

Independent Review of NDIS art and music therapy supports: A Dementia Australia Submission

Dementia Australia is the peak dementia advocacy and service delivery organisation in Australia. As the trusted source of information, education and support services, we elevate the living experience of people impacted by dementia to advocate for positive change.

Dementia prevalence in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person's functioning. Memory changes are only one of a number of symptoms associated with dementia, which can include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is ultimately a terminal condition.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia and this is projected to increase to more than 812,500 by 2054. Of the 421, 000 people living with dementia, almost 29,000 of these are living with younger onset form of the condition, including people in their 30s, 40s and 50s. This figure is expected to rise to almost 41,000 people by 2054.¹

Introduction

Dementia Australia is grateful for the opportunity to make a contribution to this important review. The 2008 United Nations Convention on the Rights of People with a Disability (UN-CRPD) recognised dementia as a cognitive disability but unlike physical disability, understanding of dementia as a disability remains limited in the health care sector and broader community. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised, misunderstood or rendered invisible.

Unlike many other chronic and progressive diseases, the trajectory of dementia can vary significantly. The condition will be experienced differently for each person, with equally variable changing abilities and needs over time. This will in turn require a diverse and evolving range of supports and services, including and importantly, allied health services.

Allied health practitioners play a critical role in assessing and supporting the abilities and strengths of a person living with dementia, and tailoring services to support independence and to meet their changing needs. Our recent policy position statements reflect this and include: **Access to Allied Health services for people living with dementia**, **Physiotherapy and Dementia**, **Speech Pathology and Dementia** and **Occupational Therapy Australia and Dementia Australia's Joint Position Statement**,

In the context of this increased focus on the role of allied health practitioners and services, Dementia Australia has highlighted the vital role that creative arts engagement, including art and music therapy, can play in maintaining the strengths and abilities and supporting wellbeing of people living with dementia, and those caring for and supporting them. Two recent Dementia Australia discussion papers explore these benefits in detail: **'I believe in the magic of it': Creative arts engagement, wellbeing and dementia** and **'People in the community' are the challenge and the solution: Towards a dementia-friendly future**.

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.

This submission draws on the research that informed these papers (see the attached reference list) and outlines the evidence for the many benefits of art and music therapy for people living with dementia.

The evidence for the benefits of art and music therapy for people living with dementia

In the absence of a definitive disease-modifying treatment for dementia, psychosocial approaches to dementia support and care have become increasingly important. The role of creativity, self-expression and social engagement have been critical in conceptualising and creating supportive environments in a range of settings.²

Creative arts-based activities and programs, including music and art therapy, have become an area of increasing interest and significance in this context. Over the last two decades, research looking at creative arts activities ranging from programs involving 'passive' engagement in art in residential aged care settings, to participatory arts-based community activities and public institution arts-based programs have provided qualitative evidence of the tangible benefits of creative involvement for people living with dementia. Studies have shown that engaging people living with dementia in creative arts practices '... aids communication, expression, confidence, social participation, and a sense of freedom.'³

There is broad consensus in the literature on the many potentially positive impacts of involving people living with dementia in the creative arts, including art and music therapy. This includes improvements in functional capacity (increased verbal fluency, improved cognitive processes including concentration, and increased mobility, strength and balance) in addition to emotional and psychological benefits (positive effects on mood, behaviour, wellbeing, enhanced sense of meaning, purpose and identity and promotion of social engagement and connectedness).^{4 5}

There are a diverse range of therapeutic interventions and approaches that can be categorised under art and music therapy. These must be tailored to each individual living with dementia, depending on their background, interests and changing skills, abilities and needs. Rather than making unhelpful distinctions about the appropriateness or efficacy of a specific form of art or music therapy or approach, we have outlined the literature in relation to a range of activities and therapies.

Decades of research have supported the broad benefits of involvement in music-related activities for people living with dementia, including listening to music, music appreciation programs, playing musical instruments and singing. A recent meta-analysis of eight studies of music therapy and dementia found that '... the intervention with music improves cognitive function in people living with dementia, as well as quality of life after the intervention and long-term depression.'⁶ Music-related activities have been a consistent focus of research specifically exploring music-based participatory and community arts activities for people living with dementia.

² Sauer, P.E., Fopma-Loy, J., Kinney, J.M. & Lokon, E. (2016). '“It makes me feel like myself”: Person-centred versus traditional visual arts activities for people with dementia.' *Dementia* 15, pp. 895-912.

³ Zeilig, H., Killick, J. & Fox, C. Chris (2014). 'The Participative Arts for People Living with a Dementia: A Critical Review.' *International Journal of Ageing and Later Life* 9 (1): 7–34.

⁴ Baines, Patricia (2007). *Nurturing the Heart: creativity, art therapy and dementia*. Quality Dementia Care Series No. 3, September, p.9.

⁵ Basting, A. (2014). 'The arts in dementia care', in *Excellence in Dementia Care: Research into Practice*, 2nd Ed, Eds Murna Downs and Barbara Bowers, McGraw Hill Education, Open University Press, p 137.

⁶ Moreno-Morales, C., et al. (2020). "Music therapy in the treatment of dementia: A systematic review and meta-analysis." *Frontiers in medicine* 7 , p.160.

A series of recent Australian and international studies have investigated the benefits of singing in various settings, from one-on-one approaches for carers using 'mindful music' to group singing and choirs in community-based settings and aged care homes.^{7 8}

Studies have shown that listening to music 'lights up the brain' in a number of places forming a series of musical networks. These networks are thought to be relatively unaffected by changes in the brain associated with dementia. This explains in part why people living with dementia, including in the advanced stages, have excellent recall of music.⁹ The emotion associated with music is also thought to play a role in explaining why music from the formative periods of life, particularly young adulthood, is so well retained.

A modest but growing research focus has shown the specific benefits of group singing for people living with dementia including movement, social engagement, stress reduction and cognitive and memory stimulation.¹⁰

As with music-based activities, the benefits of actively engaging in painting, drawing and other visual arts-related practices have provided a concerted focus of recent research. Systematic reviews have highlighted the broad benefits of these activities for people living with dementia and the specific impacts of participatory, community-based programs and activities.^{11 12}

Researchers and practitioners working in the area acknowledge that there is a substantive body of anecdotal accounts supporting the positive impacts of creative arts engagement for people living with dementia but evidence-based research is limited.¹³ There are a number of reasons for this, the most prominent of which is the wide variation in the scale, design, context and delivery of arts-based activities and programs.

The methodologies used to evaluate the efficacy of creative arts-based programs are equally varied. This can include qualitative data gathered through interviews, focus groups, self-reported feedback and observational data looking at quality of life indicators and changes in mood and behaviour. It can also include studies incorporating physiological measures such as changes in cortisol levels.¹⁴ The impact of an activity or program can be difficult to measure accurately, particularly when compared with other psychosocial interventions and pharmacological treatments in the field of dementia support and care. There is consensus in the field that further studies are required, developing the scale and improving design and methodological rigour, particularly for programs and activities delivered in aged and health care settings.¹⁵

⁷ Unadkat, S., Camic, P. M. & Vella-Burrows, T. (2017). 'Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia', *The Gerontologist*, Volume 57, Issue 3, 1 June 2017, Pages 469–478, <https://doi.org/10.1093/geront/gnv698>

⁸ Pearce, E., Launay, J., Machin, A. & Dunbar, R.I.M. (2016). Is group singing special? Health, well-being and social bonds in community-based adult education classes, *Journal of Community and Applied Social Psychology*, Volume 26, Issue 6, pp. 518–533.

⁹ Jacobsen, J. H., Stelzer, J., Fritz T.H., Chételat, G., La Joie, R. & Turner, R. (2015). 'Why musical memory can be preserved in advanced Alzheimer's disease.' *Brain*; 138: pp. 2438–50.

¹⁰ Lee, S., O'Neill, D. & Moss, H. (2022). 'Promoting well-being among people with early-stage dementia and their family carers through community-based group singing: a phenomenological study', *Arts & Health*, 14:1, 85 - 101, DOI: 10.1080/17533015.2020.1839776

¹¹ Deshmukh, S. R., Holmes, J., & Cardno, A. (2018). 'Art therapy for people with dementia'. *Cochrane Database of Systematic Reviews*, Issue 9. Art. No.: CD011073. DOI: 10.1002/14651858.CD011073.pub2.

¹² Emblad, S. Y., & Mukaetova-Ladinska, E. B. (2021). Creative art therapy as a non-pharmacological intervention for dementia: A systematic review. *Journal of Alzheimer's Disease Reports*, 5(1), 353-364.

¹³ Basting, A. (2014). 'The arts in dementia care', in *Excellence in Dementia Care: Research into Practice*, 2nd Ed, Eds Murna Downs and Barbara Bowers, McGraw Hill Education, Open University Press, p 137.

¹⁴ D'Cunha, N. M., McKune, A. J., Isbel, S., Kellett, J., Georgousopoulou, E. N., & Naumovski, N. (2019). 'Psychophysiological responses in people living with dementia after an art gallery intervention: An exploratory study.' *Journal of Alzheimer's Disease*, 72(2), 549-562.

¹⁵ Young, R., Camic, P. M., & Tischler, V. (2016). "The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review," *Aging & Mental Health*, Vol. 20, no. 4, pp. 337–351.

The argument for the benefits of art and music therapy for people living with dementia

While acknowledging the current limitations in the field, it is also important to foreground a shift in thinking about the impacts and benefits of engagement in music and art therapy for people living with dementia.¹⁶

As part of this conceptual shift, emphasis is given to the importance of spontaneous or ‘in-the-moment’ experiences and the broader benefits of participation and connection.¹⁷

‘There is strong evidence in support of using participatory arts for dementia, regardless of art form. In-the-moment and person-centred approaches were deemed impactful.’¹⁸

In this more nuanced understanding of the benefits of art and music therapy, encouraging opportunities for experiential, personally meaningful creative expression and social engagement are key, rather than quantitative, clinical or other outcomes or the specific production of a work of art.

‘... the proposition is to move away from the concept that creative art therapy should be used as a medical intervention with the purpose of alleviating symptoms and caregiver burden and, instead, incorporate art production as an activity for the purpose of life fulfilment and creative expression. This should lead to the focus being on more person-centred care outcomes such as quality of life and wellbeing.’¹⁹

The importance of collaboration and co-design have also been central to this conceptual shift, with the focus increasingly on designing and delivering activities ‘with’ people living with dementia rather than ‘for’ participants. Being actively involved in shaping the content and objectives of art and music therapy programs and activities encourages outcomes for people living with dementia that are less about measurables and more about supporting ‘... agency, engagement, purpose, meaning, satisfaction, and acquisition of skills.’²⁰

Conclusion

Dementia Australia believes that art and music therapy can provide an important source of functional improvement, social engagement and emotional wellbeing for people living with dementia. Recent research and practitioner initiatives have focussed on qualitative measures and outcomes of creative engagement, emphasising the importance of ‘in the moment’ and spontaneous experiences, social engagement, and a sense of purpose, identity and meaning. The strong anecdotal evidence in support of these findings should be accorded serious consideration when evaluating the therapeutic value of art and music therapy as part of a vital range of allied health services that should be available, and appropriately priced, for people living with dementia with access to the National Disability Insurance Scheme.

Dementia Australia welcomes the opportunity to discuss any of the information provided above in more detail.

The Policy team can be contacted on: policy@dementia.org.au

¹⁶ Bazooband, A., Courtney-Pratt, H., Tierney, L., & Doherty, K. (2023). ‘Engaging in participatory community-based arts: Perspectives of people living with dementia’. *Health & Social Care in the Community*, 2023

¹⁷ Collingham, H., Durrant, A., & Vines, J. (2020). ‘Making In The Moment: Insight from Participatory Arts for Co-Design Practice in Dementia Care Settings’. In *Proceedings of the 6th International Conference on Design4Health*, pp. 122-128.

¹⁸ Ward, M. C., Milligan, C., Rose, E., Elliott, M., & Wainwright, B. R. (2021). ‘The benefits of community-based participatory arts activities for people living with dementia: a thematic scoping review’. *Arts & health*, 13(3), 213.

¹⁹ Emblad, S. Y., & Mukaetova-Ladinska, E. B. (2021). ‘Creative art therapy as a non-pharmacological intervention for dementia: A systematic review’. *Journal of Alzheimer's Disease Reports*, 5(1), 353-364.

²⁰ Bazooband, A., Courtney-Pratt, H., Tierney, L., & Doherty, K. (2023). ‘Engaging in participatory community-based arts: Perspectives of people living with dementia’. *Health & Social Care in the Community*, 2023