

Playlist for Life Response to the Scottish Government Consultation to Inform a New Dementia Strategy

December 2022

Playlist for Life welcomes the opportunity to respond to the Scottish Government's consultation on the new Dementia Strategy.

The Scottish Government's current dementia strategy is world-leading in its approach to transforming dementia services through person-centred, flexible care and support at all stages of a person's dementia journey. We share the Scottish Government's vision and ambition for taking this further in the new Dementia Strategy.

Playlist for Life is Scotland's leading music and dementia charity, harnessing the power of personally meaningful music to improve the quality of life of people living with dementia. Our work is deep-rooted in real people and their lived experience of dementia. Personally meaningful music can greatly improve quality of life, ease the pressures in dementia support and significantly enhance person-centred care. It is a non-clinical, non-pharmacological intervention with a small cost but massive benefit.

To inform our response we held two engagement events, in person and online as well as conducting a survey, with people living with dementia, carers and family members, health and social care professionals and staff and volunteers from a range of community organisations. All the views gathered on dementia care in general have also been fed into the Age Scotland, About Dementia response collating views from those with lived experience. Our response, will focus specifically on personally meaningful music and why this should be a recognised, recommended intervention that is part of dementia care and support.

What support works well for you and what do we need to build on?

The conversations and themes emerging from our engagement events and survey related most to the two questions posed within the consultation discussion paper 'What support works well for you?' and 'What do we need to build on?'. The use of personalised music is a truly person-centred intervention that is currently working well for many people living with dementia in Scotland. This intervention helps improve quality of life at all stages of dementia and in all settings. We must build on this to ensure all people living with dementia in Scotland are aware of the how personalised music can improve daily life and ensure they can access it at an earlier stage and throughout their journey.

The research and science

Music in all its forms can be an uplifting and meaningful activity for people living with dementia. However, over two decades of scientific research shows that crucially, it is music that is personally meaningful to those living with dementia, and a personalised music playlist that has the greatest impact on quality of life and wellbeing. Personalised music is not just an enjoyable activity but a non-pharmacological, non-clinical intervention that can

significantly improve the quality of daily life for someone living with dementia.

A personalised music playlist can **provide respite for carers, slow down the progression of dementia and decrease use of antipsychotic medication**. This can lead to better care and support for those living with dementia and **a reduction in costs** associated with dementia care. (1) The reduction in anxiety and distress can lead to reduction in falls, further reducing costs. (2) This can also reduce the burden on caregivers and care staff. (2) Following a personalised music intervention, caregivers have not only felt less overwhelmed but also increased their bonding with the people living with dementia. (3) It also focused attention of the people living with dementia and enabled carer respite. Evidence also shows that **the cost of implementation is greatly offset by cost savings in other areas of care due to reduced agitation or falls**. (2)

In 2018 personalised music playlists helped bring about a **60% drop in the use of sedative drugs** at Lillyburn Care Home in Kirkintilloch. (4)

In an NHS dementia ward in Fife researchers found the use of personalised music playlists significantly reduced levels of agitation and led to them **becoming markedly less stressed during clinical procedures in 96% of cases**. (5)

Personalised music playlists are non-invasive and non-pharmacological, pose little to no risk to patients, require minimal training, and offer large potential for implementation in various settings. (6)

The lived experience of people living with dementia, their family and carers

We have over 9 years' experience of engaging with people living with dementia, their families, and carers as well as training those working in health, social care and care home settings. Below, we share direct quotes from those we have engaged with.

“It's probably **one of the very few positive things that has happened in my husband's life** since his dementia took over. It took him away from his condition and back to his tastes as a person. It actually brought a little bit of him back for a while. I found it a very moving experience.” – Family member/carer

“Music has a way of connecting to you...and that really can make you better. So, in a very genuine sense **I think we should be prescribing it**. Doctors should be saying go away and listen to the music you grew up with when you were 16. What we tend to do is to treat that a bit flippantly, but I think **we need to be taking it more seriously**” - Person living with dementia

“Music from your youth never leaves you” - Person living with dementia

“I've seen the power of using Playlist for Life in hospitals. I'd love to see this more widely used across all health board... it shouldn't be a luxury item. **It should be a part of care for every person living with dementia**.” - Dementia Nurse Consultant, NHS

“Life-saving” - Person living with dementia

“Music is often and certainly in my case the last piece of communication...my own father could not speak but he could sing a song until the end of his life. This provided an opportunity for shared leisure and love.” - Family member / carer

*“Playlists **lift some of the pressure off being a carer.**”* - Family member / carer

“Using playlist is the best thing I ever did for my mum...I wish I'd known about it sooner” – Family member / carer

*“(Personalised music) it's part of someone's care, like a prescription. **We use it prior to medication** and sometimes medication isn't needed if the person can connect with their playlist”* - NHS dementia nurse

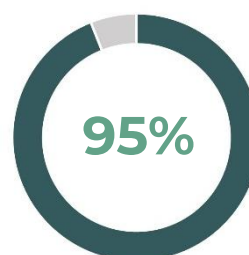
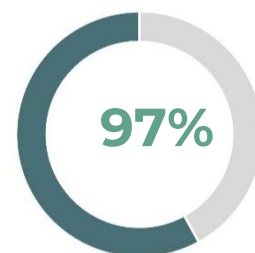
*“builds the trust and it **inevitably makes caring easier** for everybody.”* – Professional carer

Diagram 1: Key themes from our engagement events and how personalised music can help

People we engaged with:	How personalised music playlists can help
Want to be supported to stay in their home, with flexible support and flexible use of their Self-Directed Support (SDS) budget.	Personalised music can reduce stress, falls, improve mood and alertness making daily live tasks at home more manageable. Some suggested their SDS funding could be used to pay for music, a device, or a streaming service
Want information on interventions that help people better support themselves or be supported should continue to be given at diagnosis	Personalised music is a positive and enjoyable task that can improve quality of life 'now' at an early stage which can ensure better person-centred care along their journey
Want a more social model of dementia care and support rather than a clinical model	Personalised music can be used to improve quality of life at all stages of dementia and in all settings. A truly person-centred intervention that can reduce the need for some medication

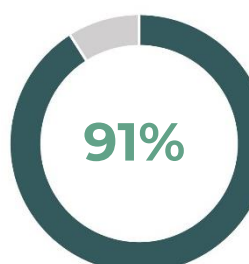
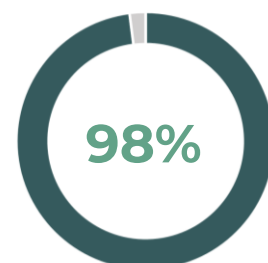
Diagram 2: Data from our online survey. 57 individuals responded including people living with dementia, family members or carers and people working or volunteering to support someone living with dementia

97% reported at least one benefit of using personalised music playlists. 58% reported 3 or more benefits, including improved quality of life



95% feel personalised music should be included, promoted, and encouraged in the new national dementia strategy

98% think information about personalised music playlists should be more widely available in health and social care settings



91% feel it'd be helpful to have information on personalised playlists at the time of diagnosis

Our offer of support

We have a tried and tested training programme for health and social care staff, care home staff and other community health professionals to integrate the use of personalised music into person-centred dementia care. We have delivered our training to over 8000 health and social care professionals across the UK so far. We also have a growing network of over 500 Help Points in Scotland, places where people in the community can access free resources and support to make and use personalised music playlists. Our resources are available for people to access and use now and our training and e-learning courses can be easily rolled out to the NHS, health and social care staff and students.

Case study 1: Harry

Harry had severe dementia and lived in a care home. Margaret, his wife, visited every day and left most days in tears. Prior to introducing his playlist Harry hadn't spoken for around 6 months and rarely opened his eyes. After listening to his playlist, Harry opened his eyes, started to sing and speak again. His mood was lifted, and his nutrition also improved.

Margaret said *"Being a carer is hard and I found I started to see Harry as a patient. But those last two years listening to his music together let me fall in love with him again...Playlist for Life made a big difference to Harry it brought him back to me."*

Case study 2: Carol

Carol lives with young onset dementia. She first came across personalised music playlists at a Playlist for Life 'Help Point' at St Andrew's Church in Carluke. Carol was supported at St Andrew's Church 'Help Point' to make a personalised music playlist with help from volunteers from the local school. Since then, Carol has helped other people living with dementia to learn about the power of personalised music by delivering talks, making videos and encouraging others to make their own personalised music playlists.

Carol said *"Playlist for Life is a wonderful thing. You've no idea how happy it makes me. I don't need to remember I've got dementia. I can just put my playlist on and I'm dancing and singing my heart out. It just makes you so happy."*

Carol's husband and carer Malcom said *"It's made our relationship stronger. We have been married 18 years. Carol has a lot of memories which I knew nothing about. It really has enriched my life. We always have something to talk about and it's because of this playlist."*

FIND OUT MORE

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