading to the death of brain tissue. The main sub-types of dementia are: Alzheimer's disease, vascular dementia, mixtures of these two pathologies ('mixed dementia') and rarer types such as Lewy body dementia, dementia in Parkinson's disease and fronto-temporal dementia. The term 'Alzheimer's disease' is used sometimes as a shorthand term to cover all forms of dementia. The dementias all share the same devastating impact on those affected and their family carers. Dementias affect all in society irrespective of gender, ethnicity and class. They can affect adults of working age as well as older adults. People with learning disabilities are a group at particular risk."

What do we mean by 'music-based interventions'?

The term 'music-based interventions' is used throughout the report to refer to a very broad range of activity and approaches, both formal and informal. This term is used in a collective sense in order to refer to this range of work, but it is also important at certain points to speak of specific styles and methods. Examples of 'music-based interventions' can include³:

- **Music therapy, delivered either one-to-one or in a group setting, by a qualified and registered music therapist.** Chief Music Therapist at MHA, Ming Hung Hsu et al⁴ highlight that music therapy is a state-registered health discipline in the UK: 'On completion of the two-year training at master's level, graduates register with the Health and Care Professions Council in order to practice and obtain a legally protected title "music therapist"'. As outlined by the British Association for Music Therapy⁵, in a formal music therapy session, therapists draw on the client's innate musicality and develop a therapeutic relationship via engagement in live musical interaction and play between a therapist and client, ensuring client participation. This approach frequently draws significantly on improvisation so that the therapist can build on the input and responses of the client. A range of instruments are used, including the voice. There are currently seven music therapy MA training courses for professional music therapists in the UK. Over 100 music therapists are qualified each year, although not all will specialise in music therapy for people with dementia. Further details about the role of a music therapist can be found in Chapter 3.
- **Listening to music, either live or recorded**, is another type of intervention. Playlists can be tailored to an individual's preferences in some instances, for example by making use of online apps or personalised CDs. In other examples, care homes can become venues for musicians to play live music to a group of individuals living with dementia. Some individuals may be given the opportunity to attend orchestral performances. Live music can be tailored to the group, for example by purposively designing playlists which draw on childhood music. Music can be listened to either solo or in a group, and clients can actively participate, for example by expressing their musical preferences or by moving to music.
- **Playing music and/or singing** is a further form of intervention. Again, this can be in either an individual or group setting. Individuals can be supported to continue playing an instrument, thereby

maintaining a lifelong skill, or to join in singing along to well-known songs. Examples include a multitude of community choirs, singing groups and orchestras which are open to people with dementia. An individual could continue to practice an instrument that they have played for their whole life, or could be encouraged to learn something new, such as by taking part in a drumming class.

Limitations

The term 'dementia' is highly complex; it refers to a range of diseases with different causes, symptoms, and progression. This high degree of variability is challenging when trying to create definitions, or to speak collectively and summatively about this subject. Similarly, dementias are progressive and experiences vary both over time and day-to-day. The report largely focusses on music-based interventions for mild-to-moderate dementias as this appears to be where the literature and delivery has focussed. However, ILC-UK also note the value and potential impact of music, especially music therapy interventions⁶, for those with advanced dementias, during palliative and end of life care and this is discussed further in the report.

Throughout this report, ILC-UK have endeavoured to avoid over-generalisation of both dementias and of the people who live with these diseases. To this end, several of our recommendations focus on the fact that further and ongoing research is required to differentiate the role of music for different types of dementia and for different groups of individuals.

Commissioners and expert witnesses have keenly emphasised the importance of adopting a person-centred approach to the subject of dementia and ILC-UK have sought to reflect this in the present report. In particular, we wish to note the important role that culture and heritage have in music and dementia and, again, call for more research and attention to be paid to this important aspect.

Where generalisations are made in the report, these are done tentatively and with the recognition that further research is needed to help explore this topic moving forwards. Where groupings and classifications are used, ILC-UK appreciate that they may not always reflect the diversity and plurality of individuals. However, this approach has been taken for matters of practicality. For example, whilst we are conscious that all individuals experience dementia differently, we utilise resources such as the National Institute for Health and Care Excellence (NICE) Dementia Pathway in order to help guide our narrative. Moreover, we see people with dementia as active participants and co-producers of music and are keen to avoid language which labels individuals as passive recipients. We urge readers to adopt this lens when reading the report.

Further to this, people with dementia often also live with diagnosed or undiagnosed comorbidities, some of which may be long-term conditions in themselves (such as diabetes or cancer), whilst others might be shorter-term (for example, urinary tract infections). Comorbidities may well further influence a person's behaviour, preferences and general mood and may therefore be important considerations when deciding upon the most appropriate music-based intervention for an individual. Given the wide range and various impacts of comorbidities, the present report does not seek to guide on this dimension. It is, however, noted that carers, families and friends will need to be aware of comorbid conditions and may need to adjust music interventions accordingly.

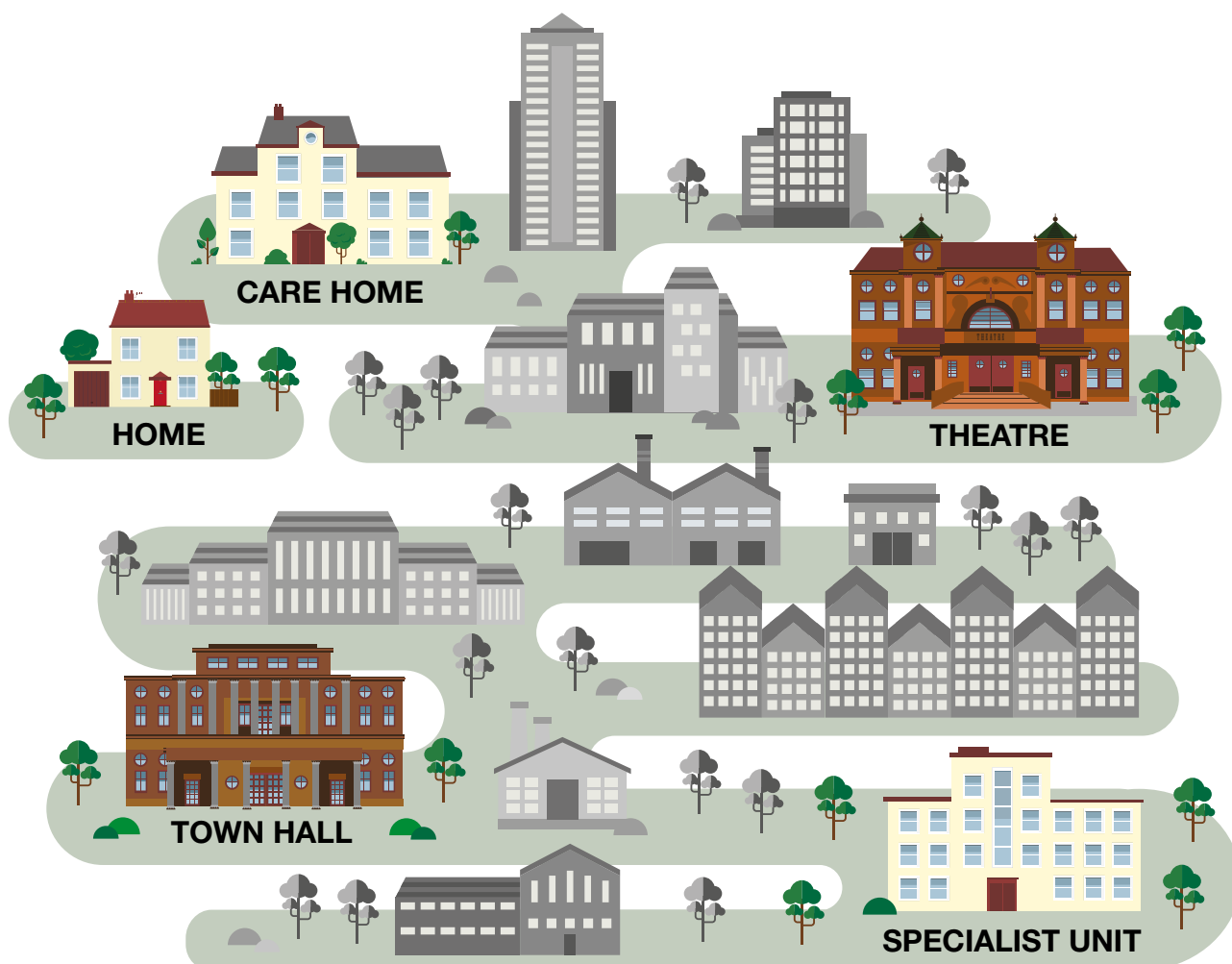
CHAPTER 3: DEMENTIA AND MUSIC – THE EXISTING ECOSYSTEM

The current landscape

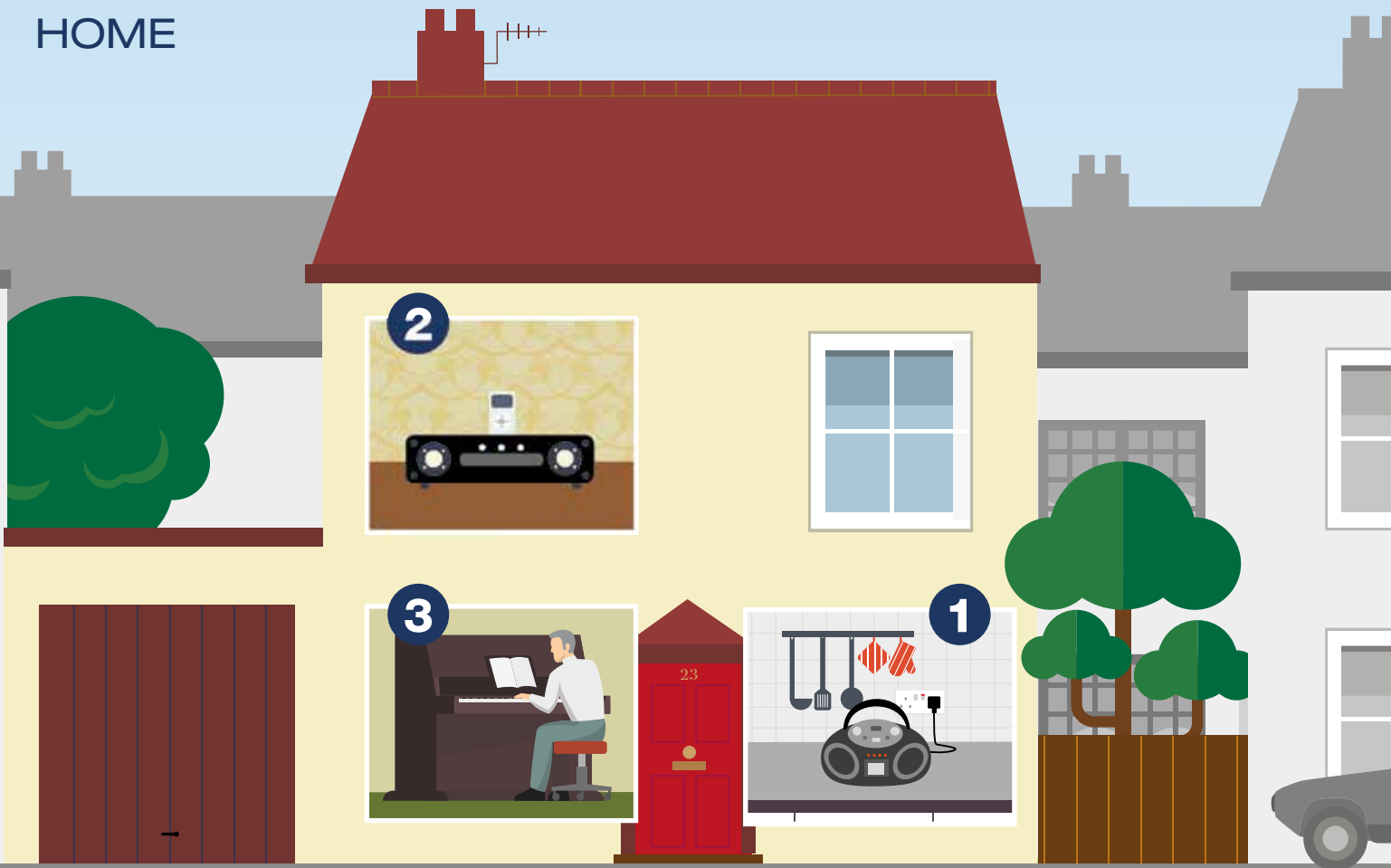
Music-based provision has been delivered sporadically for many years within the UK, and appears to be fairly well-developed in some areas. However, there is a complicated and often confusing picture of the different options and provision available. Provision appears to be patchy and there are many important, outstanding questions to be answered. Not enough is understood about what is being done, by/with whom, and why, and there is little in the way of simple and effective information for the public.

The Commission has highlighted the importance of simplifying and making-accessible information about the availability of music-based provision for people with dementia. From a review of available literature, existing projects and written evidence submissions, it is clear that music-based provision is not consistent and operates with a high degree of variability. This is despite pockets of standardised delivery such as professional music therapy practice⁸. Penetration of the market appears to vary between regions (although there is a lack of quantitative evidence to demonstrate this), and there is no centralised database of activities and provision. The closest available database is likely the Alzheimer's Society's Dementia Connect tool⁹, which will include some music-based provision but does not yet fully reflect the landscape.

The illustrations below are therefore designed to reflect (at a broad level) the different types and forms of provision on offer, whilst noting that this is not exhaustive and that activities will vary from these descriptions. Variables will include differences such as personal interest and abilities, local culture, ethnicity and heritage, location, type of dementia and many, many other variables. The high degree of variability at once speaks to the helpful flexibility of music as a form of provision, but also to the opportunity for increased standardisation and coordination of activity. Images are linked to text on subsequent pages through a numbering system.



HOME



CARE HOME

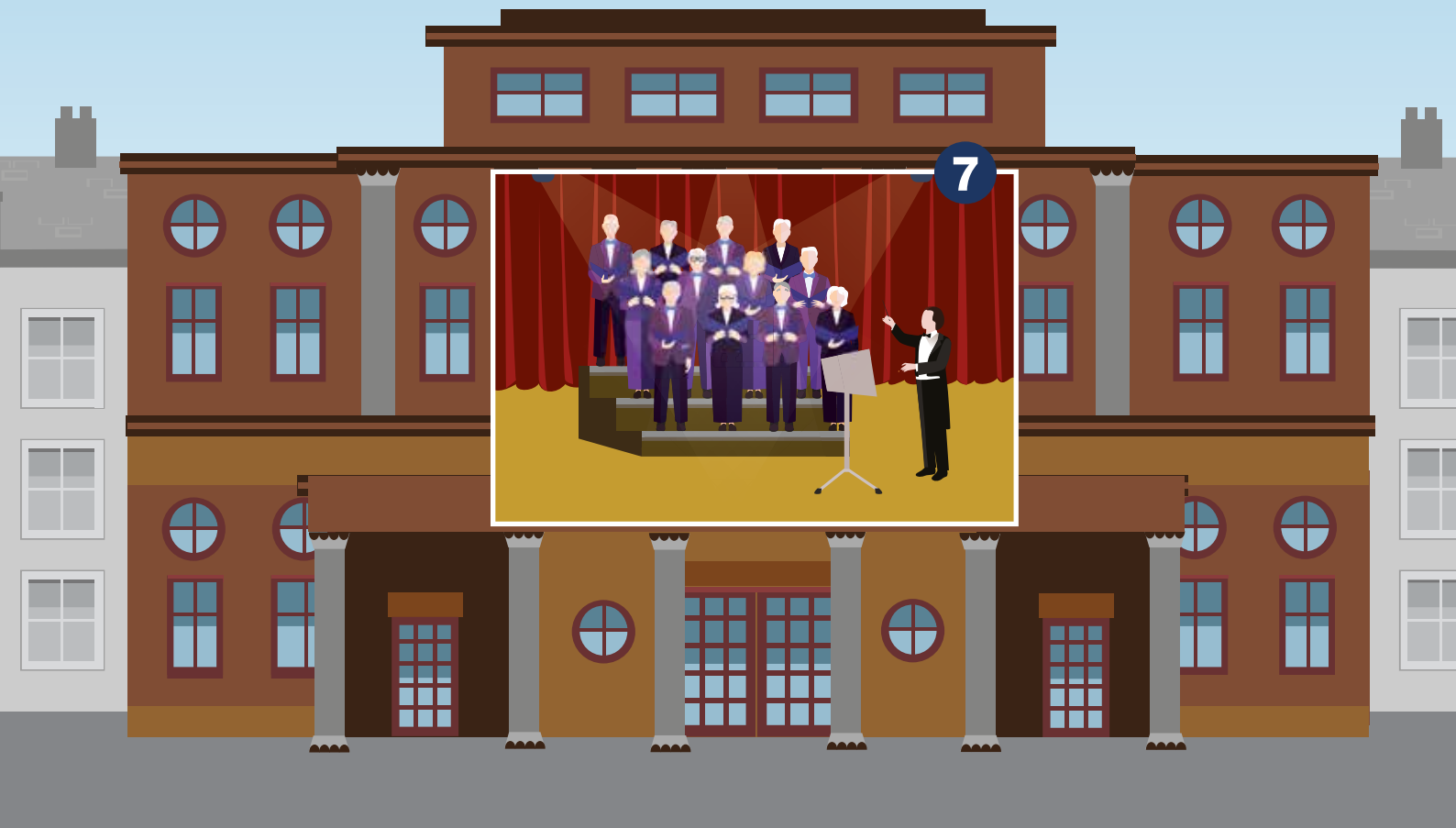


SPECIALIST UNIT



THEATRE





1. Listening to music can provide a valuable source of enjoyment, entertainment and therapy for people with dementia. It can provide a relatively cheap and simple way for individuals to enjoy music, and can allow friends and family to share quality time with them. In addition to some of the specific interventions outlined below, simply listening to the radio or to a CD can provide a valuable opportunity for people with dementia to listen to music.

It is important that music is not used indiscriminately. Carers and loved ones must note the value of silence, as well as that of sound. Music should be tailored to the interests and preferences of people with dementia in order to minimise distress, and to be in keeping with the principles of personalised care. In residential settings, carers should avoid leaving the radio on all day. Some people with dementia become fearful or intolerant of sound, whilst others may enjoy short and purposeful sessions of music, but may become distressed if music is played for too long, too loudly or in an unregulated way¹⁰.

As explained by the Social Care Institute of Excellence (SCIE)¹¹, ***'dementia can worsen the effects of sensory changes by altering how the person perceives external stimuli, such as noise and light. As hearing is linked to balance this also leads to a greater risk of falls either through loss of balance or through an increase in disorientation.'*** As such, music needs to be used appropriately in order to avoid unintentionally causing additional agitation.

2. Personalised, recorded music is a growing area of delivery in the UK. Charities such as Playlist for Life encourage carers and loved ones, as well as people with dementia, to compile lists of digital music which are particularly significant to the individual. Over 2016/17 the charity spoke to more than 21,000 people about the power of music, trained 1,600 health and care professionals in 98 organisations and research indicates that around one in eight people who attend a Playlist for Life talk will go on to create a full playlist for themselves or someone else¹². Playlists can provide a source of comfort and enjoyment for individuals and help to ensure that music-listening is person-centred. Playlist for Life has begun to receive support from the medical profession, for example with GPs for Lillyburn Care Home in Glasgow officially incorporating the work into patients' medical care¹³.

In thinking about designing playlists for people with dementia, evidence suggests that there is a ‘memory bump’ for music. It appears that people with dementia retain clearest memories for music they enjoyed and heard between roughly the ages of 10 and 30¹⁴. Meanwhile, the development of ‘wearable’ technologies could well bring new opportunities for this field. Cutting-edge research at University College London¹⁵ highlights the potential for using technologies such as FitBit to monitor a person’s response to particular music and thereby determine the optimal playlist. This could be particularly valuable for those people with dementia with communication problems, or for those without family or friends to help design personalised playlists.

Soundtrack to My Life (STML)¹⁶ offers another type of support, delivered by JoCo Learning and Development. Through their written submission, JoCo Learning and Development stated that **“STML is a little book designed to help draw together the pieces of music that are significant to the person with dementia. It is unique in that it is not just a list of ‘favourite tunes’ but allows you to record accompanying life stories. It enables personalised music playlists to be made and give their care givers insight into the individuals’ music memories so that you can use music in a therapeutic way.”**

Personalised playlists, supported by the use of new technologies, remain an under-researched area. Playlist for Life’s review of the evidence states that **‘despite the anecdotal evidence that permeates the accounts of caregivers, researchers and staff (Gerdner, 2010¹⁷), there currently exists no standardised or empirically validated personalised music, technology-based intervention for individuals with dementia, despite the obvious potential’¹⁸**. This is a rapidly growing area of design, implementation and delivery, and further research is required to evidence the specific benefits that this kind of intervention could provide. This could, in turn, help in discovering new ways of harnessing technology to improve the lives of people with dementia.

“The very first time I put the headphones on she said: ‘thank you for the music.’” [The daughter of a person with dementia, quote provided by Playlist for Life]

3. Learning and playing an instrument, evidence suggests, might help to prevent the onset of dementia. A study¹⁹ of twins in California, whilst unable to provide conclusive evidence, argued that the research suggests that music may be a modifiable protective factor against dementia and cognitive impairment.

After taking into account variables such as sex, physical activity and education, those twins who played a musical instrument in older adulthood were 36% less likely to develop dementia and cognitive impairment. The authors stress that the study cannot demonstrate a causal effect, but they draw attention to other studies which support this finding. For example, Hanna-Pladdy and Alicia MacKay (2011)²⁰ have suggested that musical ability might help older people to maintain their cognitive function.

4. Live music in care homes is delivered by a multitude of different individuals and organisations in care homes across the UK. Some charities, for example Music in Hospitals and Care (MiHC), Live Music Now (LMN), Lost Chord and Musical Moments bring professionally qualified musicians into the care home setting to perform and engage with residents.

Charities delivering this type of work range widely in scope and scale. Larger, national charities such as LMN can reach up to 120,000 people a year²¹ covering a range of ages and needs. Smaller, often regional, charities may be more likely to deliver programmes specifically tailored for people with dementia. For example, Lost Chord delivers 1,300 interactive musical sessions a year in 130 care homes. MiHC, meanwhile, delivers about 5,000 live music sessions each year to vulnerable adults and children in healthcare. This type of delivery ranges in its degree of interactivity from performances, to tea dances, to participatory singing.

Another example is the work of Beatie Wolfe, a singer-songwriter who began looking at the therapeutic power of music for people with dementia in 2014, with support from The Utley Foundation. The partnership looked at direct, ground level impact through working with residents in care homes as well as broader, awareness raising initiatives like the Music and Dementia Festival, held in August 2017. Her four-month research tour in Priory Care Homes used new music in performances for people with dementia and saw positive impacts through the use of pre-assessments and post-performance questionnaires. Noted improvements were observed in

the areas of response and interaction, relaxation, singing and movement and dancing. The pre- and post-assessments allowed short and longer-term improvements to be monitored across the project. Carers reported that even at the mid-project point there were significant improvement in the individual's level of worry, memory and communication. These changes remained evident after Beatie's performance, and even after the study had concluded.

As highlighted by Evan Dawson, Executive Director of LMN, during the Commission's first evidence session, it has been speculated that just 5% of the 20,000 UK care homes may currently be providing good quality arts and music activity for residents²². There is clearly a low level of work being delivered, and our call for written evidence suggested that there may be an increasing demand for this kind of provision from care homes:

"I feel that there is a demand from carers to have more music in care settings – our organisation is constantly receiving enquiries from all areas of the UK but unfortunately we are only able to provide our service in some of the North-West areas, although we are working on trying to expand through our franchise model and to be able to fill the demand that we know is out there." [Musical Moments written evidence submission]

Some charities specialise in training care staff to deliver music-based interventions themselves. Just one example of many is Music as Therapy International²³, which works in multiple countries providing training to employees working in schools, care centres and residential homes. The theory of the teaching is based in music therapy, and whilst their clients do not become fully-trained music therapists, they are able to adopt some simple therapeutic techniques to use with their pupils, patients and residents. The charity delivers three strands of activity: introductory training, sustainability, and capacity building. The aim is for their clients to reach a point *'where they take ownership of the future of the practice in their care settings and beyond'*²⁴. This 'train-the-trainer' model promotes cascaded learning and aims to foster sustainable practice beyond a distinct period of funding. It is the only UK charity with this sole focus and its innovative approach has gained recognition from the Advancing Healthcare Awards, the British Association for Music Therapy, the World Congress of Music Therapy and third sector award bodies.

"It releases so much, the music. At home I get so [hunches shoulders] tight and stressed but doing the music session lets it out." [Person with dementia, quote provided by Music as Therapy International]

Meanwhile, some other charities deliver training alongside their wider programme of delivery. One such example is Mindsong²⁴, a charity which trains care staff to run their own singing groups and Playlist for Life who support professionals, communities and families to utilise their app and design playlists for people with dementia. Providing dementia training to musicians is also an important element in delivering music-based provision. For example, in their written evidence submission, The Salvation Army mentioned the local roll-out of their new 'Singing by Heart' resource designed to help individuals to set-up and run their own dementia-friendly choirs²⁶. They spoke of the necessary provision of dementia-specific training through regional specialists to volunteers, employees and officers.

5. Music therapy refers to a distinct profession regulated by the Health and Care Professions Council (HCPC), with clear Standards of Proficiency (SOPs)²⁷ and Standards of Education and Training (SETs)²⁸. Music therapists hold a postgraduate clinical qualification, as well as a degree in music (or equivalent); they will also have achieved Grade 8 or equivalent, in at least one instrument. It can be accessed through statutory services (NHS, local authority and social care services), charities, third sector provision, social enterprises, or privately in people's homes. As an example, MHA, a large national charity for older people, runs an innovative and leading music therapy service for people with moderate to severe dementia in its dementia care homes. MHA is one of the biggest employers of music therapists in dementia care, employing 26 music therapists; in 2016 they provided 10,940 sessions in MHA care homes.

'I have been amazed by the response the music therapist has been able to get from my mother by her skill, empathy and persistence.' [Daughter of a person with dementia, quote provided by MHA]

Music therapy, as distinct from the above-mentioned work, focusses on therapeutic goals. It may be

delivered one-to-one or in a group setting. People with dementia who are engaged in music therapy will be involved in the creation of music themselves, and the music is often improvised by both therapist and individual. The role also involves advising other health and care colleagues, training musicians and therapists from other disciplines and advising on an individual's general care.

The British Association for Music Therapy (BAMT)²⁹ is the key professional body operating in this field and has recently undertaken a survey of the membership base in order to shine a light on the practice and working habits of music therapists. Music therapists make up the smallest of the Allied Health Professions (AHPs): the BAMT survey has found that there are currently 900 music therapists in the UK and about 250 of these practitioners work with people with dementia³⁰.

Two thirds of this group (N=142) responded to the BAMT survey and findings included:

- Music therapists in dementia work on average 20 hours per week, demonstrating that few are employed full-time.
- Most (61%) work in hospital or residential settings, meaning that only a minority work in the community and in people's own homes.
- Statutory services employ about 60% of music therapists working in dementia. About 13% are in private practice (self-employed) while the rest work for private or voluntary sector employers.

6. Community-based musical performances and events are delivered by many charitable organisations around the UK. These tend to be offered to people with dementia in the community, and their carers and loved ones. Examples of this kind of provision include the collaboration between Wigmore Hall, Westminster Arts and the Royal Academy of Music, delivering a project called Music for the Moment. This project organises and delivers periodic performances by students at the Royal Academy of Music for people with dementia and their carers and loved ones, as observed during a Commission site visit. Meanwhile, dementia-friendly operas are staged by Opera Scotland, with the aim of ensuring that people with dementia are able to comfortably enjoy performances.

Dr Julia Jones, CEO, Found in Music also emphasises that community activities can be offered to those with and without dementia alike: *'The Sanctuary night club in Glasgow has recently started running a "Daytime Disco" on Monday. Welcoming over 50s (including those with dementia) to strut their stuff on the dance floor. We also run an outdoor disco in Kent during the summer that successfully attracts three generations, including those with dementia and mental health issues'*³¹.

7. Community-based music groups: Some of the best-known examples of music for people with dementia fall under this bracket, perhaps most notably the Alzheimer's Society's 300 Singing for the Brain™ groups which are available across England, Wales and Northern Ireland. As described in the charity's call for written evidence:

"...Singing for the Brain™ is a structured activity designed for people with dementia that aims to reduce the social isolation, depression and withdrawal often associated with dementia. Research has shown that when communication through speech becomes difficult, people with dementia can still be actively involved in vocal expression through singing – especially through singing well-known and familiar songs. The Singing for the Brain model largely uses familiar songs with regard to musical 'eras' e.g. the forties, the sixties, but also includes new pieces of music so that it not only facilitates recall but also stimulates learning and brings people together.

[Alzheimer's Society's written evidence submission]

However, responses to the Commission's call for written evidence unveiled a very wide range of community-based activity, being delivered by many different organisations and ranging considerably in scale and scope. Some groups may just be organised by one person, whilst others have a broad geographical reach and membership base. Whilst it would be virtually impossible to list all examples, a few are noted below, to help reflect this diversity:

- Age UK Trafford's³² weekly 'disco' and bi-monthly cabaret for people with dementia.
- Come Singing³³, offering therapeutic singing groups for people living with memory loss and run by a small charitable organisation in Norfolk. Twenty groups are run monthly, in a range of settings.
- Turtle Song³⁴, run by Turtle Key Arts, offers a series of different 10-week projects for people with

dementia. Participants are supported by musicians and music students to compose their own songs, with accompanying lyrics. The music is then recorded on a DVD for participants to take home.

During one oral evidence session, an ex-participant of the programme reflected fondly on his experience:

“As my first such group, Turtle [Song] was thoroughly rewarding, and by the end we had prepared a simple opera on the theme of travel, which we performed to an invited audience in our local concert hall. My own musical highlight was singing a duet with a young Spanish bassoon player... And my dementia-d brain felt amazingly reinvigorated by active involvement with the experts and by participating in music in new ways. What? Me - a composer?” [Peter Smith’s oral evidence submission]³⁵

- Manchester Camerata’s Music in Mind project³⁶ is “a music therapy group run by Manchester Camerata that offers free music therapy sessions for people with dementia and their carers. The sessions aim to improve the quality of life and wellbeing of the attendees through music making”³⁷. Activities are led by qualified music therapists and supported by musicians from the orchestra. The programme reaches over 30,000 people each year across the North West³⁸.
- *Together in Sound*³⁹ is a new collaborative community project between Saffron Hall (a state of the art concert hall) and Anglia Ruskin University, working together with music therapists, carers and people with dementia; including visiting musicians.
- Music for Life (Wigmore Hall)⁴⁰, delivers music improvisation workshops for people with dementia (eight weekly sessions for eight weeks), alongside experiential employee training and training and development for professional musicians.
- In Wales, there are several small-scale, local community singing groups and choirs. Respondents to the call for evidence highlighted the Musical Memories Choir⁴¹ in Swansea (held twice weekly in local churches), the Forget-Me-Not Chorus⁴² in Cardiff (weekly singing sessions in five locations) and With Music in Mind⁴³ based in the Vale of Glamorgan (weekly sessions in two locations).

CHAPTER 4: KEY STATISTICS

People with dementia and their carers

- There are currently **850,000 people with dementia in the UK**. Numbers are set to rise to **1 million by 2025** and **2 million by 2051**⁴⁴.
- There are nearly **700,000 unpaid carers for people with dementia**. Alzheimer's Research UK (ARUK) estimate this number would need to more than double to 1.7 million by 2050 to maintain the current ratio. However, given changes in fertility rates and household demographics, it is anticipated that demand for unpaid care will likely begin to outstrip supply imminently.



The cost of dementia

- The **annual cost of dementia to the UK is £26.3bn**. This is expected to exceed £50bn over the next 3 decades⁴⁵. To compare, planned spending for the Department of Health in England alone for 2017/18 is approximately £123.8 billion in real terms.
- **Dementia has higher health and social care costs (£11.9bn) than cancer (£5.0bn), stroke (£2.9bn) and chronic heart disease (£2.5bn) combined**⁴⁶.
- Luengo-Fernandez et al. (2010) estimate that **1.5 billion hours of unpaid care for people with dementia were provided by Britons in 2006**. Approximately **34% of these hours were supplied by economically active individuals** - this demonstrates the opportunity cost of dementia.
- Luengo-Fernandez et al.'s (2010) **estimated that unpaid care amounts to £12.4 billion**.
- Considerable savings could be made if the onset of dementia could be delayed. Looking at **Alzheimer's alone, if we could delay the onset by 5 years then it is estimated that £100bn could be saved between 2020 and 2035**⁴⁷.



Pervasiveness of the behavioural and psychological symptoms of dementia (BPSD)

- Neuropsychiatric symptoms of dementia such as agitation, depression, apathy and anxiety are reported to affect approximately **80% of people with dementia living in care homes**⁴⁸



80% PEOPLE IN CARE HOME
HAVE NEUROPSYCHIATRIC
SYMPTOMS OF DEMENTIA SUCH
AS AGITATION, DEPRESSION,
APATHY AND ANXIETY

Music and dementia

- **Educated estimates suggest that good quality arts and music provision may currently only be available in just 5% of care homes**⁴⁹.
- According to the latest Laing and Buisson survey, **there are 421,100 people aged 65+ in residential care (including with nursing)**⁵⁰.

- It is estimated **that 80 per cent of people in care homes have dementia** or severe memory problems⁵¹.
- $(421,100 \times 0.8) = 336,880$. I.e. **336,880 people with dementia live in residential/nursing care.**
- If we accept the educated estimate that 5% of care homes provide good quality arts and music provision, this suggests that there may be as many as **320,000 people with dementia in residential settings who do not have access to meaningful arts provision.**
- In 2011 the Alzheimer's Society estimated that around 2/3rds of people with dementia live in the community. If we assume there are 850,000 people with dementia then **an estimated 566,700 people with dementia live in the community** without access to projects based in care homes. There is, as yet, **no available data to demonstrate how many of these people are able to access music-based interventions** and the Commission calls for further consolidation and centralisation of information in order to better access this picture.
- Weekly availability of music therapy equates to roughly half a minute per person with dementia. In other words, only a tiny minority of people with dementia have regular access to music therapy.



**80% OF PEOPLE
IN CARE HOMES**
HAVE DEMENTIA OR
SEVERE MEMORY
PROBLEMS



**AN ESTIMATED
5% OF PEOPLE**
IN CARE HOMES HAVE
ACCESS TO ART AND MUSIC

CHAPTER 5: WHY MUSIC MATTERS - THE KNOWN BENEFITS

In a complex picture often lacking readily accessible or collated information, it can be difficult for members of the public and people with dementia to both understand the potential value of music in improving lives and access provision.

A review of existing evidence supports what is often said anecdotally: music offers a potential lifeline for people with dementia, their carers and loved ones, one which can sometimes be unmatched by other interventions. The Commission received an evidence submission from a spouse caring for her 62-year-old husband who is living with dementia. In this submission, she says that

‘Music is now the one thing I can share with my husband that seems to give him pleasure’. In another submission, a wife of a man living with frontotemporal dementia says that music ‘...can bring a smile when other attempts at communication fail, & can bring use of language, i.e. singing, when normal speech fails’.

Emerging academic evidence is beginning to support this wealth of anecdotal evidence. One example of this developing research base includes a 2017 study by Abraha et al⁵². The authors undertook a systematic overview of reviews in order to provide an outline of non-pharmacological interventions for BPSD. Interventions included sensory stimulation, cognitive and emotion-oriented interventions, behaviour management techniques and other therapies. Of the large number of non-pharmacological therapies identified and examined, the review concluded that music therapy was one of just two forms of intervention for which there is convincing evidence of effectiveness in reducing the behavioural and psychological symptoms of dementia. As such, this chapter summarises the range of known benefits of music-based interventions for people with dementia.

A definition: There are a number of psychological and psychiatric symptoms that are often associated with dementia such as agitation, depression, and sometimes delusions and aggression. These have been described under the umbrella term ‘behavioural and psychological symptoms of dementia’ (BPSD)

A note on the evidence

A 2017 Cochrane Review⁵³, focussing on studies using randomised control trials (RCTs), has concluded that this is a field of research with clear gaps and areas for development. The review states that there is very little good-quality RCT evidence testifying the impact of music for dementia, and there needs to be more and better-quality studies undertaken. The authors state that *‘the quality of the evidence was moderate for depression and for agitation or aggression at the end of treatment. For all other outcomes it was low or very low.’* Meanwhile, *‘the quality of the reporting was sometimes poor’*. Both of these factors limited the authors’ ability to draw robust conclusions from the 17 RCT studies included in the review.

Areas of improvement should include employing larger sample sizes and outcome tools, especially for positive outcomes such as emotional wellbeing and social outcomes. Research studies should also try to understand the duration of impact/effect, in relation to the length of the intervention. Of course, RCTs are not the only form of evidence gathering and should also not always be presumed to be the best. Therefore, one must be cautious in applying the conclusions of the Cochrane Review. Other methodologies can and do offer a considerable amount of value in this field. ‘Developing NICE guidelines: the manual’⁵⁴ provides useful advice on this:

‘RCTs provide the most valid evidence of the effects of interventions. However, such evidence may not always be available. In addition, for many health and social care interventions it can be difficult or unethical to assign populations to control and intervention groups (for example, for interventions which aim to change policy). In such cases, a non-randomised controlled trial might be a more appropriate way of establishing cause and effect... There are also circumstances in which an RCT is not needed to confirm the effectiveness of an intervention... In these circumstances, there is sufficient certainty from non-RCT evidence that an important effect exists.’

Given the complexities and ethical considerations of conducting RCTs with people with dementia, and in particular the challenges inherent in performing a water-tight RCT in a residential setting, other forms of evidence may be just as effective in evidencing the impact of music-based interventions.

It is outside the remit of this report to provide detailed recommendations and solutions to the complex debate around the relative 'value' of different forms of evidence, but given the value that would come from further embedding music-based interventions into NICE dementia guidelines, it would be worth readers studying the NICE methods of reviewing research evidence⁵⁵, in particular the use of the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach.

The below summaries of the emerging evidence base should therefore be read through this lens; evidence is promising and demonstrates a range of potential outcomes. However, more and better-quality evidence is still needed to further strengthen the conclusions which can be drawn.

Summary of findings

Music and the brain: Regions of the brain associated with musical memory may overlap with regions relatively spared in Alzheimer's disease. Meanwhile, music is multi-dimensional and underpinned by widespread cortical plasticity, suggesting that even if certain areas of the brain are badly affected by dementia, a person may still be able to understand and enjoy music. Music may help in the recall of information for people with dementia, in a similar way to mnemonics, and playing a musical instrument may be associated with a lowered likelihood of developing dementia.

Minimising BPSD: Music-based interventions have the potential to help minimise BPSD, including agitation, abnormal vocalisation and aggression.

Tackling anxiety and depression: Music-based interventions could help to reduce anxiety and depression amongst people with dementia. Some research has suggested that the impact of music therapy on anxiety and depression could potentially be lasting, but more evidence is required.

Retaining speech and language: Music-based interventions may have the potential to improve the retention of speech and language for people with dementia.

Enhancing quality of life: Research suggests that music-based interventions can help to facilitate increased social interaction or 'flow', improve well-being, decrease stress hormones and enhance the quality of life of people with dementia.

Impact on caregivers: Early-stage research indicates that improvements in caregiving after music-related training are reported by care givers, families, service providers and music therapists. Feedback suggests that engaging carers in music-based interventions can help them to better understand residents. Further research is needed to help demonstrate behaviour change of carers and statistical significance of changes.

Palliative and end of life care: There is a paucity of studies relating to the use of music in the palliative and end of life care of people with dementia. Qualitative evidence suggests that music therapy in end of life care may help to minimise anxiety and discomfort, but a lack of quantitative data makes generalisations about the value of music near-impossible, in particular in dementia end of life care.

Music and the brain

- *Regions of the brain associated with musical memory may overlap with regions relatively spared in Alzheimer's disease. Meanwhile, music is multi-dimensional and underpinned by widespread cortical plasticity, suggesting that even if certain areas of the brain are badly affected by dementia, a person may still be able to understand and enjoy music.*
- *Music may help in the recall of information for people with dementia, in a similar way to mnemonics.*
- *Playing a musical instrument may be associated with a lowered likelihood of developing dementia.*

Why is musical memory preserved?

Scientific understanding of the retention of musical memory is a rapidly developing area of research. Jacobsen et al. (2015)⁵⁶ discuss the concept that musical memory could be somewhat independent from other memory systems. The authors first examined brain responses to unknown music, fairly-known music and well-known music so that they could identify those brain regions that encode long-term musical memory. The authors then analysed data of three essential Alzheimer's disease biomarkers in these areas of the brain.

The authors found that the regions identified as being important in musical memory corresponded to areas that showed substantially minimal cortical atrophy, and minimal disruption of glucose-metabolism, when compared to the rest of the brain. However, amyloid-b deposition was not substantially less than in the rest of the brain, which suggests that the regions of interest were still in a very early stage of decline. The authors therefore suggested that the overlap of musical memory regions with areas that are relatively spared in Alzheimer's disease, can help to explain why musical memory appears to be better-preserved than other types of memory.

Stevens (2015)⁵⁷ highlights that musical memory is a form of implicit memory, whereby previous experiences help an individual to perform a task, without being consciously aware of these previous experiences. Detecting a wrong or mistimed note is a good example of this kind of memory. Reber (2013)⁵⁸ argues that implicit memory is not part of a single distinct memory system but is, instead, underpinned by widespread cortical plasticity. This is because music has many dimensions, including auditory, visual, verbal, expressive emotional, and other dimensions.

Playlist for Life present a helpful visual summary of this for a non-expert audience, demonstrating how music affects multiple parts of the brain⁵⁹. Bearing this in mind, some specialists have argued that it is the pervasive presence of music in the brain that is the key to its preservation beyond other forms of memory.

Another theory is that music promotes or supports 'associative learning', whereby an individual strongly associates a piece of music with a person or event, as argued by Juslin and Västfjäll (2008)⁵⁹.

Using music to help retain memory

Simmons-Stern et al (2010)⁶⁰ discuss the potential use of music as a memory enhancer for individuals with Alzheimer's disease. Building on the concept of musical mnemonics as a frequently effective way of recalling information, and the fact that musical memory may be spared by Alzheimer's disease, the authors investigate the effect of using music to help individuals with Alzheimer's disease to recognise information. The authors demonstrated that individuals with Alzheimer's disease were better able to recall information when sung rather than when spoken, when compared to healthy older adults who showed no significant difference in recall. The authors suggest that two reasons could help to explain their findings: firstly, that the brain areas dedicated to music processing may be preferentially spared by Alzheimer's disease, and secondly, that music heightens stimulation in individuals with Alzheimer's disease, therefore allowing for improved attention and memory.

Another area of developing research is in understanding how different emotions in music might help in retaining memory. Alonso et al. (2015)⁶¹ highlight two important variables within music: arousal⁶² and valence⁶³. Their paper examines the role of emotion in the consolidation of memories; a review of the evidence demonstrates that research is inconclusive when examining the respective impact of arousal and valence in memory consolidation, although evidence suggests that this is an area of research worthy of further study.

Using music to delay the onset of symptoms of dementia

As outlined in the recent All Party Parliamentary Group (APPG) on Art, Health and Wellbeing report (2017)⁶⁴, emerging research suggests that music can play a role in delaying the onset of symptoms of dementia. The APPG report points to the work of Korte et al. (2013)⁶⁶ in exploring the potential role that music could play as a preventative tool for older adults. An intervention group learnt an instrument, whilst a control group underwent 'activity as usual'. The authors argued that their results painted a positive picture, suggesting that learning an instrument and making music can be very positive for older adults. Authors particularly pointed to the potential for music to improve wellbeing and hand flexibility.

Meanwhile Balbag et al. (2014)⁶⁷ published a study examining whether or not playing a musical instrument could help to prevent the onset of dementia. Using pairs of twins, the authors collected

information on whether or not each twin played a musical instrument when they self-reported their leisure activities. The authors found that, once they had controlled for factors such as sex, education, and level of physical activity, **playing a musical instrument was significantly associated with less likelihood of dementia and cognitive impairment.**

However, the APPG on Art, Health and Wellbeing's report also emphasises that more research is needed into delaying the onset of dementia, and in particular in delaying admission to residential care for people with dementia.

Minimising the behavioural and psychological symptoms of dementia

- *Music-based interventions have the potential to minimise BPSD, including agitation, abnormal vocalisation and aggression.*
- *More evidence is required in order to demonstrate the longevity of positive impacts associated with interventions, whilst further studies also need to incorporate larger sample sizes in order to increase potential confidence in results.*

Agitation

As outlined by MHA's Chief Music Therapist Ming Hung Hsu et al⁶⁸, in the report of their RCT music therapy study at MHA, "*many current approaches in dementia care regard behaviours such as agitation as a reflection of underlying unmet psychosocial needs, and an attempt to communicate such needs*". Music-based interventions can offer a means of communication to attempt to address this void. The implications of this study for caregivers is discussed in further detail later in this chapter.

Ridder et al (2013)⁶⁹ demonstrate that individual music therapy could help to reduce agitation amongst individuals with dementia living in a care setting. Forty-two participants with dementia were randomised to a sequence of six weeks of individual music therapy and six weeks of standard care. Results showed a significant reduction in agitation disruptiveness. Moreover, the prescription of psychotropic medication increased significantly more often for the cohort that did not receive music therapy than for the cohort which did receive music therapy.

Meanwhile, a study by Raglio et al (2008)⁷⁰, involving 59 people with dementia, sought to provide additional evidence of the impact of music therapy on BPSD. The NPI (Neuropsychiatric Inventory) total score significantly decreased in the experimental group, whilst specific instances of BPSD significantly improved. The authors therefore concluded that music therapy has the potential to be a valuable approach in minimising BPSD.

Further to this, three other studies by Garland et al. (2007)⁷¹, Svansdottir and Snaedal (2006)⁷² and Holmes et al. (2006)⁷³ reported significant reductions in neuropsychiatric symptoms during different types of music-based interventions (recorded music, music therapy and live interactive music respectively). Lasting benefits of music therapy were found to be present at 15 minutes (Garland et al.). However, in a separate study (Svansdottir and Snaedal), benefits were seen during a six-week period in which there were repeated sessions of interventions but benefits were no longer seen four weeks post-treatment. This could suggest that the positive impact of music therapy may not have a lasting impact, but further research in this field would help to better understand longevity of impact.

Physically aggressive behaviour

Clark et al. (1998)⁷⁴ randomly assigned subjects into two groups, one with no music and one with preferred music. Using an aggressive behaviour checklist and observation, the researchers noted a significant decrease occurred in 12 of 15 identified aggressive behaviours during music playing.

Meanwhile, Johnson & Taylor (2011)⁷⁵ also suggested that there is a reduction of aggressive behaviour in some people with dementia as a result of playing relaxing music during meal times.

Abnormal vocalisations

A study by Cohen-Mansfield & Werner (1997)⁷⁶ compared three types of intervention for people with abnormal vocalisations, and found that music therapy significantly reduced the behaviour.

Tackling anxiety and depression

- *Music-based interventions could help to reduce anxiety and depression amongst people with dementia.*
- *Some research has suggested that the impact of music therapy on anxiety and depression could potentially be lasting, but more evidence is required.*

Guetin, S. et al., (2009)⁷⁷ investigated the effect of music therapy on anxiety and depression in patients with mild-to-moderate Alzheimer's disease. The RCT used a sample of 30 individuals with dementia, half of whom formed the intervention group and half the control group. The Hamilton Scale was used to measure the level of anxiety at several points during the study, and the Geriatric Depression Scale was used to measure depression. The study showed significant improvements in both anxiety and depression in the music therapy group from week 4 until week 16. The effect of music therapy was sustained for up to 8 weeks after the discontinuation of sessions between weeks 16 and 24, thereby confirming the valuable effect of music therapy on anxiety and depression in patients with mild to moderate Alzheimer's disease.

Moreover, a study by Sung, Chang and Lee (2010)⁷⁸ undertook an RCT using a preferred music listening intervention. This study aimed to understand the intervention's effectiveness in lowering anxiety in older adults with dementia living in a nursing home. Anxiety was measured by a tool called *Rating Anxiety in Dementia* at baseline and in the sixth week. Results suggested that the intervention of preferred music listening had a positive impact and reduced the level of anxiety in older adults with dementia living in a nursing home.

Retaining speech and language

- *Music-based interventions may have the potential to improve the retention of speech and language for people with dementia*

Dementias see a progressive deterioration of language functioning. It is thought that 'possibly, the fundamentals of language are musical, and precede lexical functions of language development'⁷⁹. Using the bookcase analogy⁸⁰ of the progression of dementia, it could be that the musical elements of language out-live the lexical elements as the disease progresses.

Brotons and Koger (2000)⁸¹ explored the impact that music therapy could have on helping individuals to retain their speech and language for as long as possible. The authors compared a group receiving a music therapy intervention to a second group participating in conversational session in order to see if a difference could be demonstrated. The Western Aphasia Battery (WAB) was used to test language ability, and results from 20 participants revealed that music therapy significantly improved performance on both speech content and fluency. The authors argued that neurological material shows that language and musical abilities can be separated which is why music can be recalled. The authors hoped that the study's findings would encourage further research in the field with larger samples.

Enhancing quality of life

- *Research suggests that music-based interventions can help to facilitate increased social interaction or 'flow', improve well-being, decrease stress hormones and enhance the quality of life of people with dementia.*

Spintge (2000)⁸² explains that 'listening to music itself may decrease stress hormones such as cortisol', suggesting why everyone (not just people with dementia) can enjoy listening to music and can benefit from its soothing effect.

Särkämö et al (2014)⁸³ undertook a randomised control study to investigate the cognitive, emotional, and social benefits of regular musical activities in early dementia. The study showed that, compared with usual care, both singing and listening to music improved mood, orientation, and remote episodic

memory and to a lesser extent, also attention and executive function and general cognition. Singing also enhanced short-term and working memory and caregiver well-being, whereas music listening had a positive effect on quality of life. Meanwhile, a study by Marmstål et al. (2011)⁸⁴ concluded that music therapy enhanced interaction, cooperation, and communication for both the people with dementia and the caregivers as well.

Furthermore, Lord & Garner (1993)⁸⁵ demonstrated increases in levels of well-being, better social interaction and improvements in autobiographical memory in a group of nursing home residents who regularly had music played to them. These improvements were not seen in the comparison group who were engaged in other activities.

Meanwhile, Keeler et al. (2015)⁸⁶ have explored the neurochemistry and ‘social flow’ of group singing. One group of participants performed pre-composed music, whilst the others improvised. From measurements of plasma oxytocin and adrenocorticotrophic hormone both before and after the performance, the authors determined that group singing can reduce stress and arousal, and induce social flow in participants. Evidence therefore suggests that music can help to improve an individual’s sense of belonging and social connectivity.

Moreover, using Dementia Care Mapping, Hsu et al (2015)⁸⁷ found a potential positive effect on the wellbeing (e.g. mood and engagement in daily activities) of care home residents who received weekly individual music therapy sessions over a 5-month period. This potential effect was also observed two months after the music therapy treatment was finished.

Given that, when music is used in a meaningful and appropriate manner, there are no known negative side-effects to its use, its ability to improve quality of life and wellbeing can be whole-heartedly embraced. This should particularly be noted when comparing to interventions which can have tangible negative impacts, such as the use of anti-psychotic medications.

Impact on professional caregivers

- *Early-stage research indicates that improvements in caregiving after music-related training are reported by care givers, families, service providers and music therapists. Feedback suggests that engaging carers in music-based interventions can help them to better understand residents. Further research is needed to help demonstrate behaviour change of carers and statistical significance of changes.*

Hsu et al. (2015)⁸⁸ have emphasised the **importance of involving caregivers in the provision of psychosocial interventions for people with dementia**. An intervention of one-to-one music therapy for care home residents with dementia was accompanied by weekly training video presentations to employees showing clips from the interventions. Employees were then encouraged to apply learning in their own daily practice. Qualitative feedback indicated improvements and changes in care-giving, as carers felt they had gained a greater understanding of their residents.

Participant 1: ‘I would be singing, saying, (sings) ‘We’re going to get you washed, here we go today’ and then I’d start into a song, using their name, like... (sings) ‘Come on then G [resident], we’re going to go G, let’s get ready and we’ll get washed’ (laughs). And then G would then look and she’d give a little smile. So it’s like a communication that you never knew you had.’

However, the study was unable to produce statistically significant results for the carers, likely due to the low sample sizes involved. Hsu et al. call for further research in this field to support their early findings.

Meanwhile, Melhuish et al. (2015) have also looked at the impact of music therapy and dance movement therapy interventions on carers. The authors conclude that using **both interventions can help care staff to better understand their residents**, and can help care staff to provide a meaningful caring environment.

Palliative care and end of life care

- *There is a paucity of studies relating to the use of music in the palliative and end of life care of people with dementia.*
- *Qualitative evidence suggests that music therapy in end of life care may help to minimise anxiety and discomfort, but a lack of quantitative data makes generalisations about the value of music near-impossible.*

As outlined by Marie Curie, *'Palliative care is for people living with a terminal illness where a cure is no longer possible.... It's also for people who have a complex illness and need their symptoms controlled. Although these people usually have an advanced, progressive condition, this isn't always the case... It includes caring for people who are nearing the end of life. This is called end of life care.'*⁸⁹

Given the relative paucity of studies (and in particular meta-reviews) relating specifically to music-based interventions in the end of life care of people with dementia, it is useful to draw on a broader end of life care (EOLC) literature base. Hilliard, in his 2005 empirical review⁹⁰ of the evidence of music in EOLC, highlights that *'the primary goal of palliative care is to promote patients' quality of life by alleviating physiological, psychological, social and spiritual distress, and improving comfort.'*

Hilliard states that there are some rich qualitative studies on music therapy in EOLC but that, generally-speaking, quantitative data are extremely limited. In his review of the evidence, Hilliard found some evidence to suggest that music exerts a limited ability to minimise anxiety for people with a terminal illness. He also highlighted that music therapy could help to minimise discomfort, could help to improve spiritual wellbeing and quality of life. However, there is a lack of robust data supporting these findings and quantitative studies need to exercise higher levels of control (e.g. controlling for diagnosis) and randomization of subjects. Hilliard also comments that studies should consistently use reliable outcomes tools designed for use with terminally ill patients, as well as urging for larger sample sizes to be included in future studies.

The research base has been moving forwards since this 2005 review, for example including a study⁹¹ currently underway and being conducted by Marie Curie Northern Ireland⁹² and Every Day Harmony⁹³. Whilst this study is not specifically dementia based, it nevertheless demonstrates that further research is underway in understanding the value of music-based interventions at the end of a person's life. The study *'will focus on 52 palliative care patients at the Marie Curie Hospice. Around half will receive a three-week programme of music therapy in addition to standard care. The other half will receive standard palliative care. The music therapy will be offered twice weekly.'* This will act as a feasibility study in order to determine whether or not a fuller study should take place.

Meanwhile, Adrienne Freeman is a researcher seeking to investigate the benefits of music therapy for people with advanced dementia, for example by highlighting the beneficial sensory properties of holding instruments in promoting non-verbal engagement and reducing isolation, and exploring the value of music therapy in the last hours of life in an NHS setting⁹⁴. Overall, however, research in this field appears to be limited to date. Hilliard's comments and recommendations, whilst not specifically-related to dementia EOLC, nonetheless provide useful recommendations for future research. Qualitative studies, whilst highly valuable in illustrating potential benefits, cannot be sufficiently generalised. More research for EOLC of people with dementia, along the lines outlined above, would be useful in developing this research area.

CHAPTER 6: BARRIERS AND CHALLENGES

System-level barriers and challenges

Lack of real traction in the policy environment

Music-based interventions in national dementia policies

References to music-based interventions for people with dementia in policy documentation is tentative. The Department of Health's 2009 national [English] strategy for living well with dementia⁹⁵ made a small reference to arts therapies, stating that '*...the provision of therapeutic activities within care homes, such as art therapy, music therapy or drama therapy, may have a useful role in enabling a good-quality social environment and the possibility for self-expression where the individuality of the residents is respected.*' Given the length and complexity of the strategy, one worries that this single reference could effectively be lost or disregarded by many readers.

Meanwhile, the Welsh Government's Strategy for Older People in Wales 2013-23⁹⁶ advocates lifelong learning, including the arts, although this is not dementia-specific. Meanwhile, Northern Ireland Executive's Active Ageing Strategy 2016-21⁹⁷ mentions that older people should have access to cultural resources, but falls short of formally recognising the value of arts participation. Scotland's action plan on ageing for 2014-16⁹⁸ perhaps went the furthest in advocating the value of the arts. The plan included a section dedicated to the arts and cultural activities, acknowledging the benefits of the arts in improving and maintaining health and physical and mental health. It also advocated the promotion of local and national arts festivals and cultural activities for older people.

NICE's dementia pathway (last updated September 2017) provides an overview of recommended dementia interventions⁹⁹. Whilst music is noted as an option, it is not specifically highlighted for its unique value. Three areas of intervention are outlined:

- Interventions for cognitive symptoms and maintenance of function: NICE highlight that cognitive stimulation programmes should be offered and note that these can include (but are not limited to) the **use of sound and music**.
- Interventions for non-cognitive symptoms and behaviours that challenge: NICE emphasises that non-pharmacological interventions should act as a professional's first-port-of-call, recommending a wide range of options such as aromatherapy, multi-sensory stimulation, **therapeutic use of music/dancing**, animal-assisted therapy, and massage.
- Interventions for comorbid emotional disorder: Alongside drug therapies, NICE recommend reminiscence therapy, multisensory stimulation, animal-assisted therapy and exercise. Again, **music and sound** can form a part of multisensory stimulation.

Meanwhile, due to a lack of robust and convincing evidence, NICE guidelines *on Interventions to delay or prevent onset of dementia, disability and frailty*¹⁰⁰ have not specified music as a recommended means to help prevent the onset of dementia. Professor Gillian Leng¹⁰¹, in oral evidence to the Commission, concluded that until more robust evidence is made available, NICE will be unable to make more concrete recommendations. **NICE will be updating their dementia guidelines during 2018, creating a potentially key opportunity for this sector.**

Speaking generally, music is not often featured in mainstream dialogues about dementia. Whilst there is a proactive, passionate and engaged core of music therapists, researchers, charities, volunteers and funders dedicated to the issue, the topic has not yet gained the requisite traction to become a fundamental feature of conversations about dementia. Increasingly, awareness of the power of music and its links to memory are becoming part of public discourse. The recent Radio 3 three-day feature as a part of the Wellcome Collection's 22-month Created Out of Mind residency¹⁰² is one such example of raising the profile of the subject matter by presenting it in an easily accessible and engaging format.

The APPG on Arts, Health and Wellbeing (launched January 2014) has also taken considerable steps in raising the profile of integrating the arts into health commissioning for people of all ages. Their 2017 report, *Creative Health: The Arts for Health and Wellbeing*¹⁰³, has received a good degree of press coverage¹⁰⁴, demonstrating the widespread impact of the report and its message. The Commission are hopeful that the present report and recommendations can seek to build on and strengthen this positive

platform with a more tailored and specific look at dementia and music, which formed just one element of the APPG's report.

Music-based interventions in local agendas

One way in which this subject could gain further traction in mainstream discourse could be by engaging local governments in the topic, thereby generating greater awareness and traction. A Baring Foundation report¹⁰⁵ examined the position of local authorities in securing a creative and healthy later life for their populations. The report noted that local authorities have responsibilities for local arts, public health and wellbeing, social inclusion, community cohesion and older people's services. As such, they could play an important role in joining together services and provision, in order to widen the availability of arts provision for older people.

Whilst not specifically focussed on dementia, the report concludes that developing an arts offer for older people is a good way for local authorities to deliver key policies such as prevention, and to support older people continuing to live at home. The authors argue that there is potential for leveraging the value brought by the arts, thereby helping social care services run better, for example by improving the working environment and encouraging the retention of care home employees.

However, the report also concludes that (despite some examples of good practice¹⁰⁶), most local authorities are yet to fully engage with and recognise the potential of older people and the arts. There are gaps in coordination and delivery here which could provide useful opportunities for embedding and expanding music-based offers.

Some important features of the local authority landscape include:

- **Public Health Directors**, who have a statutory place on **Health and Wellbeing Boards**. The latter identify local needs through Joint Strategic Needs Assessments, important tools for local authorities to advise and influence Clinical Commissioning Groups (CCGs). Any work in developing the music offer for people with dementia could be supported through the engagement of both Directors and Boards.
- The **National Arts and Health Alliance**, launched in 2012, has been formed to promote the issue of arts for older people, and they have coordinated the recent APPG report on Arts, Health and Wellbeing¹⁰⁷. The Alliance is governed by a board of trustees made up of representatives from nine regional organisations, emphasising the role of local areas and regions in planning for arts-based services. The presence of a national body, with regional arms and influence, will be highly valuable in championing this area of work, and could help to unite and centralise some of the more disparate strands of existing work and provision.
- **Arts Council England** has commissioned a consortium, led by the **National Council of Voluntary Organisations**, to undertake a broad look at 'cultural commissioning' including health and public health.
- Many local authorities have **local dementia strategies**; in 2011, the Department of Health published a paper¹⁰⁸ drawing out good practice from around England and reflecting the local work underway to help support the delivery of the 2009 National Dementia Strategy. Moving forwards, integrating new and existing music-based projects and activities into new and existing dementia strategies (where this has not already been done) will offer an effective way to frame the work being done in the field.
- Several local authorities have become **Dementia Friendly Communities**, another avenue through which arts-based provision can be envisaged and delivered. Ensuring that music clubs, choirs, orchestras, music shops, performance venues and specific shows/performances are made 'dementia friendly' could offer a valuable way of integrating the lives of those with and without dementia, through a shared love of music.

Data collation and centralisation

In order to make reliable estimates of the cost-benefit of music-based interventions, and to compare to other interventions, medications and therapies, it will be necessary to centrally collect data on what is being provided across the country, the content of provision and its scale.

ILC-UK requested such information from the Local Government Association (LGA) through the statutory duty of local authorities to establish and maintain information and advice services relating to care and support for adults and carers, under the Care Act 2014. ILC-UK queried the availability of a centralised

database summarising provision of music-based interventions for people with dementia in localities. A centralised record of locally-available care support services (including for people with dementia) is not currently an area of work undertaken by the LGA.

Meanwhile, the Alzheimer's Society is making significant progress in establishing a database of local provision of dementia-friendly services through their Dementia Connect tool¹⁰⁹. Whilst this will undoubtedly prove to be a highly useful tool for people with dementia and their carers and loved ones, it does not provide a sufficient coverage or the right level of detail to be used for research purposes such as cost-benefit analysis and extrapolation at this stage. This ambition also, understandably, falls outside the remit and intention of such a tool.

A more formalised process of data collection (for research and commissioning purposes) will be required in order to develop this agenda further.

Funding

As highlighted in one written evidence submission, when asked about barriers many respondents' thoughts turned immediately to one common issue: *'Funding. This is probably the second and third reason as well, because people often won't think beyond "we can't afford it" even when funding options exist'*¹¹⁰.

Funding requirements for music-based activity sit within a broader landscape of budget-cuts and belt-tightening, as highlighted in oral evidence from Councillor Gillian Ford in the Commission's second oral evidence session. Councillor Ford cited an existing local authority funding gap of £1.3 billion, due to reach £2.3 billion by 2020¹¹¹. As highlighted by The King's Fund, squeezed budgets are also being experienced by the Department of Health: *'Though funding for the Department of Health continues to grow, the rate of growth has slowed considerably compared to historical trends. The Department of Health budget will grow by 1.1 per cent in real terms between 2009/10 and 2020/21 under current spending plans. This is far below the long-term average increases in health spending of approximately 4 per cent a year (above inflation) since the NHS was established. Under current plans, health spending per person in England will fall in real terms in 2018/19 and 2019/20'*¹¹².

Likewise, various funding gaps for music provision were highlighted in written evidence submissions, including funding for training employees, for transport, and for music therapists. It is challenging to understand where funding can and will come from in the coming years, placing pressure on the sector to define unit costs, demonstrate cost-effectiveness and highlight the potential for music in saving money for the public sector.

The absence of evidence of cost-effectiveness has been widely discussed in this field. Meanwhile, some respondents to the call for written evidence mentioned concerns that even when funding is made available, priority is often given to the larger organisations and charities. Others highlighted the 'patchy' nature of funding, both over time and across different regions.

The two oral evidence sessions highlighted the issue of funding at several points, making clear that there are funding restrictions at almost every step of the way, from care homes, to local authorities, to national bodies and charities. As highlighted by Professor Gillian Leng, Deputy Chief Executive of NICE, evidence-generation in this field should focus on the cost-effectiveness of music-based interventions in order to generate further funding.

Challenge of defining incurred costs

Whilst some organisations responding to the Commission's call for written evidence could demonstrate their own organisation's costs, applying and extrapolating these costs at a national level is near-impossible and unlikely to garner reliable data.

This is because, given the lack of nationally-collated data on delivery content, methods and scale, it is very difficult to estimate (to any reasonable degree of confidence) national 'unit' costs for different types of delivery. Where programme-level costs can be provided, these are inherently linked directly to the type of provision described; given the high variation in provision, it is not possible to apply programme-level costs in any meaningful way to other projects and activities.

There is one exception to this. The one area of delivery in which there are established and regulated unit costs is in NHS/social care-funded music therapy. Music therapists are ranked as Band 7 on the NHS Agenda for Change 2017/18 pay scale. The annual salary of a music therapist employed by the NHS will range £31,696 to £41,787, translating into hourly rates of between £16.21 and £21.37¹¹³.

Again, however, there is variation. Some music therapists do not work for the NHS/social care services and their hourly fee will vary accordingly, although standards of delivery are still regulated. For example, a recent survey conducted by BAMT stated an average sessional rate of £50 for freelance music therapists. This will depend on the type of intervention being delivered and whether or not the therapist is being required to absorb overhead costs which would normally be covered by the employer.

Who pays?

The costs of music-based interventions are absorbed in a variety of ways. For example, some care homes will fund music-based interventions; funding may be provided through NHS continuing care budgets; some provision may be supported by local authorities, by charities and by philanthropic trusts; other expenses will be self-funded. Data is not currently available to demonstrate the numbers or proportions involved, however.

Live Music Now's (LMN) survey¹¹⁴ findings suggest that music budgets in care homes may be large as compared to other activities' budgets¹¹⁵. Music budgets in the surveyed homes were twice as big as for other activities, but still very small at around £100/month per home. Bearing in mind that LMN spend (as according to their written evidence submission) a total average unit cost of £280 for a single 60-minute session¹¹⁶, care home activity budgets are often too limited to deliver meaningful music provision. This unit cost may well offer good value per individual engaged (LMN cite an average of £11 per individual per session) and a fair fee for musicians. However, it still appears to be too steep for the amount set aside by care homes.

As highlighted in a piece of written evidence submitted by the spouse of a person with dementia¹¹⁷, sometimes the cost of music-based interventions falls to the family or to the individual themselves: *'I have to pay for his music therapy sessions & also buy age appropriate DVDs for him. So there is a cost implication I have to consider... I make access to all that is available'*.

Ultimately, expectations of who will pay for provision vary considerably and, whilst concrete data is not available to prove this definitively, it appears that experiences for people with dementia in accessing music will differ depending on where they live and their personal financial resources.

The need to demonstrate cost-effectiveness

Livingstone et al.'s 2014 study into the cost-effectiveness of different interventions in reducing agitation for people with dementia evaluated 11 interventions using the Cohen-Mansfield Agitation Inventory (CMAI) score. Types of intervention ranged widely in both scope and scale. The study found that the incremental cost per unit reduction in CMAI score ranged from £162 to £3,480 for interventions labelled as 'activities'. Meanwhile, the incremental cost per unit reduction in CMAI score was £4 for music therapy, £24 to £143 for sensory interventions, and £6 to £62 for training paid caregivers in person-centred care or communication skills with or without behavioural management training and Dementia Care Mapping (DCM)¹¹⁸. Whilst this study does suggest that music therapy may prove to be comparatively cost-effective in reducing agitation for people with dementia, the range in costs is concerning and could potentially lead to an overestimation of the cost-effectiveness of music therapy.

Moreover, early and emerging research suggests that the cost-effectiveness of music-based interventions is likely to depend on willingness to pay. Coulton et al. (2015)¹¹⁹ undertook an RCT comparing community group singing with usual activities for those aged 60 years or more¹²⁰. The total cost per session of group singing was estimated at £176.84 and the cost per participant over 14 sessions was estimated at £18.88. The group singing intervention was more costly than usual activities. The authors found:

- A cost-effectiveness acceptability curve indicated that the probability of the intervention being more cost-effective than the control activity tips at a willingness-to-pay of just under £15,000.
- In other words, in order for the group singing intervention to be deemed more cost-effective than the usual activity, the organiser (e.g. care home) would need to be willing to pay just under £15,000.

As highlighted in the Commission's second oral evidence session, the Allied Health Professions are currently developing cost-effectiveness outcomes tools for music-based interventions for people with dementia. These outcomes tools will aim to demonstrate outcome and impact cohesively and in a standardised way across studies.

Qualitatively, practitioners often speak about the potential for cascaded benefits of music. For example, practitioners speak of the positive impact that a music-based intervention may have on an individual's

spouse in terms of improved quality of life or improved mental health. Cost-effectiveness studies could provide additional value and accuracy by seeking to quantify the value (or social value) or these cascaded benefits, as well as those directly attributed to the recipient of the intervention. MHA, for example, has spoken of their experience of the ‘ripple effect’ – direct positive impact for the individuals receiving music, a positive impact on those around them such as relatives and care giving staff and a wider beneficial impact on the community of the whole home as symptoms are managed and minimised.

The importance of highlighting potential savings

Emerging evidence suggests that the provision of music-based interventions may help to reduce the use of some medications. Thomas et al. (2017)¹²¹ compared for the outcomes of a group of nursing home residents with dementia before and after implementation of an individualized music program. The intervention was designed to address BPSD; alongside measuring BPSD, the authors recorded the usage of anxiolytic and antipsychotic medication of the participants.

The study showed that the proportion of residents who discontinued antipsychotic medication use over a 6-month period increased from 17.6% to 20.1% for those receiving the music intervention. For those in the control group, usage of these medications did not change significantly.

The study does not compare the cost of the intervention to cost-savings from a reduction in medication, but further studies could explore this area in order to investigate the cost-effectiveness of music-based interventions compared to medication.

The sector will need to increasingly dedicate resources to demonstrate not only cost-effectiveness, but also the potential for demonstrating real savings. Without this crucial evidence, it will be an ongoing struggle to move music-based interventions up the agenda with commissioners and policy-makers, in an era of tightened-budgets.

Community-level challenges and barriers

Recognising the therapeutic potential of music

Some organisations and individuals already recognise the therapeutic potential of music and are proactive and leading and innovating in the sector, including many of those already mentioned throughout this report. However, both oral and written evidence submissions to the Commission have highlighted that this is not consistently the case, citing the often-prohibitive challenge of ensuring that music is recognised as a form of therapeutic intervention, rather than ‘just’ as entertainment. As mentioned by Live Music Now in a written evidence submission:

‘...actually the main barrier is probably attitudinal, i.e. that is to say that it is believed that music is merely entertainment, and a nice to have add-on, rather than an understanding that it can form a fundamental part of the way that a person centred care provision can be delivered, and a central part of the carers toolkit, as well as a means of benefiting relationships and supporting communication within settings’.¹²²

Key to overcoming misconceptions about the benefits of music will be education and training. If the therapeutic potential of music is more clearly explained to the public, demand will likely increase for provision. Meanwhile, for professionals such as care staff, a programme of awareness-raising and publicity could help to extend the message that music is more than entertainment and can be integrated meaningfully into care plans. As highlighted by Dr Claire Garabedian in her written evidence submission:

‘The attitudes of funders and staff – from the top down, needs to become more receptive to the value of music – for all involved. This can be achieved through dissemination, training, and active observation on the part of staff. There is also need for greater dissemination of the benefits of music with people who have dementia for medical professionals, care institutions, hospitals, hospices, and the general public’.¹²³

Awareness-raising is a key ambition of the Commission and of this report, both for a professional audience and amongst the general public. Without a well-designed campaign to reach out to both audiences, it will continue to be challenging to widely convince people that music can have important therapeutic benefits and outcomes.

Instilling confidence, enthusiasm and belief

Even when the therapeutic value of music is recognised, it can be challenging to instil the necessary confidence and enthusiasm for music in carers, family and friends of people with dementia. As highlighted by Kerr, Hardy and Marshall in their combined written evidence submission, *'in residential care and in the community people often think they are not musical enough'*¹²⁴.

The idea that a carer needs a high level of musical ability in order to deliver a music-based activity is not necessarily true; whilst some types of interventions are suited to delivery by trained professionals, others thrive when delivered by day-to-day carers. For example, singing during personal care or the use of personalised playlists can often be best undertaken by those who know the individual well and can judge the suitability of certain pieces of music and musical styles. Meanwhile, convincing carers that the individual would be able to take part and benefit can also often be a challenge: *'Some care home staff think people living with dementia are unable to do anything for themselves, this is often not the case. It is empowering to be able to do something, and to make music they gain instant feedback which is great for self esteem'*¹²⁵.

However, it is important to remember that, for many care homes and services, this is not the beginning of the journey and confidence and engagement has already been built over a number of years. As an example, one caregiver in an MHA home using music therapy stated: *'It lifts your mood as well – it's not just the resident. Like it lifts my mood, I love to see them come back from a session if they're really smiley and happy - or to hear them sing back to me when I'm singing a song.'* [Caregiver, quote provided by MHA]

Reaching the hard-to-reach

As with many interventions designed to support vulnerable individuals, reaching the most in-need is an inherent challenge to delivery. Identifying those individuals who may be the most socially-isolated, those with severe anxiety or depression, or those who are not receiving any statutory or voluntary support, can be very difficult. By the very nature of their lack of engagement with other forms of provision, these hardest-to-reach people with dementia rarely appear in datasets and are unlikely to be referred through the system until points of crisis. This challenge is not unique to music-based interventions, but nonetheless is an important issue to note. Therefore, whilst music therapists can and do work with vulnerable individuals, improvements could be made to ensure that the most in-need are able to access a range of music-based interventions, including those outside the more formalised NHS system.

In some areas, services are trialling new engagement methods such as through local area coordination¹²⁶ and care navigation¹²⁷. The ambition for these forms of intervention is to identify those hard-to-reach individuals who would benefit greatly from support, and link them to relevant services and provision in the local area. Those charities and organisations running music-based programmes and activities in the community should seek to engage with coordination activities such as these wherever possible, with the ambition to reach some of the most in-need individuals.

Reflecting and promoting diversity

Music is thought to be a feature of all cultures¹²⁸. It is an incredibly diverse medium, with different genres, tempos, timbres, instruments, heritage, meanings and connotations. Oft-mentioned by Commissioners, in evidence contributions and by audience members in oral evidence sessions, it is highly important that we recognise the need and right to musical diversity. Musical preferences and understanding vary not just by culture, but also by generation. Someone who was a young adult in the 1930s will likely have an entirely different musical repertoire and preferences to someone who was a teenager in the 1960s.

'I think it's important to remember the age group is changing and that "it's a long way to Tipperary" and other WW1 songs are now no longer appropriate to stimulate memories. Yet you often still hear them in some dementia settings. People now need the likes of Frank Sinatra, Elvis and the later singers such as ABBA etc. to stimulate their memories of going out to dances with their friends and loved ones.' [Age UK Trafford written evidence submission].

The challenge is to ensure that professionals are mindful and attentive to this diversity and engage with people with dementia in a way which is most suitable. In a written evidence submission, the Alzheimer's Society highlighted this by noting:

'There can be a perception that some music groups are not inclusive for all. Alzheimer's Society S4tB [Singing for the Brain] sessions are open for all, especially for someone who identifies

with any of the protected characteristics under the Equalities Act. Based on local demand and where funding can be secured, we run community specific S4tB groups facilitated and led in languages other than English e.g. in Sylheti for the Bangladeshi community in Tower Hamlets, Greater London, funded by the Local Authority'¹²⁹.

As highlighted, the onus must be on the provider to accommodate for all people, languages and musical preferences. This brings with it the challenge to ensure that charities and organisations can staff sessions with volunteers or practitioners who are able to engage with the local community (be this in a community setting, or in a residential setting) by speaking the language and/or having the relevant knowledge and understanding of the local culture. Encouraging 'bottom-up' programme design is one way of trying to ensure that music-based activities embody diversity. Training is also highly important. Music therapists, for example, are trained to work across cultures and to utilise a range of musical styles; this comprises an integral element of music therapy qualifications.

CHAPTER 7: OPPORTUNITIES

Funding

Personal Health Budgets and Integrated Personal Commissioning

Personal Health Budgets (PHBs) and Integrated Personal Commissioning (IPC) can offer routes to personalised funding for people with dementia. Both programmes take existing statutory money and pool it into an individual budget which can then be used to purchase services and provision specifically chosen by the individual.

Currently, PHBs are largely offered to those adults who are eligible for Continuing Healthcare (CHC) funding. In 2015-16, almost 160,000 people received, or were assessed as eligible for, CHC funding in the year¹³⁰, reflecting that this funding provision is reserved for those with the most severe health needs. For those assessed as eligible for CHC, health and social care costs are paid for by their local CCG. For those deemed ineligible, the local authority and/or the individual (depending on their financial situation) may have to pay their social care costs instead.

Frail older people with conditions such as dementia and Parkinson's can be eligible for CHC funding and therefore also for PHB funding. Moreover, local areas in the UK are also being encouraged to consider offering PHBs to other patient groups who fall outside of the CHC funding criteria. An eligible person with dementia can use funding in a PHB to choose their support and therapies, meaning that they have a clear say over managing their condition(s). Music-based interventions can form part of this provision, and this is already the case in some areas. However, this opportunity for funding music-based interventions needs to be more widely advertised so that it is actively promoted and taken up.

The NHS Mandate has set an ambitious target that between 50,000 to 100,000 people will have a PHB by 2020/21.

In addition to PHBs, the IPC programme has been rolled out since 2015. Currently adopted by just a few CCGs, IPC aims to integrate health and social care spending into a single budget which can then be used in a similar way to a PHB. Participating CCGs have been permitted to choose their initial cohorts for roll-out; two CCGs (Lincolnshire and Luton) have specifically stated that people with dementia will form one of their target cohorts in the first instance. Whilst work is still underway to take the IPC project off the ground, IPC budgets could also offer an avenue for funding for music-based interventions.

Health and social care professionals, in particular GPs, could play a valuable role in promoting music-based interventions during care planning sessions. As highlighted in a written evidence submission from Dr Julia Jones, CEO, Found in Music, *'We believe that the NHS should make more efforts to encourage GP practices and all relevant NHS Trust teams at local level to accept offers of help from the local music ecosystem.'*

It should, however, be noted that PHB and IPC funding will remain reserved for those with the highest levels of health and social care need. It is not, therefore, feasible to consider that all or even most people with dementia will be able to use personalised statutory funding to access music-based interventions.

Other funding options

Given the dual pressures of tightly-constrained expenditure on statutory services alongside the increasing pressures of an ageing population, it appears unlikely that health or social care funding will stretch much further. Participants in oral evidence sessions and those submitting written evidence to the Commission tended to accept the limitations on statutory funding and demonstrated creativity in suggesting new avenues and opportunities for funding.

Some such examples included leveraging existing good practice and local resources. As mentioned by Councillor Gillian Ford at the second oral evidence session, there could be substantial value in expanding existing work on intergenerational projects utilising existing school and university music groups. Bringing local music venues on board and promoting the development of relationships between the private and voluntary sectors could also help to promote new partnerships which may not always require statutory input.

'A local special needs primary school comes to sing for our Drop in support users and this provides intergenerational activity using singing and allowing children with learning difficulties to share their love of music and enthusiasm with their audience who are always appreciative.' [St Andrews Parish Church of Scotland Carluke written evidence submission].

However, whilst local and central government bodies may not be able to directly fund provision (or this may be very limited), there can still be a valuable role played by local authorities and central bodies in coordinating activity, collecting data and in endorsing good practice. The potential value of this important role is emphasised throughout this report.

Meanwhile, private philanthropic individuals and organisations, such as The Utley Foundation, could play a valuable role in funding various strands of activity in this field moving forwards. This could take the form of both directly funding provision, utilising resources to leverage funding raising and also providing support and financial backing to awareness-raising activities and campaigns. Funders with an interest and commitment to music, the arts more generally, older people, and health and social care could all support work in testing and scaling initiatives, supporting proofs of concept, growing the evidence base and working to influence others. Philanthropists can also play a key role in unlocking funding from private sector organisation with an interest in this field, be that as a part of corporate social responsibility, or through a corporate interest such as in developing new technologies in this space.

Finally, innovative approaches to fundraising allow some care homes to offer music-based interventions where otherwise this might not have been possible. For example, MHA currently fundraises just over £500,000 per year for music therapy which is provided free to the residents living in the organisation's 60 care homes with a dementia care service. The current provision of music therapy is only meeting 25% of the actual need, and so MHA aspires to quadruple the current fundraised income to enable every resident in their care homes to have the opportunity to receive individual music therapy. Ensuring a broad base of funders appears to be a key way to ensure ongoing delivery. For example, Mindsong fundraises so that they can subsidise courses of music therapy for care homes and private individuals, and to provide its Meaningful Music Singing Groups. Raised funds range from small grants through to major philanthropic giving and individual giving. To support this, the charity will also soon contract through a CCG.

Training

Further embedding training for the 'everyday' use of music

Professional caregivers

Respondents to the Commission's call for written evidence emphasised the potential value in further embedding good music-based practice into carer training and day-to-day practice, expanding programmes and organisations already dedicated to this. A submission from Life Song references their own work in training carers to use music in a therapeutic way:

'Activity coordinators working in dementia care, have been trained through the Life Song programme, to use music as a therapeutic intervention in care homes... The two-part programme... trains staff who work with older people to effectively deliver therapeutic music and offer gentle touch, through The HEARTS Process¹³¹. It highlights how to use these supportive and relaxation techniques in everyday care as a group activity, one to one activity and passive listening; and in palliative and end of life care... Training staff who work in care homes, is a cost-effective way to enable music to be provided internally on a regular basis, to residents as part of their everyday care; as opposed to relying solely on external providers who visit on a less frequent basis and are less cost effective.' [Life Song written evidence submission].

In some settings, this appears to already be happening. In MHA care homes, for example *'therapists work closely with the care team to identify those most in need, and to share effective music therapy techniques for use in day-to-day care.'* [MHA written evidence submission]. Moreover, Playlist for Life deliver training in using personalised playlists for caregivers (both professional and unpaid).

However, some submissions called for greater consistency in training: *'one agreed upon and recognised form of training that ensures a basic knowledge of dementia, of nonverbal communication, of working within various institutional settings (care/nursing homes; hospitals; hospices; acute care settings; private homes)'* [Dr Claire Garabedian written evidence submission]. *'I think there is an opportunity for establishing standardised practice in regard to training and resources.'* [John McHugh, Music in Mind,

written evidence submission].

With the ambition of rolling out best practice in music-based provision to all residential, inpatient and community settings (including in the home), it would be valuable to bring together existing models and training guidance into a single, inclusive document for use by caregivers. This could draw on and integrate existing training recommendations which currently exists for different forms of intervention, and would therefore provide the caregiver with guidance about utilising music with people with dementia as the disease progresses. Endorsement of these nationally-relevant tools, for example by the NHS, Skills for Care and/or Skills for Health (and other relevant bodies) would be highly valuable in helping both the public and service commissioners to feel confident in the quality of the materials.

Such guidance could emphasise the potential for music to be used as a preventative tool and in managing behaviours that challenge, thereby helping carers to understand that music can act as a supportive tool, rather than as a burdensome addition to existing workloads.

Multi-disciplinary working

Likewise, training in the basic principles of therapeutic music should be extended to other specialists who may work with people with dementia, again ensuring the aforementioned consistency in approach. This could include occupational therapists, physiotherapists and nursing staff, alongside other specialists. By ensuring consistency and parity in training, multi-disciplinary working could be promoted to ensure rounded care for the individual.

Training for periodic and specialist interventions

Professional musicians

Professional musicians engaged in delivering music-based interventions for people with dementia equally require and deserve appropriate training. In particular, this should include suitable dementia-awareness training. This could build on recognised training already offered by universities and national charities and be adapted so that it is specifically suitable for the kinds of situations a musician might find themselves in.

Currently, given the multiplicity of interventions, there is no standardised or recommended course of training for musicians to undertake. Training for musicians (not music therapists) is delivered in varying ways by different charities and universities. Whilst instances of best practice can certainly be highlighted, this lack of consistency may lead to uncertainty around quality for service commissioners. It would be useful to map existing provision, be that relevant modules in undergraduate music degrees and their uptake (e.g. music for health, community musicianship, arts and health), or existing provision of training in the charity sector.

Nationally-endorsed training (again by bodies such as the NHS and Skills for Care), building on examples of best practice already demonstrated by the charity sector, would be highly valuable. This would help to assure service commissioners and care homes of the quality of an intervention, and will likewise ensure that musicians feel confident in delivering therapeutic music for people with dementia.

Meanwhile, reaching out to musicians and engaging them in music and dementia is highly important. Qualitatively, participants in the Commission's oral evidence sessions mentioned that there is not enough 'room on the stage' for everyone who graduates with a degree in music. Working with people with dementia should be further promoted at universities and colleges in order to emphasise the viability and enjoyment which can be had from this career path. As Evan Dawson highlighted in his oral evidence submission, however, paying a fair wage is crucial to this; without proper payment, rolling out more and larger programmes of delivery using professional musicians will continue to prove challenging.

Music therapists

Given the aforementioned limitations in funding, the working environment for music therapists will likely remain challenging over the coming years. Written evidence submissions have highlighted the potential for music therapists to further adopt a role as trainers and in cascading best practice and the principles of music therapy.

'Music therapists to be employed to provide training sessions for family carers and supervision sessions for less-experienced facilitators.' [Dr Orii McDermott written evidence submission]

Some organisations already work to link up music therapists with non-specialists to promote skill-sharing.

Moreover, this type of indirect role is also considered to be a part of a music therapist's job, even when employed by statutory services¹³². Designing training programmes, skill sharing and training, alongside work in delivering music therapy, enhances the everyday care of people with dementia. As noted during an oral evidence session, many music therapists do not work full-time and there is demand for more work from the sector. Making the most of a music therapist's role in training others, and continuing to include musicians and other colleagues in their work, could help to reach many more people with dementia than could be by specialist music therapy intervention alone, whilst also ensuring the continued value and support of the music therapy profession.

Signposting and referrals

Formalising the process through which people with dementia are referred to music-based interventions could prove to be a highly effective way to reach more people and to ensure a steady flow of participants to activities such as community choirs and other music groups. Whilst signposting routes are established in many settings, in particular in signposting to music therapy, these can be greatly improved and should include a wide range of activities and interventions.

‘Social prescribing and referral pathways from GPs and other health and social care providers should be put in place to alert people to their existence and offer “medical / health” opinions about the value of the services. Often ideas from GPs or other health care professionals are well received’. [Music in Mind submission].

Integrated working will be crucial in ensuring that the most vulnerable and in-need individuals can be referred to suitable music interventions and services, both within the statutory system and through voluntary and community organisations. Ongoing work in various local areas to integrate health and social care data systems will be highly valuable in identifying individuals who might benefit from targeted provision. Interventions can range widely in scope, from specifically designed programmes for the newly-diagnosed, to provision tailored to those with advanced dementia, including those still living in their own home. Trialled in many areas, social prescribers could offer valuable support for this process. Ultimately, a united focus and collective professional understanding of the value and potential of music will be pivotal in ensuring that signposting and referrals work smoothly.

Recent media attention

Undoubtedly, the message that music can be a powerful resource for dementia is starting to gain traction in mass media and amongst the public. A clear opportunity exists in capitalising on work already done in this field and promoting the message still further.

BBC Radio 3's recent weekend dedicated to music and the memory, delivered in partnership with the Wellcome Collection's Created out of Mind residency, has demonstrated the appetite for this topic amongst radio listeners. Meanwhile, several national newspapers have covered projects and pieces of research in this field, including The Guardian recently promoting the conclusions and recommendations of the *Creative Health* (2017) report from the APPG on Arts, Health and Wellbeing¹³³. Meanwhile, The Guardian also featured a Day in the Life of a Music Therapist¹³⁴ article in 2015, helping to awareness of the role amongst the general public.

The potential exists for a high profile, national campaign bringing all sectors together in order to promote a unified message of the individual's right to music and the powerful effect that music can have on people with dementia. Such a campaign could unite the health and social care sectors, care homes, people with dementia and their loved ones, charities, trusts and foundations, the policy world, researchers, and parliament. In particular, the expertise and gravitas of the music industry could be leveraged in order to help promote the message and create valuable new working partnerships across sector. The impact of such a campaign could well be considerable in changing the existing landscape and in moving the debate forwards.

The broader landscape

Continuing work to ensure that society is becoming ever-more dementia-friendly should help to encourage the idea that music-based interventions do not necessarily need to be dementia-specific, especially for those with mild-to-moderate dementia. Pursuing a welcoming and inclusive society for people with dementia will help to avoid stigmatisation and ensure that people with dementia are able to continue being active and valued members of the community.

Enveloping and promoting local work already underway, regional networks (overseen potentially by a

national umbrella network) could be set up to bring together lines of work and provision. These regional networks could be developed in a similar way to the existing Dementia, Arts and Wellbeing Network (DAWN)¹³⁵, a University of Nottingham innovation group, funded by the Arts and Humanities Research Council. Such groups would not necessarily need to be based in Universities, however, and should be inclusive to all forms of regional delivery in order to promote interconnectedness and multi-disciplinary working. These networks could offer support to practitioners, raise the profile of work in the field, and promote mutual learning and collective power.

Evaluation

Alongside the potential for establishing best practice in training, there is also an opportunity to do so with programme evaluation. In order to further promote music, in particular amongst members of the public and care homes, establishing and utilising a standardised evaluation practice could offer a valuable way for quality and value for money to be assessed. In order to reflect the diversity of provision, it would be useful to create different ‘tiers’ of evaluation best practice. This would mean that smaller organisations and charities could undertake evaluation activities which would be feasible in terms of overall programme expenditure, and organisation size and capabilities. For example, whilst evaluation is a fairly standard part of delivery for some music therapy programmes, particularly those commissioned by NHS Trusts, it is not the case for many other forms of intervention.

One useful way to promote cohesive evaluation practices would be for different organisations to use standardised outcomes tools. Moreover, best practice evaluation guidelines for music-based interventions could be endorsed by governmental bodies and departments, in order to add weight.

Technology

Emerging technologies, combined with creativity and a passion for music, offer a huge number of opportunities for this field of work. As already discussed, the use of digital music is a growing area. It is popular with many due to its relative affordability, the fact that it can be used at any time, anywhere, and its replicability. Harnessing new types of technology could mean using virtual reality to simulate watching an orchestra perform, or being at a concert. Exciting developments could be made in this field if technology companies and the music industry are brought on board, with a shared commitment to improving the lives of people living with dementia and a mutual interest in making music and musical experiences more accessible.

Moreover, technology can offer a relatively affordable option for those who want to help people with dementia to access a vast array of music. As cited by Playlist for Life in written submission, it currently costs £250 in year one and £120 in subsequent years to provide a person with dementia with limitless music, through providing hardware and access to Playlist for Life and Spotify services. If music publishers and streaming platforms were able to make music available for free or at a reduced price, this could help to considerably lessen the price and make music available for all.

Developments in this field are rapid. Those working in the dementia and music space could benefit from the cross-fertilisation of ideas, for example by raising relevant issues at the newly-formed APPG on Artificial Intelligence, or by engaging with specialist technology companies.

CHAPTER 8: CONCLUSIONS AND RECOMMENDATIONS

Conclusions

The field is currently characterised by **devoted advocates operating in a complex and poorly coordinated ecosystem**. The dementia and music environment is supported by a dedicated network of individuals and organisations, looking to grow the sector and keen for pragmatic options and recommendations to take this field of work forwards. However, an historic lack of coordination has made the ecosystem sporadic and complex, with different providers and specialists often operating in silos and without a good understanding of what else is available and how different lines of work should or could fit together. Accessing information and provision is currently unduly difficult due to a lack of formalised local information for the public to use. Moreover, there is currently no oversight over provision due to a lack of centralised data.

As such, **the field is defined by sporadic provision which is currently delivered only to the few**. Educated estimates suggest that very few people currently receive the full range of music options and support. This is likely due to multiple reasons, including a lack of public understanding about the benefits of music, the high cost (or perceived high cost) of some types of intervention and the lack of a centralised overview of current provision. Furthermore, it is difficult to ascertain with any certainty exactly what proportion of people with dementia have access to music, largely due to the sporadic nature of delivery and a lack of cohesive data and information.

However, **the sector is supported by a promising evidence base which is gaining traction**. A growing research base, spanning some twenty to thirty years, is beginning to demonstrate the range of benefits of music for people with dementia. The use of more rigorous research methodologies, such as increased use of randomised control trials (RCTs) and other quantitative methodologies, would help to improve the credibility of the research. The inclusion of larger sample sizes, wherever possible, would also help researchers to draw more robust conclusions. However, the value of qualitative and mixed-methods methodologies should be better recognised and valued, in particular given the unfeasibility of producing large-scale RCTs which might be expected in the testing of other forms of intervention such as drugs trials. Future studies should examine issues and variables including: type of dementia, method of delivery, longevity of impact, impact on carers and loved ones, prevention of onset, and impact during end of life care.

The sector struggles with **minimal levels of funding and squeezed budgets**. Further developing **cost-effectiveness research** could be a critical factor in boosting recognition and funding. Statutory budgets, both of central and local governments, are currently tightly restricted and are likely to continue to be closely monitored in the coming years. This is combined with health and social care pressures associated with an ageing population. In this light, those dedicated to dementia and music need first-and-foremost to focus on providing convincing cost-effectiveness evidence in order to be granted funding. Embedding cost-benefit analysis into programme-level evaluations would be a good way to promote the collation of evidence. Developing best practice recommendations for evaluations in this field, and using a tiered system to help smaller charities and organisations to understand how to evaluate within their means, would help greatly in this. Innovative practice in fundraising and skill-sharing will also be valuable in expanding this area of work.

A low level of public awareness is another area which needs to be addressed in order to maximise the potential of this field of work. As yet, the range of benefits that music can offer people with dementia appears to have not yet reached the general public. The value of music for people with dementia should be more clearly expressed in public-facing literature. This includes advice and guidance distributed by both central and local government, alongside materials created and shared by the health & social care sector, voluntary organisations, care homes, arts organisations and all other relevant bodies and organisations. Undertaking a large-scale PR campaign could help to raise awareness, win over hearts-and-minds and ensure an increased demand for music-based interventions for people with dementia. Adopting a clear message that 'music helps', and a strategy to support this, would undoubtedly help in improving dementia care.

Recommendations

Recommendation	Ask	Associated stakeholder(s)
Coordinate delivery and build intelligence	<p>An independent, non-political, high profile Ambassador for Dementia and Music needs to emerge as a leader in the field. Utilising a substantial budget, sourced from a mix of charitable, philanthropic and private funding, the Ambassador should lead a dedicated task force to deliver transformational change in music access for people with dementia and their carers. With an ambitious campaigning agenda to ensure the effective co-ordination of national and regional activities, co-opting the efforts of the music industry with the arts sector and new technologies.</p> <ul style="list-style-type: none"> • The Ambassador and task force should be able to speak for and to all strands of work across all sectors. • The Ambassador and task force should work with various sectors, to ensure universal access to music for people with dementia, for example free or subsidised music downloads for people with dementia. 	<p>Music and dementia sector</p>
	<p>We need clearer local offers of activities and interventions for people with dementia, including in residential settings</p> <ul style="list-style-type: none"> • To include music-based interventions • To follow a consistent format between local areas 	<p>Local authorities</p>
	<p>We need a national framework to collate information from local offers, generated into a centralised database summarising local provision for people with dementia</p> <ul style="list-style-type: none"> • This should include music-based provision • Data should be made publicly-available 	<p>Local Government Association</p>
	<p>In the meantime, all providers of music-based interventions should register their provision through the Alzheimer’s Society’s Dementia Connect tool</p>	<p>Music and dementia sector</p>
	<p>The dementia and music sector should work to coordinate, unifying and further develop tool kits and training guides to enable new practitioners to develop necessary skills. The resources should reflect and draw together best practice from a range of existing programmes, thereby acting as conclusive guides. Endorsement should be sought from recognised bodies (e.g. NHS England, CQC, Skills for Care, Skills for Health)</p>	<p>Music and dementia sector</p>

Develop the research base	NICE's upcoming review of the dementia care guidelines (2018) is imminent. It will not be feasible for researchers to produce a wealth of new evidence ahead of this review. Instead, researchers should focus efforts on proving the cost-effectiveness of music-based interventions. This will be crucial in the ongoing development of the field.	Academics Music and dementia sector
	Other important areas in which to develop the research base are: <ul style="list-style-type: none"> Continuing to propose new research studies, using randomised control trials wherever practical and feasible Clearly voice the challenges inherent in undertaking RCTs with target cohorts, and propose studies which best suit the interventions in question, be that mixed-methods, non-randomised, qualitative etc 	Academics Music and dementia sector
	Meanwhile, we encourage NICE evidence reviewers to: <ul style="list-style-type: none"> Question the burden of proof, both considering challenges and feasibility of RCTs with target cohorts and the inherent costs involved in such studies Value the existing research base and reflect this in the new dementia care guidelines Continue to provide constructive advice to researchers in this field about building good-quality evidence in this sector 	Non-departmental public bodies (NICE)
Raise public awareness	All relevant organisations must ensure that public-facing advice and guidance clearly highlights the value of music for people with dementia	Central and local government Health & social care sector Government Voluntary organisations Care homes Arts organisations The music industry Any/all other relevant organisations

	<p>A national campaign should be launched to recognise the value of music for people with dementia, capitalising on recent media attention</p> <ul style="list-style-type: none"> • Engaging, approachable and informative mass media • Utilising varied platforms (e.g. television, social media, radio, public events, performances, festivals) 	<p>Voluntary organisations Care homes Professional bodies Philanthropic trusts and foundations The music industry Arts organisations Lobbyists Think tanks Health & social care sector Government Parliament Celebrities and high-profile figures Academics Music and arts festivals (e.g. the Proms, Glastonbury) Any/all other relevant organisations</p>
Coordinate and grow funding	<p>Philanthropic trusts and private sector organisations should leverage their collective networks and funding to pioneer work in this area; this topic provides an opportunity for philanthropists to make a tangible difference and develop new schemes of work</p>	<p>Philanthropic trusts and foundations Private sector organisations</p>
	<p>We propose the roll-out of integrated personal budgets to people with dementia</p>	<p>NHS</p>
	<p>We call for the recognition and promotion of music for people with dementia, including through personal health budgets and integrated personal budgets</p> <ul style="list-style-type: none"> • The therapeutic potential of music should be specifically recognised 	<p>NHS CCGs Local authorities</p>
	<p>Service commissioners must take music-based interventions for people with dementia seriously when planning both preventative and dementia care services</p> <ul style="list-style-type: none"> • This should be reflected in funding allocations 	<p>Local authorities CCGs</p>
	<p>Where directly funding provision is not possible or practical, we call on statutory services to play a role in better coordinating and supporting work in this sector, in order to support delivery by others</p> <ul style="list-style-type: none"> • This would include liaising with the proposed task force on dementia and music 	<p>Voluntary sector Statutory services</p>

Make the best use of technology	We need a consensus on the clear potential of digital interventions in this field and a celebration of their unique value, alongside the benefits brought by other forms of music-based interventions	Music and dementia sector
	Given the relative affordability of digital interventions, we want all people with dementia to be able to access interventions such as (but not limited to) Playlist for Life by 2020 <ul style="list-style-type: none"> It currently costs £250 in year one and £120 in subsequent years to provide a person with dementia with limitless music, through providing hardware and access to Playlist for Life and Spotify services. If music publishers and streaming platforms could make music available for free or at a reduced price for people with dementia, this could help to considerably lessen the price and make music available for all. 	Music and dementia sector Music industry
	We call for ongoing creativity in deciding how technology can support dementia and music. Urging engaged organisations and individuals to explore the value which can be derived from new and emerging technologies e.g. virtual reality and artificial intelligence	Music and dementia sector Technology companies of all sizes Music industry
	We want the dementia and music sector to build strong and mutually beneficial relationships with major technology companies and start-ups	Music and dementia sector Technology companies of all sizes The music industry Philanthropic trusts and foundations
Support individuals to find the right intervention at the right time	We want the proposed task force on dementia and music to create and roll-out a clear, public-facing tool or 'roadmap' designed to help explain which interventions might be more suitable for a person with dementia as the disease progresses <ul style="list-style-type: none"> This should be informed by the evidence base but easily understood by non-expert audiences It should include, where possible, different strands and emphases depending on variables such as type of dementia, age, ethnicity, comorbidities etc. 	Music and dementia sector Think tanks Academics Philanthropic trusts and foundations

CHAPTER 9: A SNAPSHOT OF MUSIC AND DEMENTIA IN PRACTICE

Beatie Wolfe

*This case study comes from the partnership between **The Utley Foundation and Beatie Wolfe**, who began looking at the therapeutic power of music for dementia patients in 2014. The partnership observed ground level impact working in care homes as well as broader, awareness raising initiatives like the Music and Dementia Festival, held in August 2017.*

Influenced and united by the work of neurologist Oliver Sacks, in late 2014 and early 2015, the artist Beatie Wolfe teamed up with the former Marketing Director of HSBC, 20/20 Research & the Priory Group to conduct a 4-month research tour looking at the ‘Power of Music’ for people living with dementia, funded by The Utley Foundation. Beatie Wolfe performed her original music at a series of Priory Group care homes across the UK while responses were monitored both during the live performance and in the weeks following as the same patients listened to Beatie’s music on headsets. The care home tour was spread over three months, reaching four homes and 40 residents. There was a detailed pre-assessment for each selected dementia resident as well as live performance observation and 6 post-performance questionnaires. Beatie worked to select popular music alongside her own original pieces to perform for the patients. The post-assessment of each dementia patient, alongside the questionnaires, drew out interesting qualitative and quantitative initial outcomes.



This study was, at the time of testing, the first of its kind to test the positive impact of previously unknown music. Beatie’s work with these patients, through the power of music, improved both memory and communication significantly. Over 72% of patients responded positively; clapping, singing along and tapping. Carers noted clear positive behavior changes across several key areas; response and interaction, relaxation, singing and movement and dancing. The pre- and post-assessments allowed short and longer-term improvements to be monitored across the project. Carers reported that even at the mid-project point there were significant improvement in the patient’s level of worry, memory and communication. These changes remained evident after Beatie’s performance, and even after the study had concluded.

There were some heart-warming personal stories as a result of the study. Anne, who had not spoken in seven months, started singing along with great volume to songs that she had never heard before. David’s family had stopped visiting because it was too difficult to see him inert and out of it. The carers were hopeful that the music would produce some sign of engagement that they could share with David’s family to say, “he’s still here”. Before the music began nothing could rouse David, then within the first few bars of the first song, David’s arm started to move in perfect time to the music. Then his eyes widened. Later in the set he got up and he danced. Edna was besides herself with grief, feeling “worthless” and alone in a room full of people. At the start of the music she sat sobbing uncontrollably but during the performance she quickly found her confidence and transformed into a joyful state, clapping and singing along.

This pilot study has been called “profound” and “a first of its kind” by The Times, “a musical miracle” by The Independent, “ground-breaking” by BBC Radio 4 and “inspiring” by WIRED. As a result, Beatie was invited to present at DLD Health in Munich, Social Innovation Summit in Silicon Valley (in the process met Stephen Friend), WIRED’s Conference in London, The Royal Institution, UCSD, Berklee Music College and Apple’s HQ theatre.

Live Music Now

This case study comes from an Arts Council England funded project called New Age Music delivered by Live Music Now (LMN) in partnership with The Orders of St John Care Trust (OSJCT) and Creative Inspiration CIC, in 2016 and 2017. Trained professional musicians from LMN visited 12 OSJCT settings for older people to deliver music residencies. This case study focuses on the experience of a resident, Fred, who was diagnosed with Alzheimer's in December 2014, and was written by Stephen Moore, Activities Co-ordinator at Westbury Court.



Westbury Court provides a mix of nursing, respite and residential care. As with other homes, we have many residents that have diagnosed and undiagnosed dementias, residents with restricted physical capability and also residents who suffer with lower motivation and confidence.

When we were offered the opportunity to be involved in Live Music Now's programme, we were very excited. Over 12 weeks, LMN musicians Sadie Fleming and Julia Turner became friends and welcome guests with our home. The sessions were divided into, firstly, a performance to our residents and, secondly, involving residents in music making.

Fred was one of a group of residents who were regularly involved in the LMN sessions. Fred had been with us a month or two prior to the sessions commencing and had been a little unsettled and tended not to enjoy noisy group activity. He was an intelligent, articulate and talented man and had always enjoyed good music, having taught keyboard playing with the Yamaha School of Music.

Initially Fred was saying that he had not played keyboard for years and that he didn't feel he would be able to now. As Fred relaxed, he began to respond with his great sense of humour to the music. He would respond to the end of songs with his "trademark hook"; "dum dum de dum dum, dum dum"!

At the start, he appreciated the performance but was reserved about participating, but Sadie was able to tease him into action by playing the flourish on her keyboard. As Fred began to use the iPad tablet interface with a music making app, he was saying that, "at last, he was famous", as he saw his own image appear on the screen. Playing the mini iPad keyboard and getting a tune from it encouraged Fred and soon he was happy to play the keyboard, often accompanying the singing by other residents, playing along with Sadie and Julia and improvising. When his daughter witnessed him playing the keyboard again, she was moved to tears of joy! Fred was enjoying himself and achieving satisfaction.

Some staff were initially reserved but seeing Fred and others having so much fun and being within such relaxing space, had a great effect on everyone. Staff were encouraged to overcome their nerves and get involved. Fred undoubtedly became happier and more fulfilled after the sessions. He seemed to regain a spark, he was more focussed and was seen to play the piano in our pink lounge without encouragement. Fred, sadly, passed away recently. We have a recording of the performances he was involved in and that is now even more precious when we replay it.

Playlist for Life

Paula Bain is a Training Officer with Playlist for Life, a charity that helps people with dementia, their families and carers to use personal playlists, often on iPods or mp3s, and harness the benefits of music in their lives on a daily basis. Paula is 44 with 2 children. She unashamedly includes 'I Won't Let The Sun Go Down On Me' by Nik Kershaw on her playlist for life.

One of the things I love about my job is the variety – no two days are the same. I might start the day with a phone enquiry from a Care Home Manager or someone in the NHS who has received a leaflet or heard someone talk about Playlist for Life. I think people are attracted by the fact that Playlist for Life uses the music that people already



love. It's something we all have and something we can all do. We teach people Music Detective skills to find the right music for someone with dementia and then how to schedule listening sessions to harness its effects.

I manage our UK network of sessional trainers, so once someone has booked their training I match them up with one of our trainers. I like it in the training when I show our films of people listening to their personal music. It's a penny-drop moment about the power the right music can have and there's rarely a dry eye. And I like the planning section, when the carers start working out how to implement Playlist after the training and they begin to unlock their creativity.

My favourite bit of my job is probably doing the follow up visit to care homes and hospital wards who are working towards being certified in using Playlist. Most homes turn this into a really special day. There might be bunting and cakes, and very often the home invites family members and residents, and even the local paper, so that everyone is involved in celebrating the achievement. I've done lots of these now and they are all amazing. What shines through is the way that Playlist empowers staff to be genuinely person-centred in their care.

Last week, a carer told us of a woman who was completely 'locked in' – she wouldn't speak and rarely came out of her room. Her son had stopped visiting because he found it so distressing. The home contacted the son as part of the Music Detective process and he said his mum used to sing 10 Green Bottles when they were out in the car. So later the carer started to sing 10 Green Bottles and the woman instantly opened her eyes and began singing. Then they showed us a film of the woman listening to her playlist – Memory from Cats was playing. She was alert and engaged, stroking the carer's face. And the son had started visiting again because they would listen together. It was amazing.

The results aren't always that dramatic, but they often are. And we're increasingly hearing about how once carers have this tool, they need to use medication less and less. The other week we heard that the GP at one care home has even started prescribing Playlist to other residents. I feel really proud to be part of something so important.

Music in Hospitals and Care

Demelza Stafford, Soprano: *A Yorkshire girl at heart who moved south for her studies at The Guildhall School of Music and Drama and the Royal College of Music. Now based in Sussex, Demelza works as a freelance opera singer performing roles and concerts and for more than ten years has also sung therapeutic concerts for Music in Hospitals & Care.*



Every concert day starts as if I were heading onto stage, a good warm up and the essential fluffing and buffing necessary for a little operatic glamour. This is not, however, a formal concert platform where I can lean on a piano in fancy heels and a rigid bodice: I need practicality. I want to be able to dance, get around the room and wear bright colours to help those with impaired eyesight. I know I'll spend the day climbing over chairs, kneeling at people's feet and dancing the odd jig whilst negotiating all manner of repertoire. I want to share all the fun and glitz of the theatre with these audiences!

Off I go, purposefully arriving way too early in order to meet everyone. I'm used to seeing people at all stages of dementia but approach all audiences in the same way, each person an individual who I want to reach however possible so I introduce myself to everyone and learn what I can. Names are a must and I do my best to use them throughout to help engage everyone. I also try to glean something useful by chatting with them and their carers, anything can help. I might notice an accent or they mention a film, a memory, even a football team which can pinpoint a tune that will unlock the joy in someone's heart.

I bring a ridiculous quantity of music, everything categorised and indexed to help us pick out pieces to respond quickly. Venues become assault courses as I climb round to see everyone whilst singing, ending up in all manner of positions! One to one is vital, some people want to hold hands or rest their forehead against mine, others will dance, sing, clap, laugh, sway and we often shed a tear together. We encourage everyone to get involved, introducing pieces, asking questions as we go. We have such a giggle, humour never seems to go and the odd cheeky number wins every time. I see such amazing smiles from people who cannot communicate any other way. People's hearts open to us and I get to share the most touching moments imaginable!

As we perform, we see reactions from visitors and carers too, often completely overwhelmed at seeing loved ones interact in ways they haven't for months, years even. Carers are often moved to tears when residents who can't usually engage or speak, manage to sing every word, tap a toe or even find their way to their feet to dance. Because I work with a bank of incredible musicians, I have the freedom to respond to whatever happens and anything can! We have to juggle all manner of 'odd' situations as audiences engage and express their feelings in a myriad of ways, some completely involuntary.

Sadly, we have to leave eventually but more often than not, long after our allotted time. We've all been enjoying ourselves too much to notice time passing. By the time I get home I'm exhausted and the report writing waits until the next day. Without fail, concert days end by sharing tears and laughter with my family as I recount tales of these beautiful human moments. I feel so lucky to be able to share music with individuals suffering dementia and help to unlock the person trapped inside!

MHA

Jodie Webber is a music therapist at MHA, a charity that provides specialist dementia care across the UK. She is a HCPC-registered music therapist and holds a MA in Music Therapy from Anglia Ruskin University. She currently works in four MHA care homes throughout Greater Manchester, delivering group and individual sessions for people with dementia.



My day-to-day routine can vary greatly, as I work in a different care home each day. I arrive at 9am and the first thing I do is walk throughout the home to greet residents and seek any updates from staff. As the residents awake and have their breakfast, I have a few tasks to do before I begin my day. This includes setting up the music therapy room (bringing out the instruments, setting up the piano, tuning my guitar) as well as processing new music therapy referrals, writing reports for care plans or learning new songs. Through the rest of my day, I usually deliver one group and five individual music therapy sessions.

In the morning, I will hold three or four individual sessions, which take place one-to-one with residents for approximately half an hour. The residents will have been referred by the care team for a specific reason, often to help minimise neuropsychiatric symptoms of dementia such as anxiety, depression, apathy or agitation. Individual sessions can take many different forms but always involve engaging the resident in the relationship using music. This often incorporates live music-making between the resident and the therapist, utilising familiar songs or improvisation and a variety of instruments. The impact that music therapy sessions can have on the residents is evident, often lifting their moods as well as highlighting their remaining abilities.

An important part of my job is to work with the care team to develop relevant non-drug psychosocial interventions for neuropsychiatric symptoms of dementia. Thus, before having my lunch, I will write my clinical notes and feedback to the team. Throughout sessions I am looking for specific aspects of the residents' presentation, including engagement, levels of stimulation and changes in mood. I am also considering how the residents may be using their remaining cognitive abilities, such as attention and memory. It is important to highlight these abilities, which may not be observable outside of music therapy sessions, and utilise this information in residents' day-to-day lives. This can contribute to overall quality of life within the care homes, and promote person-centred care.

In the afternoon, I hold three more sessions, including one hour-long open group session. The group is open to everyone, and it is incredible to see how music can be accessible to such a wide range of ages, backgrounds and abilities. My main focus whilst running the groups is to bring residents together through music, which is something that can be shared by many people despite their differences. When the group has finished, I will again write clinical notes and feedback to the team as necessary.

At the end of my day I will take some time to look over video footage from my sessions and select any clips that may be relevant to share with the team. During this process, I can also reflect on the sessions and work towards maximising the benefits of music therapy for each resident. At 5pm, I pack up all the instruments for the day and head home. Overall, it feels very natural to use music to connect with people living with dementia, as it can overcome communication barriers and encourage spontaneous interaction. I am thankful to have such a rewarding job; to be able to meet and bring joy to so many people each day.

Kent and Medway NHS and Social Care Partnership Trust

Iain Spink is employed as a music therapist for Kent and Medway NHS and Social Care Partnership Trust. He works on mental health inpatient wards for older people, including people with dementia. Iain is currently undertaking PhD studies on music therapy for people with dementia in long term care settings and the impact on patients/residents, care team staff and culture.



I arrive at the unit by 9:00 am, sign in, and go straight onto the ward and check in with the care team staff. I am part of the multi-disciplinary care team staff on the wards, which also includes Nurses, Healthcare Assistants, Occupational Therapists and Occupational Therapy Assistants, a Clinical Psychologist and a Psychology Assistant. A volunteer also joins me each week specifically to support the group session.

The care team helps enable the delivery of the music therapy sessions by providing support and/or co-facilitation within sessions and in helping patients to physically access the group. I value the supportive relationship that I have with the care staff and their input in the sessions.

My groups on each ward typically run for an hour and a half, from mid-morning until lunchtime and take place in communal areas. The musical content of the group includes singing of familiar songs and musical improvisation. A variety of percussion instruments are provided and I use my primary instruments of guitar and piano/keyboard. The participation of staff members helps to support and encourage the group members and they get to experience each other in a different way.

The unit is comprised of two separate wards for people living with advanced stages of dementia – one is all-male and the other all-female. The majority of the patients are in receipt of NHS “continuing care” and are long term residents. As a therapist, this provides opportunities for long term work and the capacity for meaningful therapeutic relationships. I have worked at the unit for nine years and there is one lady who has regularly attended my sessions throughout this time, including a prior stay on a different hospital ward. I recently spoke with two of her daughters and we reflected on the benefits of music therapy for their mother and how this has provided her with an additional strand of continuity within her care over the years. Music has always been a big part of her life

The long-term nature of this setting also offers the potential for carer involvement and interaction, both in and out of the session. The family of one of the patients attends every week and they participate together.

After the group, I make a note of who attended in the ward handover folder – a document that provides an overview of the patient’s daily care - and have a debrief meeting with at least one member of staff who worked with me in the group, usually the Psychology Assistant and Occupational Therapist. I also attend the afternoon ward handover meetings where the nurse in charge of the early shift conveys information to the incoming staff of the late shift. I contribute observations regarding the participants in the music therapy group. Insights gained from the music therapy sessions are also added to the patient’s Progress Notes, which form part of the patient’s clinical record.

In the afternoon, there are sometimes other meetings to which I contribute, including patient focus groups – an interdisciplinary discussion on a single patient; or ward team meetings. I also offer 1:1 sessions for patients, usually for those who are unable to access the group sessions.

APPENDIX A: BIOGRAPHIES

The Utley Foundation

The Utley Foundation is a private family charitable trust, established by Neil and Nicky Utley in 2014, which exists to advance a range of causes close to the heart of the trustees and to act as a catalyst for wider action. One of The Utley Foundation's flagship programmes explores how music can help unlock memory, communication and enhance life quality for people living with dementia. The Foundation supports a wide range of interventions, from live music to personalised playlists, as well as the Commission on Dementia and Music, established by the International Longevity Centre - UK. The Utley Foundation is a pioneering philanthropic financier in this emergent space.

Commissioners' biographies

Chair: Baroness Sally Greengross OBE, cross-bench peer and Chief Executive of the International Longevity Centre - UK

Baroness Sally Greengross OBE has been a crossbench (independent) member of the House of Lords since 2000 and co-chairs four All-Party Parliamentary Groups: Dementia, Corporate Social Responsibility, Continence Care and Ageing and Older People. She is the Vice Chair of the All-Party Parliamentary Group on Choice at the End of Life, and is Treasurer of the All-Party Parliamentary Group on Equalities.

Sally is Chief Executive of the International Longevity Centre – UK; Co-President of the ILC Global Alliance; and was a Commissioner for the Equality and Human Rights Commission from 2006-12.

Baroness Greengross was Director General of Age Concern England from 1987 until 2000. Until 2000, she was joint Chair of the Age Concern Institute of Gerontology at Kings College London, and Secretary General of Eurolink Age. She is an Ambassador for Alzheimer's Society, SilverLine and HelpAge International.

She is President of the Pensions Policy Institute and the Association of Retirement Housing Managers; Honorary Vice President of the Royal Society for the Promotion of Health, a Vice President of the Local Government Association and Honorary Fellow of the Institute & Faculty of Actuaries. Sally is Patron of several organisations including the National Association of Care Caterers; Care & Repair England; the Association of Retirement Community Operators; the National Network of Clinical Ethics Committees; Ransackers Association, the Association for Ageing & Education; and Age UK Westminster. Sally holds honorary doctorates from nine UK universities.

Luciana Berger MP, Labour and Co-operative Member of Parliament for Liverpool, Wavertree

Luciana Berger MP has been the Labour MP for Liverpool, Wavertree since 2010. Her parliamentary career has included positions as Shadow Minister (Energy and Climate Change), Shadow Minister (Public Health) and Shadow Minister (Mental Health). She was the first-ever MP to hold the latter post.

Today, Luciana is the President of the Labour Campaign for Mental Health and an adviser on mental health to Liverpool City Region Mayor Steve Rotheram.

Luciana studied at Birmingham and London Universities, and was elected to the National Union of Students (NUS) executive. Prior to becoming an MP, she worked at Accenture and the NHS Confederation. She has also run a non-for-profit organisation working with democratic socialists and trade unions for peace and security in the Middle East. As a community volunteer she has held positions as a school governor, the chair of a tenants' and residents' association, and as a community safety representative.

Professor Alistair Burns CBE FRCP, FRCPsych, MD, MPhil

Alistair Burns is Professor of Old Age Psychiatry at The University of Manchester and an Honorary Consultant Old Age Psychiatrist in the Greater Manchester Mental Health NHS Foundation Trust. He is the National Clinical Director for Dementia and Older People's Mental Health at NHS England and NHS Improvement.

He graduated in medicine from Glasgow University in 1980, training in psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. He became the Foundation Chair of Old Age Psychiatry in The University of Manchester in 1992, where he has variously been Head of the Division of Psychiatry and a Vice Dean in the Faculty of Medical and Human Sciences, with responsibility for liaison within the

NHS. He set up the Memory Clinic in Manchester and helped establish the old age liaison psychiatry service at Wythenshawe Hospital. He is a Past President of the International Psychogeriatric Association. He was Editor of the International Journal of Geriatric Psychiatry for twenty years, (retiring in 2017) and is on the Editorial Boards of the British Journal of Psychiatry and International Psychogeriatrics. His research and clinical interests are in mental health problems of older people, particularly dementia and Alzheimer's disease. He has published over 300 papers and 25 books.

He was made an honorary fellow of the Royal College of Psychiatrists in 2016, received the lifetime achievement award from their old age Faculty in 2015 and was awarded the CBE in 2016 for contributions to health and social care, in particular dementia.

Professor Sebastian Crutch, University College London

Sebastian Crutch is a neuropsychologist and Professorial Research Associate at the Dementia Research Centre, UCL Institute of Neurology. His research focuses on rare and young onset dementias, especially posterior cortical atrophy (PCA), the so-called 'visual variant' of Alzheimer's disease (AD). The work has led to improved understanding of dementia-related visual impairment and the causes and consequences of atypical AD more generally.

Sebastian has developed several interdisciplinary research themes collaborating with experts in social science, environmental engineering, occupational health and ophthalmology (ESRC/NIHR-funded work to ameliorate the effects of vision loss in dementia), computational statistics, virtual environments and human-computer interaction (EPSRC-funded work to enhance cognitive assessment), neurorehabilitation (Dunhill Medical Trust-funded work to design an app to facilitate reading in PCA), neurophysiology, engineering and neuro-otology (in Alzheimer's Society-funded work to understand balance problems in AD).

Currently he directs the Created Out of Mind 2016-2018 residency at The Hub, Wellcome Collection, bringing together artists, scientists and people living with dementia in a collaboration of over 60 individuals, institutions and charities aiming to shape and enrich public and professional perceptions of the dementias, and explore the opportunities afforded by collaborative, interdisciplinary, publicly-situated research.

Councillor Christabel Flight, Westminster City Council

Christabel Flight was elected as a Westminster Councillor to represent Warwick Ward in May 2006. She has held the following roles: acting as Westminster's Older People's Champion, editor of Westminster Plus for Westminster's 25,000 freedom pass holders, and after her election as Lord Mayor, served as Deputy Cabinet Member of Adults and Public Health in addition to sitting on the Planning Applications Committee.

Christabel created the annual Christmas Tea Dance (held at the Grosvenor Hotel in Park Lane) which is now in its eleventh year. It is a free event for 1,000 Westminster residents aged 65+ and provides the opportunity for people to forge new friendships.

Christabel also initiated the Sir Simon Milton Foundation four years ago in memory of her mentor and has been instrumental in helping to raise funds for the Sir Simon Milton Westminster University Technical College (UTC) which will provide an academic education for 550 students aged 14-18 in addition to specialist training in Engineering. The newly, purpose built, UTC is due to open in September 2017 in Pimlico.

Silver Sunday, on Sunday 1st October started in Westminster in 2012 and since then it has gained widespread support. The aim is to turn it into a national day matching Mothering Sunday, establishing it in the national consciousness as a day when we think about older people and help them. With the help of the Sir Simon Milton Foundation, Silver Sunday has grown to the point where last year over 600 events were held nationwide – from the south of England to Glasgow and all the way to Northern Ireland.

Christabel has been married to Howard for 44 years. They have a son, three daughters and 5 grandchildren - plus a border terrier!

Professor Martin Green OBE FIAM, FInstLM, FRSA, FIPSM

Chief Executive: Care England; Department of Health: Independent Sector Dementia Champion; Chair: International Longevity Centre - UK

Martin Green has had an extensive career in NGO development, both in the UK and internationally, and

is Chief Executive of Care England, the largest representative body for independent social care services in the UK. He is also Chair of the International Longevity Centre – UK and a Trustee of Independent Age. In 2013 he was appointed Visiting Professor of Social Care to Buckinghamshire New University. In 2012, in his role as Department of Health Independent Sector Dementia Champion, he led the development of the Dementia Care and Support Compact for The Prime Minister's Challenge on Dementia. In 2008 he was named care personality of the year and was awarded an OBE for Services to Social Care in the 2012 Queen's Birthday Honours List.

Martin Green writes and broadcasts extensively on social care issues and is on the Editorial Board of Community Care Market News and Care Talk magazine.

Ming Hung Hsu, Chief Music Therapist, MHA

Ming is the Chief Music Therapist for MHA, a charity providing care, accommodation and community support services for older people throughout Britain. In this role, he heads a national team of 22 music therapists who provide weekly music therapy in 60 care homes.

Ming has recently completed his doctorate study, titled 'Individual music therapy for managing neuropsychiatric symptoms in dementia care homes'. The study included a cluster randomised controlled trial (published on BMC Geriatrics) to test the feasibility of implementing a music therapy programme including post-therapy communication with care staff in dementia care homes. The study also explored how emotion regulation techniques used in individual music therapy sessions might be embedded in daily caregiving to prevent and manage emergent neuropsychiatric symptoms, such as agitation, anxiety, depression and apathy.

Ming's research interests derive from the emerging evidence of psychosocial interventions in care homes, which aim to improve quality of care and life by addressing symptoms arising from unmet needs, biopsychosocial and environmental factors.

Liz Jones, Head of Policy and Research, MHA

Liz heads up the Policy and Research service for MHA, a large national charity providing care, support and accommodation for older people. Liz leads the policy and research service, covering a wide range of policy and influencing areas for older people including health and social care, housing and ageing and wellbeing.

Liz has extensive policy experience in both the civil service and local government, having previously run the corporate policy service at Nottingham City Council and, prior to that, was part of the Supporting People team at the Department of Communities and Local Government. Liz has responsibility for the Music Therapy service at MHA, aiming to increase the amount of MT MHA can provide as well as champion and promote music therapy more widely, especially for people with dementia.

Tim McLachlan, Operations Director – Greater London, for the Alzheimer's Society and, from September 2017, Operations Director – Local Services

Currently, Tim is responsible for all the Society's service delivery across Greater London with more than 300 projects, helping and supporting thousands of individuals affected by dementia, their families and carers. Tim chairs the Pan London Dementia Action Alliance and sits on the Leadership Group of the London Strategic Clinical Network Group for Dementia.

Prior to joining Alzheimer's Society Tim has worked in the voluntary sector for over 18 years leading and developing charities. Tim holds an MBA from Liverpool University and was their first student to apply an MBA to the Voluntary Sector, specialising in strategic planning. As a Chief Executive, Operations Director and Fundraising and Marketing Director he has worked across the UK in social care, homelessness, Olympic Legacy and education.

Away from work Tim enjoys Golf, Cricket and Choral Music, singing regularly with Chester Cathedral Choir and directing their Saturday Singing Club for primary school aged children. Tim is also a Cub Scout Leader in his local pack. He is married with two young children and lives in Cheshire and London.

Sarah Metcalfe, Chief Executive, Playlist for Life

Sarah is the first Chief Executive of music and dementia charity, Playlist for Life. Under her direction, the charity is working to raise public awareness of the power of personal music and is translating the research evidence into practical tools that help families use it every day to make living with the disease easier and happier. Sarah has also prioritised exploring ways to integrate music into the care system to

support care workers and change the culture within care settings.

Before joining Playlist for Life, Sarah worked for ten years in policy and campaign organisation at Westminster and Holyrood before taking a break to have a family. During that time she was a Board member of Emmaus Glasgow and a founder member of Fair Funding For Our Kids, a successful, parent-led campaign for improved nursery provision in Scotland. She lives in Glasgow with her husband, Jim, and their two children, Rosa and Ally.

Professor Helen Odell-Miller OBE, Anglia Ruskin University

Helen is a Professor of Music Therapy, and Director of the Music Therapy Research Centre at Anglia Ruskin University, Cambridge. Her research and clinical work has contributed to establishing music therapy as a profession, over 40 years and specifically to innovating approaches in adult mental health, including for people with dementia.

Helen has published and lectured widely, and has been a keynote speaker at many national and international conferences in Europe, Australia and the USA. She has worked with parliament and the government advising on music therapy.

She is co-editor and an author for the books *Supervision of Music Therapy* (Jessica Kingsley 2009), *Forensic Music Therapy* (Routledge 2013), and *Collaboration and Assistance in Music Therapy* (2016). She has published widely in national and international peer reviewed journals and authored many book chapters. She is a violinist, pianist and singer, and a member of Cambridge Voices

Alexia Quin, Director, Music as Therapy International

Alexia is a music therapist and the director of the charity Music as Therapy International. The charity has been developing ways music therapists can share their skills with care staff to strengthen care practice internationally for twenty years. It has recently extended this work in the UK with a particular focus on working with care settings responsible for young children under 5, adults with learning disabilities and people living with dementia.

Beatie Wolfe

Named by WIRED Magazine as one of “12 folk changing the world this year” singer-songwriter Beatie Wolfe is at the forefront of pioneering new formats for music, which reunite tangibility, storytelling & ceremony to the album in this digital age. In this vein, Wolfe has created a series of world’s-first designs that bridge the tangible and digital, which include: a 3D vinyl for the iPhone; an intelligent album deck of cards; a Musical Jacket - designed by the tailor who dressed Bowie, Jagger and Hendrix and cut from fabric woven with Wolfe’s music - and most recently the world’s first live 360 AR album stream, broadcast from the quietest room on earth.

Beatie Wolfe is the definition of a 21st century artist and perhaps the only musician to have her album’s art exhibited in London’s V&A Museum, address the VPs of Apple on innovation and have the American Alzheimer’s Association adopt the findings from her *Power of Music & Dementia* study. Forbes calls Wolfe “an Artist with a capital A” and “a true pioneer” for mixing her music with art, technology, science and taking it to entirely new dimensions.

ENDNOTES

- ¹ Please note that fuller biographies of the Commissioners and funders can be found in Appendix A.
- ² Department of Health, (2015) 'Prime Minister's challenge on dementia 2020' GOV, UK [Online] Available at: <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020> Accessed: 22/11/2017.
- ³ Department of Health, (2009) 'Living well with dementia: A National Dementia Strategy' GOV, UK [Online] Available at: <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy> Accessed: 22/11/2017.
- ⁴ It should be noted that the term 'music therapy' is used here only in the context of music therapy delivered by a trained and registered music therapist. The term 'intervention' is used to describe other forms of activity which fall outside of this area of work.
- ⁵ Hung Hsu, M; et al, (2015) 'Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study', *BMC Geriatrics* 15 (84) pp. 1-19
- ⁶ BAMT, (nd) 'What is music therapy?' [Online] Available at: <https://www.bamt.org/music-therapy/what-is-music-therapy.html> Accessed: 22/11/2017
- ⁷ Hung Hsu, M; et al, (2015) 'Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study', *BMC Geriatrics* 15 (84) pp. 1-19; Ridder, Hanne Mette O. et al, (2013) 'Individual Music Therapy for Agitation in Dementia: An Exploratory Randomized Controlled Trial', *Aging & Mental Health* 17 (6) pp. 667-678.
- ⁸ Professional music therapists operate within clearly-defined Health and Care Professions Council (HCPC) standards.
- ⁹ Alzheimers Society, (n.d) 'Find support near you' [Online] Available at: https://www.alzheimers.org.uk/info/20011/find_support_near_you#!/search Accessed: 01/11/2017.
- ¹⁰ SCIE, (2015) 'Dementia-friendly environments: Noise levels' [Online] Available at: <https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/noise.asp> Accessed: 23/10/2017.
- ¹¹bid.
- ¹²Playlist for Life written evidence submission.
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