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# **EXECUTIVE SUMMARY**

The first report Music for Dementia produced in 2018 described a music and dementia landscape that was fragmented and even considered a bit 'niche'.[1] Eight years on we wanted to survey family carers and see what role music plays in their lives today. From a poll of 1,000 unpaid and non-professional carers, the results were encouraging.

#### **SUMMARY OF FINDINGS**



80% use music as a regular part of caring for someone with dementia. 47% felt that music can help reach a loved on and turn a day around.



Listening to music is the third most popular activity dementia carers do at home with the person they care for, behind watching TV and chatting to each other.



Making a playlist is popular and this can help people living with dementia. Young male carers are 55% more likely to create or listen to playlists weekly than the average. 22% of older carers know what a playlist is but do not know how to make one



The digital divide between older and younger carers is evident. Gen Z are much more confident using technology, with 79% of 18–24-year-olds using technology with ease, compared with the baby boomer generation, where just 35% of 65–74-year-olds felt confident. Young male carers (up to age 44) specifically, are more confident using streaming services, with 65% reporting to do so.



Dementia carers themselves are a diverse group. As well as primary carers providing 40+ hours of care a week, there seem to be wider networks of support around individuals with dementia made up of friends, neighbours and more distant relatives who provide lower levels of support. A future paper will explore these networks in more detail.

#### **OVERVIEW**

Music can be seen to be an activity of choice for most carers because of its positive health and wellbeing benefits for those living with dementia. Policymakers should bear this in mind when developing strategies for dementia services and ensure appropriate levels of support for music and dementia services such as choirs, music groups and dementia friendly live performances.

The prevalence of music within the home also creates opportunities for music to become a tool to strengthen continuity of care and personalisation, as those living with dementia transition into more intensive care. For example, a personal playlist could become an individual tool every person with dementia takes with them on hospital visits or if they move into residential care allowing new caregivers to connect. This could be a cost-effective way to join up health and social care for people along their dementia journey but will require change for this to happen.

Based on the findings of our data, we found that friends and family, charity websites and GP practices were reported as being the most popular routes to seeking advice and information about dementia and caring for someone with it, and this must be harnessed. We have produced the following four policy recommendations we believe can help embed music as a core part of dementia care.

#### RECOMMENDATIONS



Introduce music and dementia training and education for all health and social care professionals. We recommend a new module should be added to the Workforce Strategy for Adult Social Care.



Dementia care strategies developed by health and social care policymakers, the NHS and third sector need to have distinct funding and development, reflecting the value family carers place on it.



Target digitally excluded demographic groups through community and peer-to-peer focused learning sessions so they have greater understanding and confidence in harnessing music as part of their care.



Develop and encourage intergenerational music projects and initiatives that foster co-creation between individuals of all ages, embracing diverse digital experiences and skills.





# INTRODUCTION

There are over 900,000 people living with dementia in the UK, yet the number of lives who are impacted is much larger, with an estimated 700,000 unpaid carers of people living with dementia (PLWD).[2] Being a carer can be tough, but evidence shows music can help.

Music can reduce behavioural symptoms such as agitation and aggression.[3] Repeated listening to personally meaningful music can stimulate 'neural connectivity' in ways that maintain higher levels of functioning.[4] It can also improve quality of life, mood and reduce depression and the need for antipsychotic medication.[5][6] It is also valuable for carers, helping to provide points of connection to loved ones, sparking joy and provide moments of ease throughout the day.

Though the positive effects of music are widely understood, less is known about the carer experience, who they are and how they use music, with the people they care for and for their own wellbeing. This report aims to help address this.

This initial report is broken into three sections.

SECTION 1: MUSIC AS A CORNERSTONE OF CARE 'Music as a cornerstone of care' provides a broad summary of who and how music is used.

SECTION 2: THE DIVERSITY OF MUSIC 'The diversity of music' looks at the variations in who and how music is used. We found the approach to using music in care varies significantly depending on the demographics of the carer and also on their relationship to the person they care for. A spouse, for example, engages differently with music when caring than a child or grandparent.

SECTION 3: THE RISING ROLE OF TECHNOLOGY IN CARE 'The rising role of technology in care' summarises the findings of how carers use technology. We can see there's a willingness to use technology through various methods, but there is a gap across generations, genders and ethnicities with varying levels of confidence to use these devices.

# METHOD

Music for Dementia conducted a survey online between the 5th and 12th of August, 2024. The survey design aimed to include an equal number of men and women and ensured that participation from ethnic minorities broadly reflected their proportion in the UK population. Beyond these criteria, the selection was left open to capture the widest variety of caregivers and their experiences. Participants were unpaid caregivers, specifically those who look after someone with dementia in the UK.

An additional representation study has been conducted analysing over **200** articles sourced from a diverse range of media outlets, 16 reports from key organisations involved in dementia care and a systematic review of materials related to dementia support services, focusing on general support offered to carers.

This report is the first output from this research, providing a summary of carers experience of music and technology. This will sit as part of a series showcasing the diversity of the care experience, how they are perceived and what more can be done to support their experience as a carer.













# SECTION 1: MUSIC AS A CORNERSTONE OF CARE

# 80%

of respondents
reported they
regularly use
music in their
caregiving routine



47%

felt that music can help reach a loved one and turn a day around For carers, music appears to be a popular tool that people are already making use of. Additionally, 70% of respondents reported that "listening to music" is a regular leisure activity they engage in with the person they care for.

It was also recognised as a method to creating a positive environment for both carers and care recipients. The data shows it's a simple tool to use at home, music ranked third behind watching TV and chatting as the most popular leisure activity the individual and the person they care for do together. 53% stated it was an activity they do together, highlighting its power to bond.

People who spend between 61-100 hours a week caring for someone were most likely to use music as a tool, with 67% reporting to do so. This dropped to 33% for someone who cares less than 10 hours a week. The number was also lower to 55-64 year olds, with only 40% reporting to do so, compared to 63% of 18-24 year olds and 60% of 25-34 year olds.

# 53%

Stated it was an activity they do together, highlighting its power to bond

# 70%

Reported that "listening to music" is a regular leisure activity they engage in with the person they care for

# 67%

Of people caring 61-100 hours per week are most likely to use music as a tool

# MUSIC AS A CORNERSTONE OF CARE - CONTINUED

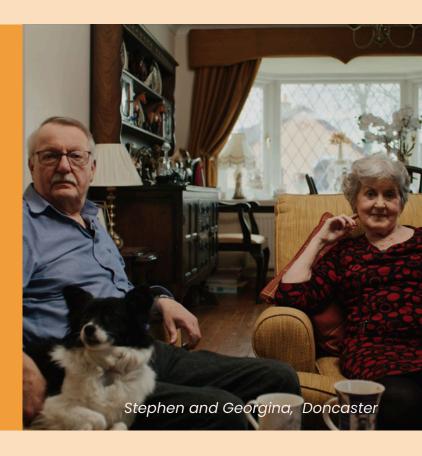
Music's popularity is evident. Only 3% of respondents reported that music did not feature in their life in a typical month, demonstrating just how far music can reach. It has unique ability to touch everyone's lives, providing the soundtrack to joyous moments, uniting people and making difficult moments that bit easier.

Music is special, neurologically. It reaches so many different parts of the brain at once, not just areas connected with hearing but also language, movement, emotions and memory.

## CASE STUDY -GEORGINA AND STEPHEN

Stephen cares for his partner Georgina at home. Georgina is a retired professional singer, so has always had music in her soul. Although some daily tasks, like dressing herself, are becoming difficult for her.

Georgina can still remember all the words to her favourite songs. 'Danny Boy' is one of her classics, and she loves performing it around the house. Stephen says that they have gone to a few music groups together, where Georgina still enjoys being the star of the show. Georgina knows that music is the thing that will never leave her.

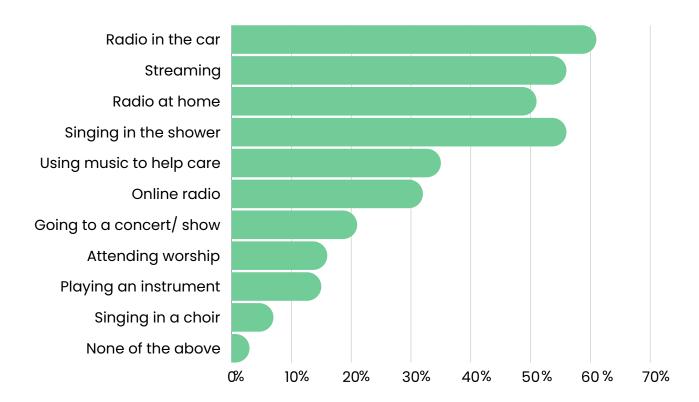


# SECTION 2: THE DIVERSITY OF MUSIC USE

It's easy to make assumptions about how music is used by carers, yet our research has demonstrated huge diversity in approaches. From singing groups and music therapy to personalised playlists and specialised radio stations, the options available to carers are constantly evolving so we were pleased to see people making use of this.

How music is used also appears to vary significantly based on the user's age, gender, ethnicity and relationship to the person they care for. It seems, there is not just a one size fits all approach to using music. This diversity also means there are gaps in how some people engage with music and could therefore be missing out on valuable supportive tools and the benefits of music.

The chart demonstrates the diversity of how music features in carers lives, showing its ability to touch on so many different aspects of caring, social and downtime



### Choirs

People of Black or Black British ethnicity were far more likely to report singing in a choir, with 41% stating they did, compared to 12% of white people.

Young people were also more likely to attend a choir, with 12% reporting to do so, compared with only 2% of 55–64 year olds and 3% of aged 45–54 year olds.

# Attending worship/ religious music

16% of carers responded that they attended worship or listened to religious music in a typical month. Again, there were big fluctuations depending on the ethnic background of the respondent.

41% of Black British or Black carers attended worship, compared to only 12% of white respondents, 25% of Asian or Asian British respondents and 24% of Mixed/Multiple/Other respondents. This suggests some communities rely on it far more than others as a musical activity and should be recognised when thinking about engagement.

## Playing an instrument

15% of respondents said they played an instrument, though it appears age is a significant factor for this activity. Those aged between 18-44 averaged at 20% playing an instrument, however for those aged 45-54 it dropped to 7% and even lower to 5% for 55-64 year olds, indicating a sharp drop-off rate amongst older adults.

#### Radio

**62%** of 45–54-year-olds listen to radio up to 7hrs a week.

51% are listening to radio at home, but there are considerate variations on who is listening to it. 54% of people who are white listen to the radio, compared to only 40% of people of Black and Black British ethnicity and 23% of Asian or British Asian ethnicity.

**35%** of carers reported to listen to BBC radio for their news and entertainment, compared to only **26%** for commercial radio stations.

### CASE STUDY - JOHN AND JO

John and his daughter Jo regularly attend a Music Cafe for those living with dementia and their family members. The groups are run by the Manchester Camerata, the groups are entirely free and open to anyone who wants to join. John particularly loves playing the snare drum at these sessions, and Jo has got him a drum to use at home now because he enjoys it so much. John's real passion has always been sport - watching, playing (back in the day) and talking about fixtures. He still loves singing his football anthems and chants.

In April 2024 Manchester Camerata was appointed the first Centre of Excellence for NASP's Power of Music Fund, working to roll out its Music Champion model across Greater Manchester and gather evidence of cost savings to the NHS.



#### PLAYLISTS IN PRACTICE

People are engaging in all forms of music. Interestingly, a higher percentage of respondents (48%) are encountering music in non-live contexts such as radio and via streaming compared to live music (15%).

Streaming, specifically playlists, is easy and cost effective, enabling people living with dementia to hear music that is personally meaningful in all kinds of settings. Research has shown that listening to personally meaningful music helps boost brain function for people with early Alzheimer's disease.[7] Playlists can be used as a part of a method called 'therapeutic scheduling', based on an international protocol[8] for using personalised music with people living with dementia, developed at Stanford University over almost thirty years. UK charity <a href="Playlist for Life">Playlist for Life</a> has developed tools, resources and training based on this protocol which advocates playing personalised music 30 minutes before difficult times or activities.

When asked about how music features in their life in a typical month, 56% of carers responded that they stream music. But the numbers vary hugely based on the individual circumstances. For example, 76% of people who are the grandchild of the person they care for reported to using a streaming service, but for those who are the spouse of the person they care for, it drops to 31%.

76%
of grandchildren
reported they
streamed music in a
typical month

Music for Dementia also asked specifically how often carers make or listen to a playlist of music. Again, the results vary depending on the answering group. Young male carers are 55% more likely to create or listen to playlists weekly compared to the average of all respondents, with 30% doing so daily.

The relationship to the carer also appears to be a signifier of how often playlists are listened to or made. 31% of spouses also reported to never making a playlist because they don't know how to make one, compared to just 1% of 18–24-year-olds. It's a similar picture if you break it down by age, 47% of 18–24-year-olds make playlists all the time, compared to just 14% of 45–54 year olds. This suggests a clear knowledge gap between different carer groups when it comes to awareness of a tool versus the ability to make use of it.

'Digital natives' are those who have grown up in a world surrounded by technology, generally considered to be anyone born after 1980. People born before 1980 are considered 'digital immigrants', in that they have learned to use technology at an adult stage in their life and are normally less instinctive about how to use and incorporate it. This divide is evident in the research as impacting the type of care different age groups provide and their ability to make full use of music. It can also be seen as an opportunity for inter-generational collaboration within care.

Young people have skills that are inherent, which could be hugely helpful to caregivers in supporting a person with dementia. For example they could work collaboratively with somebody else to piece together a family members musical history and make a playlist. It's important that policy responses, and support for families, carers and people living with dementia have this intergenerational approach embedded.

"It's encouraging to see the data shows playlists are a popular tool for people living with dementia and their carers, but a clear digital divide prevails. Despite being in an age of easy access to music, many people still rely on offline modes, turning to MP3 players, CDs, Vinyl or singing. For some this is a choice but for others it's due to a lack of skills or confidence. Playlist for Life's most viewed video on YouTube with over 1/2 million views is a video showing people how to transfer songs from a computer onto an mp3 player. We encourage people to listen to music in the way that is most comfortable and convenient to them, while doing all we can to support those wishing to access music online."

Michael Timmons, Executive Director at Playlist for Life

43%

Of grandchildren responded that they listen to or make playlists all the time, compared to just 23% of spouses 55%

Of young male carers are more likely to create or listen to a playlists weekly, compared to the average of all respondents, doing 30% daily

## Case study -Intergenerational Music Making

Dennis (aged 72) and his grandson George (aged 10) from Surrey and Hampshire used Intergenerational <u>Music Making's</u> '<u>Together With Music'</u> platform throughout the Covid-19 pandemic to stay connected. They engaged by sharing songs, stories, and musical compositions, which not only helped them maintain a strong bond but also brought joy and emotional support during a challenging time. As restrictions were lifted, their relationship continued to grow, both in-person and through digital engagement. George became a digital mentor to Dennis, teaching him how to use various applications and systems on his phone and on his iPad, enhancing Dennis's ability to stay connected, access information, and make everyday tasks easier. This intergenerational exchange not only strengthened their bond but also empowered Dennis, demonstrating the profound impact of learning across generations.

You can learn more about <u>Intergenerational Music Making</u> and <u>Intergenerational England</u> by visiting their websites or visit the <u>Together With Music</u> platform directly.





"The essence of intergenerational work lies in fostering connection across and between all generations... when older adults and younger people come together, they're not just bridging a digital divide; they're engaging in a reciprocal exchange where both generations teach, support, and connect with each other."

Charlotte Miller, Music Therapist, Founder and Director of Intergenerational Music Making and Co-Founder of Intergenerational England

# SECTION 3: THE RISING ROLE OF TECHNOLOGY IN CARE

It's estimated that 60% of people who draw on support from homecare are people living with dementia.[9] For those at home, or even cared for in alternative settings, technology is becoming an increasingly important aspect of care and can enable more dynamic and innovative activities which can make routine tasks easier. Understanding which groups are more confident using technology and potential barriers to access is therefore important to improve the experience of carers and people living with dementia.

There are already a number of music-based technologies available for carers, including m4d Radio, MusicCan, MediMusic and Resparke. There have also been innovative projects such as the Casio Light Up My Life project, which aimed to increase awareness access and participation of music-making activities through the use of lit-up key keyboards.

These evolving technologies, though welcome, are only helpful if they can be used effectively by the people that need them the most. To learn more about this, we made technology a specific focus of our polling. As well as the digital native/ digital immigrant divide discussed above, we found there are major differences depending on factors such as ethnicity or socioeconomic status that determine confidence and usage of tech.

Generally, 70% of respondents reported regularly using some form of technology, such as smartphones or tablets, to aid in caregiving tasks.

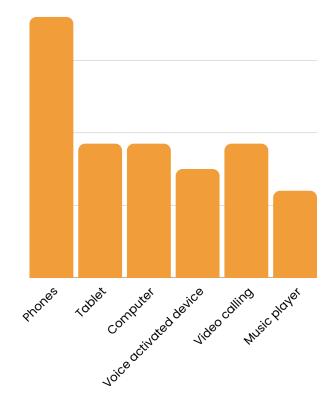
The range of technology adopted, however, varied significantly. 72% reported to use phones, 37% a tablet or iPad, 37% a laptop or desktop computer, 30% voice-activated devices (e.g. Alexa), 37% video calling and 24% simple music players

## 70%

Reported regularly using some form of technology such as smartphones or tablets, to aid in caregiving task

## 30%

Of responses stated they are more likely to face challenges when adopting new technologies



# THE RISING ROLE OF TECHNOLOGY IN CARE -CONTINUED

Ethnic minority carers may be up to 30% more likely to face challenges, when adopting new technologies, based on observed differences in comfort levels with technology across ethnic groups. To overcome this, 40% of ethnic minority carers reported to relying on community networks for technology support, demonstrating the powerful role of the community for this group.

Economic factors were also found to affect technology usage, with higher-income households more likely to use advanced technologies (34%) of households with over £50,000 reporting regular use of smart home devices, compared to households of less than £50,000 which averaged 24%. Those earning over £100,000 reported to being more than twice as likely to use advanced technology than those earning less than £10,000. While mobile phone usage is similar across both groups (71% vs. 72%), higher-income carers are 21% more likely to use tablets (41% vs. 34%) and over 50% more likely to use video calling services (33% vs. 22%).

Comfort levels using technology also vary significantly by age and demographic group, with the strong generational divide again evident. Young male carers (under 45) are 75% more likely to feel very comfortable using digital music platforms like streaming services compared to the average of all respondents, with 65% of young men reporting regular use.



Young men are the group most comfortable using streaming services

## **79%**

of 18–24 year olds are very confident using technology



## 35%

of 65-74 year olds are very confident using technology

Female carers over 65 are **twice as likely** to rely on family members for technology support compared to younger female carers, who are more self-reliant. Again, this highlights the important informal learning that takes place across generations to build confidence and teach valuable skills. Though over time the number of digital immigrants will decrease, technology is ever evolving, and it is therefore important to create structures of support for learning to continue throughout people's lives

# THE RISING ROLE OF TECHNOLOGY IN CARE -CONTINUED

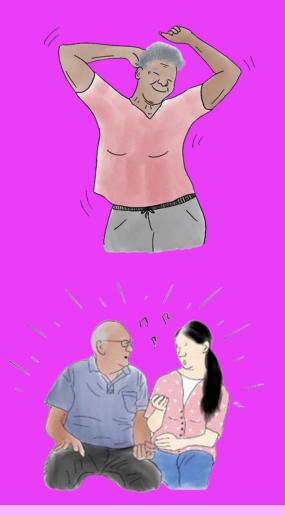
### CASE STUDY - MUSIC AS THERAPY INTERNATIONAL

Music As Therapy International is a charity that has worked all over the world supporting care settings to incorporate music into the work of caregivers. In 2023 they developed Music Helps (UK), an online training course giving caregivers an understanding of the role music can play in the care of someone living with dementia.

The training is currently free to access and uses a combination of videos, exercises and interactive games to help family members and professional care staff learn musical techniques that help them connect with the person they are caring for and also look after their own well-being. Being online, the course is widely accessible enabling Music As Therapy International to reach a broader range of the dementia caregiving workforce (including unpaid family caregivers and support workers, as well as professional caregivers) across the UK and overseas.

To find out more or sign up for the training visit:

<u>Music Helps (UK): Join the Pilot</u>





"I started singing while the client hummed along and now she has been remembering the words and adding them verbally along while singing."

A client of Music as Therapy International after completing their course

# CONCLUSION

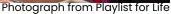
It is clear from our research that carers are using music in diverse ways to support themselves and the people they care for, but there is still much more that can be done to expand its reach.

The high percentage of carers who were confident in using tech suggest there is an appetite to use it, but sometimes knowledge is holding people back. This would suggest there is still work to be done to upskill carers, make tools and resources available to them and promote the use and benefits of music and technology. With this knowledge clearly existing amongst younger family members, an obvious solution is to work cross-generationally to both understand the needs of carers who would like to use music and enable solutions that people who already understand how to use it effectively can teach.

Caring is a diverse experience, and we must ensure as a society that there are sufficient resources and people able to support carers as they navigate the journey of looking after a person living with dementia. Government and dementia support organisations must reflect this in the support and training available to carers, recognising a one-size-fits-all approach will neither work nor lead to the best outcomes for people living with dementia.

Music is not a silver bullet, but it can be an invaluable tool to smooth over difficult moments and help bring happiness, respite and connection. It provides a soundtrack to our lives and we must embolden and enable carers to keep the music playing.









Music for Dementia is the Utley Foundation's cross-sector campaign to make music an integral part of dementia care. Music for Dementia is a proud member of the Power of Music Consortium. To sign up, visit here.

# RECOMMENDATIONS

#### **POLICY RECOMMENDATIONS**



Introduce music and dementia training and education for all health and social care professionals. We recommend a new module should be added to the Workforce Strategy for Adult Social Care.

2

Dementia care strategies developed by health and social care policymakers, the NHS and third sector need to have distinct funding and development, reflecting the value family carers place on it.

3

Target digitally excluded demographic groups through community and peer-to-peer focused learning sessions so they have greater understanding and confidence in harnessing music as part of their care.

4

Develop and encourage intergenerational music projects and initiatives that foster co-creation between individuals of all ages, embracing diverse digital experiences and skills.

#### **SUGGESTIONS FOR CARERS**

- 1. Keep using music and explore different ways to incorporate it into your day. Have a look for musical activities going on locally choirs, relaxed performances at the theatre, even religious services.
- 2. Make a playlist of meaningful music for the person you care for so you can listen at home, take it on hospital appointments or use it when you are out and about. Visit musiccan.org.uk or musicfordementia.org.uk for more ideas of ways to use music.
- 3. Make time to listen to your own music too. Being a carer can be lonely and your own tunes can raise your spirits and transport you to other times and places.
- 4.Science shows we make more memories in our teens and 20s than any other decades. Tune into a radio station from one of those decades such as Heart 80s, Boom Radio or m4dradio.com (Music for Dementia's free online radio station)
- 5.Grandchildren or children take on being the 'tech person'. Involve the wider family in thinking of tunes and turn it into a playlist. Set it up so they can easily listen eg voice activation (put a stickie on the wall to remind them what to say)
- 6.Parents and grandparents if you are stuck with technology can you ask one of the younger generation to help?

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#### **Case Studies:**

Stephen and Georgina John and Jo Dennis and George



Thanks also to the organisations featured in this report, chosen to give a flavour of the diverse and imaginative work being done around the country.

#### Manchester Camerata (p11)

Britain's most adventurous orchestra appointed the first Centre of Excellence for the Power of Music Fund in April 2024, working to roll out its Music Champion model across Greater Manchester and gather evidence of cost savings to the NHS.

www.manchestercamerata.co.uk

#### Playlist for Life (p12)

Playlist for Life support people to find the best solution for them and provides free resources and support to help people living with dementia, their families and carers create and benefit from playlists of personally meaningful music. Playlists are a simple but cost-effective tool which can have a profoundly positive impact on quality of life that can be a lifeline for the future. www.playlistforlife.org.uk

#### Intergenerational Music Making/Intergenerational England (p13)

A not-for-profit organisation bringing people together through the power of music to reduce loneliness, boost wellbeing and create stronger communities. Their Together With Music Platform sought to unite generations on a digital platform where they could exchange songs, stories, and musical creations, called 'It starts with a song!' It reached over 78,000 individuals, connecting care homes, dementia wards, children and young people, schools, and private/community homes. www.imm-music.com www.intergenerationalengland.org

#### Music As Therapy International (p16)

A charity that trains care givers to use music to connect with people living with dementia, manage anxiety and reduce medication.

www.musicastherapy.org



Music for Dementia is the Utley Foundation's cross-sector campaign to make music an integral part of dementia care. Music for Dementia is a proud member of the Power of Music Consortium. To sign up, <u>visit here</u>.

The Utley Foundation Charity Number: 1157399