

'We're doing something together'

HOMESIDE is an international study investigating the effects of music and reading activities for people living with dementia and their family carers. The project's Australian research team of **Kate Teggelove, Libby Flynn, Felicity Baker** and **Jeanette Tamplin** discuss the initial feedback from participants and plans for a related music app to regulate agitation

The University of Melbourne is leading an international study exploring music and reading as non-pharmaceutical approaches to optimising care and connection for people living with dementia. First reported in *AJDC* in 2018 (Vol 7 No 3), the HOMESIDE study is progressing with vigour, having now enrolled well over two-thirds of the 500 families it aims to recruit by the time data collection ceases in late 2022.

Whilst results from the large-scale trial will take some time to collate and analyse, interviews with study participants are already identifying positive perceived benefits for both those living with dementia and their loved ones who care for them at home.

This article gives an overview of the psychosocial interventions used in the HOMESIDE study for people with dementia, some of the initial themes and feedback emerging from interviews with study participants and plans to scale-up the music intervention by developing a music therapy-informed mobile technology platform.

Home-based interventions

Families play a vital role in providing care for people living with dementia (Livingston *et al* 2017). Their personalised care not only directly benefits the person living with dementia by enabling them to remain at home in a familiar environment, it also represents a significant economic contribution to society. Caregivers often find caregiving satisfying and rewarding, however the task of managing often-distressing



Music therapy is a research-based allied health profession in which music is used to actively support people as they aim to improve their health, functioning and wellbeing. All photos courtesy the HOMESIDE Australia team

responsive behaviours can override their capacity to cope, leading to negative physical and mental health including fatigue, depression, burnout, and illness (Papastavrou *et al* 2007). A deterioration in caregiver wellbeing may have a negative flow-on effect on the wellbeing of the person with dementia they are caring for, leading to increased responsive behaviours and a move into residential care earlier than desired.

Dementia Australia (2018) predicts there will be almost 1.1 million people living with dementia in Australia by 2058, costing the economy more than \$36.8 billion. Nearly 85% of costs are related to family and social expenses, rather than medical care. With the increase in numbers of people with dementia and the escalating costs of care, the development of home-based interventions to improve the

wellbeing of people with dementia and their families, and simultaneously reduce personal and societal health care costs, has never been more important.

The case for psychosocial interventions

The Lancet Commission on Dementia Prevention, Intervention and Care (2017 & 2020) proposed that pharmacological treatment of behavioural and psychological symptoms of dementia (BPSD)* should be reserved for those with very severe symptoms. With a turning away from pharmacological management, evidence-based, person-centred psychosocial interventions (Livingston *et al* 2020), such as music therapy, are increasingly becoming recommended first-line approaches in responding to neuropsychiatric symptoms (Guideline Adaptation

Committee 2016).

Music therapy is a research-based allied health profession in which music is used to actively support people as they aim to improve their health, functioning and wellbeing.

The Lancet Commission highlighted music therapy as a non-pharmacological intervention effective in reducing BPSD* (Livingston *et al* 2017) which aligns with research that demonstrates music therapy can reduce neuropsychiatric symptoms such as agitation, aggression, apathy, motor disturbance and psychosis (Tsoi *et al* 2018; Van der Steen *et al* 2018; Werner *et al* 2017; Zhang *et al* 2017). Further strengthening this evidence, the recent Australian Royal Commission into Aged Care Quality and Safety *Final Report*, Recommendation 38, (Commonwealth of Australia, 2021) requests that by 2024, all

aged care facilities improve access to allied health services, specifically outlining that each facility should employ either a music or art therapist.

Much of the music therapy research to date has been conducted within formal aged care residential settings and music therapy is not always accessible to people with dementia and their caregivers who are living in the community.

One home-based music therapy-informed intervention delivered by caregivers in the home setting addressed this issue of accessibility, with findings indicating potential benefits to spousal relationships, increased satisfaction with caregiving and improved wellbeing markers for both the family carer and the person living with dementia (Baker *et al* 2012). To date, no other studies have examined similar outcomes in a home-based setting in a large, fully-powered study (ie, a study that has an adequate sample size to determine statistically significant changes in chosen outcomes).

Our project, HOMESIDE,

funded through the European Union initiative Joint Programme for Neuro-degenerative Diseases and by Australia's National Health and Medical Research Council, was designed to address this knowledge gap.

Furthermore, it has created an opportunity to explore the effects of alternate leisure activities, namely literary or word-based activities, that have been also noted to benefit people living with dementia (Juniarti *et al* 2021; Longden *et al* 2016) but have similarly lacked adequate large-scale investigation.

The HOMESIDE study

The HOMESIDE study, which began in early 2020, involves participants across five countries and is overseen by a consortium of universities from Australia, Norway, the United Kingdom, Germany and Poland (www.homesidestudy.eu). Conducted entirely online, the study focuses on training family caregivers of people living with dementia to use music or literacy-based activities in strategic and targeted ways.

Qualified music therapists and occupational therapists

encourage and support carers to implement activities including reading aloud, listening to audiobooks or music, playing word games, dancing, singing, playing instruments and reminiscing over magazines (to name but a few) as a way to not only manage responsive behaviours, but to also promote positive mood and quality of life in both the carer and person living with dementia, and to create meaningful opportunities for shared experiences between loved ones.

Therapists help carers to optimise use of activities within the bounds of functional capacity for the person with dementia and take time to understand individual life experiences, tastes and preferences when tailoring activities for use by study participants. Importantly, the therapists support carers to understand which music or reading activities to use at different times of the day and for different purposes, and to optimise the use of them.

Kate McMahon, a registered music therapist and

HOMESIDE trainer, notes: "Every family we work with brings a different set of life experiences and needs, so it's been really important to work closely with them and tailor a program to suit their lives and interests. HOMESIDE is flexible enough to be adapted to so many different preferences, and the real magic happens when participants realise the ease with which they can integrate some new shared activities into their weeks".

Those who enrol in the trial are randomly allocated to either music or reading conditions, or a control group. Families in the music and reading conditions receive three online training sessions (via Zoom or FaceTime) to extend their skills and confidence to use music or reading strategies and are asked to create and/or share music or reading experiences with their loved one at least twice per week for 12 weeks.

Raw data from interviews conducted with participants who have already completed the study is highlighting some common themes. This data will eventually be analysed systematically by the research team alongside the vast amount of quantitative data. Of note during initial processing, however, is reporting from participants that music or reading has become an enjoyable go-to inclusion in daily routines:

"It's highlighted the centrality of music and the calming, almost sedative effect of that. And if my loved one is uptight or having a 'bad noggin' day, as I term it, then I'll certainly be putting music on. One of the first questions I'll pose is, 'hey, should we get some music going?'" (Music #28).

"I have enjoyed the fact that we're actually doing something together 'cause we don't have a lot of activities that we can do together... It's not something that we have thought about greatly in the past. But this, making a determined effort to do it, it's been quite enjoyable



The HOMESIDE study is exploring the effects of alternate leisure activities, including literary or word-based activities, that have been also noted to benefit people living with dementia

The MATCH app in action

To illustrate how the MATCH app works with a hypothetical example, imagine Jeff, who is in his 80s and is being cared for by his wife. He is mobile but can become confused and tends to become more agitated later in the day. He may walk around the room, begin to repeat verbalisations and find it hard to settle.

Using the MATCH integrated sensors, which have already 'learned' Jeff's typical behavioural patterns, the app will detect a change in these, indicating his arousal levels are rising and that he is at risk of becoming agitated to the point where it may be difficult for his wife to help calm him.

The MATCH app will then select music, based on Jeff's music preferences, that 'match' his agitation level, likely with a faster-paced tempo and more complex dynamics (including volume, instrumentation etc). The music will then continuously adapt through a playlist to regulate Jeff's arousal and calm him down (eg, gradually moving to music that is slower-paced and gentler in timbre, rhythm etc).

actually" (Reading #21).

In addition, there is commonality in carers appreciating the opportunity to engage in a meaningful activity that values the identity of their loved one living with dementia, and moves beyond function-only caring:

"It made me feel that I was helping my mother in a different way to the one I normally do, which is mostly practical...this was more, well, weirdly cerebral! It sort of got her memory going again and she feels empowered when she's reading things and she remembers them" (Reading #45).

"This has really taught me how to care for Mum holistically. You know, inside it makes her so happy. And that's what I was lacking. I didn't know what I was lacking as a carer until I found what Mum needed. This has been a really solid foundation for her" (Music #04).

"I mean I would say it's made life easier...altogether it has improved the quality of our relationship and the quality of her life" (Reading #45).

The perceived benefits reported by participants gives confidence to the research team that the study will contribute meaningfully to the understanding of non-pharmacological approaches to optimising quality of life for

people living with dementia, through the support and upskilling of their family carers:

"It certainly had the effect of slowing you down and relaxing you totally, taking your mind away from anything that might have been totally absorbing you, centreing you, making you feel peaceful and harmonising the atmosphere. Definitely my confidence has grown participating in the music. I was probably just needing a bit of support and purpose to motivate me" (Music #04).

Scaling it up

The research team's growing confidence led to recent exploration of ways that the HOMESIDE music intervention could be scaled up to enable greater access for

more people caring for someone living with dementia. A \$2 million grant from Australia's Medical Research Future Fund was announced in June 2021 to extend the HOMESIDE project by developing and clinically testing a music therapy-informed mobile technology platform.

In collaboration with researchers at the Commonwealth Scientific and Industrial Research Organisation (CSIRO), the Music Attuned Technology for Care via eHealth (MATCH) project aims to develop a mobile technology eHealth care program which will teach carers to regulate arousal, reduce agitation, and manage responsive behaviours in the person they're caring for. By using a combination of

wearable and in-place (environmental) sensors, the MATCH mobile application will be able to detect and interpret continuous changing levels of arousal and agitation in a person living with dementia.

Effectively, artificial intelligence and machine learning will monitor and analyse movement and sound cues that are unique to that individual. With this information, the MATCH app will be able to auto-suggest and synchronously adapt appropriate music to help regulate agitation, in turn revolutionising how people living with dementia are supported to live meaningful lives (see box above for an example).

Field testing of the MATCH app will be conducted from 2023-2025, with the finished MATCH app product scheduled for public release following the completion of the study. ■

To learn more about the HOMESIDE study in Australia and register your interest in participating, visit www.homesidestudy.eu/australia. Enrolments close in May 2022.

***Editors' Note:** The *Australian Journal of Dementia Care* (AJDC) acknowledges there is ongoing debate over the use of the term BPSD or 'behavioural and psychological symptoms of dementia' in relation to people living with dementia. The AJDC's editorial policy is to use the term 'responsive behaviour/s' to underline the importance of seeing agitation, calling out, aggression, constant walking and disinhibition primarily as expressions of need requiring an individual response in each case. However, we do publish articles that include these terms when it is clear they are used in the context of the research or practice being described and the author's intent is to promote person-centred care.



■ From left: Kate Teggelove is a Clinical Trial Manager for the HOMESIDE study in Australia, a Registered Music Therapist, and a Research Fellow and tutor with the Department of Fine Arts and Music, University of Melbourne; Dr Libby Flynn is a Clinical Trial Manager for the HOMESIDE study, associate investigator on the 'MATCH' project and an early career Research Fellow in the Department of Fine Arts and Music, University of Melbourne; Professor Felicity Baker is International Principal Investigator on the HOMESIDE project, overseeing its implementation across five countries, and Associate Dean (Research) for the Faculty of Fine Arts and Music, University of Melbourne; Dr Jeanette Tamplin is Country Leader for the Australian arm of the HOMESIDE clinical trial, a Senior Lecturer at the University of Melbourne, a Registered Music Therapist, specialising in neurorehabilitation, and President of the Australian Music Therapy Association. To contact the authors, email homeside-australia@unimelb.edu.au



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