

I believe in the **magic** of it

Creative arts engagement,
wellbeing and dementia

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“

The bottom line for me since I got my diagnosis is how do I go out into the world and show that I'm still functioning... that we still have something to contribute, we can still be creative, we can continue to be engaged? ”

Dr Janet Thomas, writer



Executive Summary

- Dementia is one of the most significant health and social challenges facing Australia and the world.
- Community understanding about dementia in Australia is still limited and people living with dementia and their family members and carers continue to experience stigma and discrimination.
- Engaging people living with dementia in the creative arts can improve their wellbeing by providing a range of benefits, including cognitive and physical stimulation, social engagement, creative expression, and a sense of identity and purpose.
- Engagement can take many forms, but active or participatory engagement, including collaborative and co-designing approaches to arts activities, provides tangible benefits for wellbeing.
- Carers and family members also benefit through their own involvement in arts-based activities and the improved wellbeing and quality of life of the person they are supporting.
- Community understanding of dementia can be deepened by showcasing the creative skills and abilities of people living with dementia and the contribution they can continue to make through arts-based activities and initiatives.
- Creative arts activities encourage cognitive, physical and social stimulation, which in turn offers significant benefits in dementia risk reduction and disease management.

Aboriginal and Torres Strait Islander peoples should be aware that the following pages may contain images or names of persons who have since passed away.

Dementia in Australia

Dementia is an umbrella term that describes a group of symptoms caused by brain diseases. There are a number of different types of dementia with a variety of symptoms, but the condition is progressive and life-limiting.

More than **400,000 Australians are living with dementia in 2023**, including more than **28,650 people with younger onset dementia**. Without a medical breakthrough, the number of people with dementia is expected to increase to **more than 800,000 by 2058¹**.

Dementia is one of the largest health and social challenges facing Australia and the world and at the time of writing, there is no definitive, accessible disease-modifying treatment or 'cure' for the condition.

Results of successive surveys show that a third of Australians (32%) find people living with dementia frightening, an increase from 23 per cent of participants a decade ago.² Survey findings also revealed that 80 per cent of carers and family members believed that people living with dementia were treated differently in the community. These results reflect an ongoing lack of awareness and understanding about dementia, and how to respond appropriately to someone living with the condition.

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, community understanding of dementia as a disability remains limited. 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 or rendered invisible. People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they don't appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.³



Dementia Advocate Juanita Hughes

The limited community understanding and lack of insight into the lived experience of dementia can lead to stigma and discrimination, which can have real and distressing repercussions for people living with dementia, their families and carers. People may avoid social interaction and be discouraged from seeking critical medical and social services and support, resulting in increasing social isolation, reduced wellbeing and poor quality of life.

Supporting wellbeing: psychosocial not psychotropic

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Music, dance, storytelling, expressive artwork, gardening, intergenerational activities, pet therapy and other creative, relationship-oriented approaches that tap into quintessential elements of our humanity improve quality of life for elders and their caregivers far more than current drugs⁴”

The absence of a definitive disease-modifying treatment for dementia, and the limited efficacy of pharmacological approaches including the use of psychotropic medications in response to changed behaviour, has focussed the attention of researchers and practitioners on the importance of psychosocial approaches to support the wellbeing of people living with dementia. Pioneering psychologist and dementia care specialist Tom Kitwood emphasised the critical role that a positive physical and social environment plays in supporting identity and wellbeing. Kitwood’s concept of ‘personhood’ – acknowledging, supporting and respecting the identity of the person living with dementia – established a foundational model for thinking about the profound impact of social interactions and the need to support an ongoing sense of meaning and purpose in the lives of people with dementia.⁵

In the decades following Kitwood’s formative contribution to the field, researchers and practitioners have developed his ideas around supportive environments for people living with dementia. The role of creativity, self-expression and social engagement have been critical in conceptualising and creating supportive environments in a range of settings.⁶

Creative arts-based activities and programs 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 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.’⁷ Family members, carers and the broader community benefit from these activities in terms of positive impacts on health and wellbeing for those supporting people living with dementia, and the contribution that meaningful involvement in the creative arts makes to improving awareness and understanding of dementia.

The Australian Government’s most recent national cultural policy document recognises the growing interest in and benefits of engagement in the creative arts in supporting wellbeing and quality of life for people living with dementia, and as a significant dementia risk reduction measure.⁸ Acknowledging these important dual benefits, this paper explores the role of creative arts engagement by profiling a diverse range of individual and group activities and programs, including initiatives led or co-designed by people living with dementia.

Defining engagement in the creative arts

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The possibility that a person living with dementia may wish to express herself or himself in words or images may seem surprising to those who have not seen those individuals deep in creative concentration⁹”

The ‘creative arts’ is an expansive field that includes but is not limited to visual arts (architecture, painting, sculpting, drawing, ceramics, filmmaking and photography), literary arts (fiction, drama, poetry and prose) and the performing arts (dance, drama, music and theatre). Decades of research has shown that engaging in creative arts activities can contribute to the quality of life and wellbeing of an individual at every stage of the life course.¹⁰ Over the last two decades, there has been an increasing interest in the positive effects of creativity in specific contexts and cohorts, from the connections between creative play and accelerated childhood development to harnessing creative practices to enhance corporate productivity.

The benefits of engaging people living with dementia in creative arts activities is a rapidly expanding area of this research focus. Studies have explored a diverse range of creative arts activities, supporting different levels of engagement and in a range of settings including aged care homes and other health care settings, community-based participatory arts, and programs facilitated in public institutions such as art galleries, museums and libraries.

Researchers looking at the benefits of creative arts engagement for people living with dementia have predominantly focused on activities involving painting, listening to and making music, dancing, singing, reminiscing, storytelling, and life review. The individual and group initiatives profiled in this paper encompass these key domains, and in some examples combine multiple art forms and practices.



Dementia Advocate Gilbert Jan and his daughter Sharon.

‘Passive’ forms of creative engagement have traditionally been described as activities done ‘for’ people living with dementia, involving staff or facilitators ‘entertaining’ rather than actively involving the person. ‘Active’ or participatory arts-based activities and programs encourage direct participation, supporting choice in creating the content and shaping the activity and its outcomes.¹¹

The idea of a ‘creative arts continuum’ offers a more nuanced way of thinking about the benefits of different levels of passive and active engagement.¹² The impact of works of art can be understood on this ‘continuum’. It could encompass the positive ‘passive’ effect of paintings on the walls of a communal area of an aged care home and gallery-based ‘art appreciation’ programs involving discussions and individual responses to an artwork, to engaging directly in the production of paintings.

There is considerable diversity in the kinds of activities and programs researchers and practitioners have developed and evaluated, and the level of engagement involved, but there is consensus on the many positive impacts of involving people living with dementia in the creative arts. These benefits include but are not limited to:

- Positive emotional responses (including opportunities for reminiscence, storytelling and life review)
- Increased verbal fluency
- Improved cognitive processes including concentration
- Positive effects on mood, behaviour and wellbeing
- Sustaining a sense of meaning, purpose and identity
- Enriched quality of life
- Functional improvements including increased mobility, strength and balance
- Reduction in stress and improved attitudes of carers to the person cared for
- Promoting a sense of play, pleasure and joy, particularly in environments where it may be absent
- Deepening public understanding of the lived and felt experience of dementia by showcasing the creative strengths, skills and abilities of people living with dementia
- Reducing stigma and discrimination in the community as a result of improved understanding and awareness of dementia
- Encouraging social engagement and connectedness^{13,14}

Col and Shirley Blake offer a compelling example of the benefits of lifelong involvement in a range of different creative activities.



Photo by Jez Smith.

Stepping up and stepping out

Col and Shirley Blake's story

Col and Shirley Blake met at a dance, and have been dancing together ever since. In November this year, they will celebrate their 50th wedding anniversary. For seven of those 50 years, Shirley has lived with dementia and Col has been her carer. As he puts it, 'long time husband, short time carer.'

Col and Shirley's busy personal lives have always included physical and creative activities, from decades of running the City to Surf race to working as extras in film and TV productions, including an appearance in Baz Luhrman's epic feature film *Australia*. They have been avid fans of jive dancing, a lively style Col describes as the 'jazz of dancing'. It is a shared passion that has been an important form of creative connection all their married life. It has become even more important since Shirley's dementia diagnosis.

As Col observes,

“ When we jive, Shirley hasn’t got dementia...it is something she can do without thinking about it... she gets so much enjoyment out of it. ”

The couple were chosen to participate in the two-part ABC TV Catalyst special, *Keep on Dancing* (2022). The program aimed to demonstrate the many benefits of dancing for older people. As the only participant with cognitive decline, the 12-week filming schedule was demanding, but as Col observed, ‘I could really see the difference in Shirley ...she really picked up during the program.’ The changes Col noticed were also reflected in the pre- and post-program evaluations conducted during the filming of the series. Of the nine participants in the program, Shirley showed the most improvement in both the physical and cognitive domains. Shirley’s response to the program, and the important role that dance continues to play in her life, reflects recent research highlighting the physical, cognitive and psychosocial benefits of dance. These benefits are particularly significant for people living with dementia. Physical activity, cognitive stimulation, and perhaps most important of all, the social interaction involved in dancing, has been shown to improve the quality of life of people living with dementia.¹⁵

Col believes that social engagement, as much as the creative activity itself, offers them a tangible benefit. ‘She’s more upbeat when she comes out. She’s more relaxed and more of her old self. You can see the enjoyment.’ For this reason, he has signed them up for other creative activities, including a community choir and an art program at the Museum of Contemporary Art (MCA). The weekly Singalong

choir provides a fun, enjoyable and supportive atmosphere for people living with dementia, and their partners and carers. The musical director knows they love to dance and makes sure the repertoire includes at least one song they can get up and dance to. Col finds talking to other partners and carers valuable while Shirley's comment at the end of a recent rehearsal sums up her positive experience with the choir. 'Aren't they lovely people?'

The 'Artful: Art and Dementia' program at the MCA has provided a similarly stimulating experience for the couple. The program is led by contemporary artists and is unique in combining viewing and art-making practice - participants are given materials to take home and extend their creative engagement between weekly visits. The artist educators have observed there was often a feeling of joy within the groups, highlighting the value of shared experiences. Formal evaluation of the program has revealed consistently positive feedback with 92% of respondents agreeing that the program helps improve their overall mood, something Col can attest to.¹⁶

Col has other creative activities in his sights, including adult ballet classes for Shirley, in the firm belief that remaining socially and creatively engaged is supporting them both to live as well as possible. As he and Shirley decided when she was first diagnosed: 'we are going to go as hard as we can for as long as we can.'




Community-based creativity

Participatory, community-based creative art practices are typically delivered in community, arts, and cultural venues rather than in clinical settings, and facilitated by artists or art facilitators rather than art therapists. These activities are underpinned by encouraging direct engagement in art making itself and spontaneous interaction.¹⁷ Rather than measuring program and activity outcomes through health indicators, community-based creative arts activities and programs aim to support a sense of purpose and identity, and encourage social engagement.¹⁸

In a recent Australian study of participatory arts activities, people living with dementia identified social engagement and educational opportunities to reduce stigma associated with dementia as two of the key benefits of their involvement in these activities.¹⁹ The authors of the same study noted that ‘community-based arts activities have the potential to empower people to rely on what they can do and learn, as opposed to the abilities they are lacking or struggling with as a result of dementia.’²⁰

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.’²¹ Music-related activities have been a consistent focus of research specifically exploring music-based participatory and community arts activities for people living with dementia.



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.^{22,23}

Ross Wiseman can testify to the profound and wide-ranging impacts of being involved in a community singing group. As the driving force behind the recently formed Logan Dementia Choir, he has witnessed how group singing supports the wellbeing of people living with dementia, and the positive impacts for family members, carers, volunteers and the broader community.



The Logan Dementia Choir. Images courtesy of Ross Wiseman.

I believe in the magic of it

The Logan Dementia Choir

Ross Wiseman is a retired social worker with a lengthy career in community development and is passionate about the benefits of community activities and group work. He described being 'very shocked and angry' when he was diagnosed with dementia at the age of 74. After his diagnosis, Ross admits that '... all I was doing was sitting around feeling sorry for myself..'

The BBC two-part documentary Our Dementia Choir was his light bulb moment.

'I was sitting watching the TV and Vicky McClure and Our Dementia Choir came on ... I watched the whole show and thought, holy smoke, that's what they can do for people with dementia. That brightness, I could feel it and see it ... I thought it was a way of getting out of depression.'

Ross did some research looking at similar choirs in Australia and set about forming his own. Music teacher and therapist Gail Godfrey was initially drafted to help find a director but ended up taking on the role herself. Gail describes Ross as the driving force behind the choir and a source of continual inspiration for everyone involved in the group.

“

I was pleased that you could bring all your knowledge and passion to the group ... everyone that comes to choir is uplifted by you being there and telling your story. ”



With the support of the Logan Dementia Alliance and Support Groups Queensland, the choir started with six people and has now built to around 30 members, comprising people living with dementia and a partner or support person, and volunteers. The weekly rehearsals involve a mix of activities starting with guided meditation to relax, followed by a physical and vocal warm up. The choir listens to choral recordings, and sings unaccompanied and to recorded tracks. The repertoire is varied and primarily drawn from songs suggested by choristers, and includes everything from the Eagles and Australiana to the Seekers and Black Sabbath.

Over the last couple of decades, studies have highlighted the many benefits of choral singing.²⁴ Being part of a choir at any age has been shown to increase optimism and resilience, and the rewards are even more pronounced for older choristers. They enjoy improved physical and mental health and a better overall quality of life compared with their non-singing counterparts.²⁵ 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.²⁶

Gail has observed these powerful effects in the Logan Dementia Choir. The songs chosen by choristers are well known and often associated with earlier, formative periods of their life. 'They evoke memory and real emotion, particularly when you are 16 and 17, it's a very strong emotional tie...and a physical tie too because you move to it.'

Interestingly, there are more men than women living with dementia in the choir, and Gail has noticed the camaraderie this has created.

‘When we have a male part to sing, they all stand up together ... there’s something about the Australian male, they need each other, there’s a different energy when they’re all standing together and I think that’s really good.’

With his background in community development, Ross believed that the choir would also offer broader psychosocial benefits for his community.

‘I could see a mile away that this was going to be an obvious vehicle for people to socialise with each other and support each other so I’m expecting it’s not just the music and the singing but that that will lead also to people having close friends for the rest of their lives...and we’ve already noticed that people are doing that in the choir.’

Gail and Ross have both observed that in the course of four short months, the choir has become increasingly close and connected. Within the group, the partners of people living with dementia have formed friendships, and share experiences and support each other. Ross has also noticed that despite their initial reluctance, many partners have eventually joined in.

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I’m watching the women - they come in and sit next to their men and say I’m not going to sing and then 8 weeks later, they’re bloody well singing! ”

Since its formation in May 2023, the choir has been interviewed on Logan radio, has developed a repertoire of over 30 songs and already has four performances scheduled for the second half of the year. There are over 2000 people living with dementia in Logan, so Ross and Gail are keen to build the current choir membership to around 50, in addition to expanding the volunteer support base.

For Ross, the benefits of singing together are both individual and collective. The choir has helped him deal with his own diagnosis but the equally rewarding part has been witnessing the impact it has had on his community.

‘When they’re singing, it really lifts their spirits...we walk out on air... Eight of them came up to me after we were breaking up (for the day), saying, ‘by God we’re coming along...they were really excited about it. That was really good feedback.’

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^{27,28} and the specific impacts of participatory, community-based programs and activities.²⁹

Mornington Island Art Centre director John Armstrong sees the direct impact of engaging people in community-based visual arts activities on a daily basis at the remote island’s painting studio.

Connecting with culture and country

The Mornington Island Aboriginal Art Centre

Mornington Island (also known as Kunhanhaa and Gununa) is located in the Gulf of Carpentaria and is described as a fusion of cultures that includes the traditional custodians, the Lardil people, and the Yangkaal, Kaiadilt people and Gangalidda peoples. The island has a small community of 1200 people but a cultural history extending for 8,000 years, passed down through songlines, stories, dance and Aboriginal Lore.

The island has a long tradition of creative arts production and performance in music, visual arts and dance. The renowned Mornington Island Dancers performed at the Sydney Opera House opening ceremony in 1973. The Mornington Island Art Centre is one of the longest established Aboriginal art and cultural organisations in Australia and includes an artist studio currently supporting about 25 artists.



Painting by Agnes Kohler, Burrkunda (My Mother's Country)

The remoteness of the island has encouraged a concerted focus on cultural and spiritual themes and above all, a connection to Country. The studio is described as ‘a place of shared Culture and creativity – a place where stories are told and memories are kept alive.’³⁰

Supporting memory is particularly significant as a number of past and current artists have lived or are living with dementia. The opportunity to paint regularly and reinforce songs, stories and cultural connection has played a vital role in supporting wellbeing and ensuring they remain connected to the wider community and Country.

The centre’s director, John Armstrong, is an artist and academic with a longstanding interest and involvement in supporting Aboriginal art. John’s parents and his mother-in-law lived with dementia, so he has experience and insight into how to support people living with the condition. John has witnessed the tangible impact of creative expression and connection to the community that the studio provides for the artists living with dementia.

The sense of individual and collective identity associated with being part of the studio group is integral to this.

“

You can see when they walk in the studio they know, ‘I am here, I have come to work and I am a professional artist.’ After a couple of hours of creative work, they are slightly different people... they walk a bit taller. ”



The positive impact of the creative practice itself is illustrated by the story of one of the centre's best known artists. She lived with dementia in the last years of her life and was unable to speak for much of that time. The studio operates three days a week and John recalls the transformative effect on her mood and speech each week. Unable to speak on the first day, she would manage a word or two such as 'good morning' on the second day.

"On the Thursday, after three full days of working, she'd come up to me and throw her arms around me and say, 'I did good this week. I'll see you next week.' She went from having no words, to having full sentences because of the creative act...that reconnected those missing bits."

The studio also provides a regular opportunity for social engagement, reducing the risk of social isolation for those living with dementia. Given the community is small and many of the artists are related, the sharing of stories and memories of loved family and community members plays a crucial role in maintaining social connection.

'We get 12 – 15 artists in the studio and someone will mention someone who has passed away and I'll go and get the box of Kleenex as I know we are all going to be in tears – and we are – but it's all really therapeutic. Everyone is kept here; we have photos up in the studio of all our artists who've passed away...and we talk to them.'

Photo courtesy of John Armstrong.



Mornington Island



John was successful in applying for a Dementia Australia Dementia Friendly Communities Engagement Grant for the Arts Centre to explore the critical role of creative activity in supporting memory of stories, places and culture for Aboriginal artists living with dementia. The grant is funding a project, currently underway, working directly with the artists to identify actions and policies that encourage creativity and provide appropriate psychosocial support. The project also aims to educate studio staff, support workers, family members and carers about how to support wellbeing for people living with dementia.

The findings and resources developed from the Mornington Island project will be shared with the 14 Aboriginal and Torres Strait Islander Art Centre members with guides and recommendations for how each centre can adapt the approaches in the context of their own cultural protocols and social structures. As John observes, it is important to share the positive impacts of creative arts engagement for people living with dementia with the broader community.

“ The difference we make with the artwork is enormous. The difference we make in people’s lives is equally enormous. ”



Shifting the creative goalposts

The benefits of creative arts engagement for people living with dementia is a growing but relatively recent field of research inquiry. As both researchers and practitioners working in the area acknowledge, while there is substantive anecdotal evidence for the positive impacts, the current research data is limited.³¹ There are a number of reasons for this, the most prominent of which is the wide variation in the scale, design and delivery of arts-based activities and programs.

An expansive range of activities can be tailored to an individual person or groups and delivered across a wide range of settings. 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, through to studies incorporating physiological measures such as changes in cortisol levels.³² 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.³³



Further research is needed to explore the importance of setting, material culture and the methodological or theoretical perspectives in participatory arts and dementia research.³⁴



In addition to the call for expanded research efforts, a shift in the way researchers and practitioners think about the process of creative arts engagement has opened up a more expansive way of considering the benefits of these activities and programs. In moving away from a medical conception of the creative arts as a form of ‘intervention’ or as necessarily ‘therapeutic’ (though many activities and programs clearly do have therapeutic benefits), emphasis is given to the importance of spontaneous or ‘in-the-moment’ experiences and the broader benefits of participation.³⁵

“ 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.”³⁶

In this expanded understanding of creative arts engagement, encouraging opportunities for personally meaningful creative expression and social engagement are key rather than a clinically measurable outcome 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-centered care outcomes such as quality of life and wellbeing.³⁷



Collaboration and co-design are equally central to this shift in thinking about the impacts and benefits of engagement in the creative arts. Rather than traditional notions of programs and activities designed and delivered by facilitators ‘for’ participants, the focus is increasingly on designing and delivering ‘with’ people living with dementia. Being actively involving in shaping the content and objectives of creative arts 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.’³⁸

Collaborative and co-design approaches are also important in offering the arts sector and the broader community a powerful illustration of the skills and abilities of people living with dementia, and their capacity to continue to make a meaningful contribution. Two recent Australian projects, ‘Comusichiamo’ and ‘To Whom It May Concern’, foreground the benefits for people living with dementia of a deepened form of participation, engagement and collaboration in creative arts activities and initiatives.

Coming together with 'Comusichiamo'

'You brought me back to the past...'

Comusichiamo participant living with dementia

Dr Simone Marino migrated to Australia more than a decade ago, so he knows firsthand the rewards and challenges of making a new home and a new life in another country. As a music ethnographer, anthropologist and musician, he also is acutely aware of the potential of music and storytelling to elicit powerful memories and emotions.

Simone's grandfather lived with dementia for 10 years and he witnessed his need to tell and retell formative stories and experiences as a way of reinforcing his core beliefs and values to family members. Simone created a song for his grandfather incorporating those life stories, which they sang together. Professor Loretta Baldassar had similar experiences supporting family members living with dementia and suggested Marino combine his ethnographic research skills and musicianship to explore the relationship between a first language, music and memory. Working together in the Social Ageing (SAGE) Futures Lab established by Baldassar at Edith Cowan University, they developed the 'Comusichiamo' methodology. The approach combines personal migration stories and music associated with earlier periods of life to support the wellbeing of older Italian-born Australians living with dementia.

With the support of SAGE, Simone trialled the approach at two aged care homes in Adelaide, and with Baldassar's ongoing support, has further developed Comusichiamo as a music engagement activity as part of a collocation partnership between SAGE and Italian home care provider InCasa.

As Simone observes, older Australian migrants often experience a form of 'triple absence' in the course of their lives. First, they leave their country of origin, with the loss and grief this often involves. The process of migration can involve repression or denial of aspects of language and culture. As a consequence, a migrant might not have felt truly present or embraced in their adopted country. Living with dementia, and the associated cognitive and communication challenges, can impose a third form of loss or absence.

Simone's approach aims not only to stimulate memories, but to restore a sense of self and identity. 'Comusichiamo' involves interviews with participants and family members, exploring their stories through key themes including departing Italy, settling in Australia, career and work, marriage and children and other significant life course events. As with his grandfather's experience, Simone has found these stories are often well remembered, but if necessary, visual cues such as photos or objects, are used as memory prompts.

The other crucial component of the process is identifying the musical instruments and songs specific to the region the person migrated from. Simone believes these instruments, including the Italian lyre, bagpipes and organetto (accordion), are



the key to enter the participant's world, to access through folklore and songs and bring back their memories...



The co-composing process involves combining each person's story in a song, sung and played in a style redolent of their birthplace. Simone describes the resulting song as 'the soundtrack or soundscape of their lives.' Playing live is integral to the sensory effect of the music, allowing participants to feel the vibration of the instrument, as well as hearing the sound, replicating their past experiences.

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.³⁹ 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.

The profound impact that Comusichiamo has had on project participants can be understood in this context. Testimonials from participants and family members confirm the immediate - and lasting - benefits of the collaborative process and the potent combination of song and story.

“

I saw him come back to life.

Daughter of a participant

”

“

What did you do to Dad? It’s magic.

Daughter of a participant

”

Simone recalls an older man who had barely spoken at the start of the project, gradually opening up, making jokes and even intermittently reverting to English. Another man remarked ‘This thing is making my life longer.’ Video footage shows participants engaged, joyful, and at times deeply moved by the music.

There were also tangible benefits for family members and carers, an unanticipated but welcome outcome. As with Ross's experience with the partners of singers in the Logan Dementia Choir, Simone noted that many family members initially stayed in the background but became increasingly interested or involved. The time spent in the co-composing process allowed these 'invisible second participants' a break from caring, or encouraged improved mood and wellbeing through active involvement in the collaborative process.

Over the course of the project, Simone has remained in contact with many of the participants and their families and has on occasion been approached to play a participant's song at their funeral, testifying to the enduring impact of music as memento.

Given his background and language skills, Simone's focus has been on Italian migrants but he believes that the project's basis in storytelling and song has clear relevance for any migrant community in Australia. With the support of academic colleagues, he is seeking funding to expand the project.

**“ Witnessing the results is so gratifying,
I want to implement the approach as
widely as possible. ”**



Dementia Advocates from left, Val Schache, Dennis Frost and Nell Hawe, performing with the Australian Chamber Orchestra

Photo: ©Maria Boyadgis

Telling it how it is

To Whom I May Concern

‘To Whom I May Concern’ draws on the same elements of autobiography, storytelling and music and employs an equally collaborative creative process as Simone’s *Comuischiamo* approach, but in the production of a formal, multidisciplinary creative arts performance. Inspired by her decades of experience working with people living with cognitive impairment, American academic Dr Maureen Matthews developed a co-design process supporting people living with dementia to write a series of letters addressed “To Whom I May Concern.” The resulting script, read in performance by the authors of the letters, reflects the unique experiences of people living with dementia and puts the issues and challenges the group want to highlight, literally centre stage. It is described as ‘... a rare opportunity for people with dementia to speak without being interrupted.’⁴⁰

Tamar Krebs, Executive Director of Group Homes Australia initiated the Australian version of the production, working in collaboration with University of New South Wales academic Dr Gail Kenning, with Dementia Australia as a presenting partner. Krebs believed that Dr Kenning's research exploring the way in which art, design, and creativity can contribute to the health and wellbeing of older people, including those living with dementia, made her the perfect fit for the project.

The production involved a series of intensive workshops with the seven participants living with dementia. Over three months, the workshops focussed on different topics, from noticing changes and sharing a diagnosis of dementia to contemplating the future. Common themes emerged but the workshops refined and consolidated individual experiences so that each letter in the final script was addressed to a different person and raised specific issues.

Retired psychologist, Dementia Australia Advisory Committee Chair and cast member Bobby Redman addressed her letter to the doctors involved in her diagnosis and care. 'Doctors would not take me seriously or put my symptoms down to me working too hard but I knew something was not quite right.'

The Australian production had an additional layer of creative complexity, with the involvement of the internationally acclaimed Australian Chamber Orchestra. The musicians listened to shared stories and experiences and worked closely with Krebs, Kenning and the participants to select music that amplified the emotions and feelings expressed in the letters. Redman observed how much the music enhanced the content and impact of the script.

“

They played out what we were saying through the music and I thought it was just amazing and very powerful. ”

For Kenning, the production reinforced many of the key tenets of her research in relation to creative arts involvement for people living with dementia including the benefits of encouraging a deeper level of engagement, finding joy in creative expression and staying in the moment, the importance of genuine collaboration and the opportunity to find connection to self, others, culture and community.

For the seven participants, staging the production several times was an important chance to convey the diversity of their experiences to different audiences, including one comprised primarily of health professionals. Seeing and hearing people with dementia recount their stories with uncompromising honesty and humour gave health professionals and the broader community critical insights into the lived experience of dementia. The production also offered a powerful affirmation of the participants' strengths and abilities and their capacity to make a meaningful contribution, something Bobby Redman was acutely aware of.

“

Writing the letter and preparing for the performance gave me the chance to process what happened and to also to advocate for people living with dementia which is very important to me. ”

Advocacy, and an emphasis on supporting the creative strengths and abilities of people living with dementia, is something that writer Janet Thomas has embraced since her own diagnosis.

Rewriting the ‘misery narrative’ of dementia

Janet Thomas has been a writer for as long as she can remember. At around four years of age, she was so intrigued by the look and feel of the books her mother read, she cobbled together pages from her grandmother’s note pad, drew stick figures and squiggly lines, and fashioned a literary facsimile of her own. The fact that she could read but not write did not deter her. As she recalls, even at that very young age, ‘I thought if I could read it, I could write it.’

It was the beginning of a lifelong fascination with reading, writing, studying and teaching literature. Inspired by Germain Greer’s feminist call to arms, *The Female Eunuch*, Janet began a personal journal that she has continued for most of her life. It was an endeavour she describes as a ‘form of dialogue with other women and other female writers’, as much as a recording of her own lived experiences. A teaching career that spanned schools, TAFE, universities and adult women’s groups, and topics from literature and communications to religion and spirituality, has provided a constant source of inspiration for her writing practice.

A decade ago, Janet completed a doctoral dissertation on the challenges and complexities of writing therapeutic life narratives. More recently, she has become interested in the short form literary genre known as ‘flash fiction’. Compared with academic scholarship, the discipline of writing within a 500 word limit brings with it a very different set of demands but it is a challenge she relishes.

Janet was diagnosed with dementia shortly before her 70th birthday. Perhaps not surprisingly, she chose to inform her extended family and friends of her diagnosis through the written word, as part of the invitation to what was a ‘really good, and really big’ 70th birthday party.

Janet’s mother lived with dementia, so she has a clear-eyed understanding of the potential consequences of her diagnosis. She has an equally determined commitment to not only maintain her personal creative practice but to advocate for the benefits of the creative arts for people living with dementia.

“

The bottom line for me since I got my diagnosis is how do I go out into the world and show that I'm still operating in the world...that I'm still functioning, that we still have something to contribute, we can still be creative, we can continue to be engaged.”

Janet has always believed in the ‘benefits of writing no matter what ...’ but observes that her diagnosis of dementia has made her reflect on her creative practice. Aware that her abilities may change over time, she is keen to ‘produce something that is therapeutic, something more than me, something that will help and support others, something that is a legacy’.

Within the increasingly crowded field of writing about dementia, both clinical and creative, Janet is focussed on a more experiential approach that conveys the felt experience of the condition and makes an original contribution to the field.

‘I want to convey the feeling of living with dementia, rather than a straight autobiography ... something more lyrical and creative ... something beautiful that people can read about dementia so people get a real sense of how the soul copes.’

Janet is involved in a number of different writing initiatives, from a weekly ‘flash fiction’ email exchange with a fellow writer, to a University of Tasmania Wicking Dementia Research and Education Centre research project. In recent years Janet and her partner Patrick Frost commissioned writers to produce a series of short stories, which were then read by professional actors. She is keen to develop this project further as a way of encouraging people living with dementia to write and have the opportunity for their work to reach a wider audience.

“This might be a way for people with dementia who write to have their stories ‘performed’ as a way of getting their voices heard.”

Getting creative with the National Dementia Action Plan

The National Dementia Action Plan outlines a 10-year vision for improving the lives of Australians living with dementia and their family members and carers by placing them at the centre of all decision-making and action on dementia. The Plan lists seven objectives to achieve the 10-year vision.⁴¹ The research outlined in this paper and the compelling examples of individual and group activities and practices suggest how the wide-ranging benefits of engagement in the creative arts can contribute to achieving a number of those objectives.

Working with people living with dementia and witnessing their purposeful engagement in creative arts endeavours can make a powerful contribution to improving awareness and understanding of dementia, and reducing stigma and discrimination associated with the condition.

The many benefits of involvement in creative arts activities, from cognitive and physical stimulation to supporting identity through connection to family members, carers and the broader community, can have a tangible impact on the quality of post-diagnostic care and support for the person living with dementia.

Support for people caring for those living with dementia is a critical Plan objective. As illustrated in the examples of the Logan Dementia Choir and the Comuisciamo project, family members and carers benefit from involvement in creative arts activities in a number of ways. Undertaking arts-based activities can have direct physical and mental health benefits for family members and carers. Equally, if engaging in arts-based activities improves the wellbeing and quality of life for people living with dementia, this in turn has significant positive consequences for the health and wellbeing of the family members and carers supporting them.

The importance of minimising the risk of developing dementia is an important objective in the National Dementia Action Plan. The World Health Organisation's list of recommendations to reduce the risk of developing dementia includes undertaking regular physical activity, maintaining an active social life and keeping mentally stimulated.⁴² As noted in Australia's national cultural policy document Revive, engagement in the creative arts has a significant role to play in this context.

“ Studies also show that regular reading, playing board games, playing musical instruments or dancing are associated with a lower risk of dementia among people aged seventy-five and older. ”⁴³

An intriguing recent study highlights the multiple benefits of arts-based activities, and the strong claims associated with a specific activity. Researchers compared the effects of a range of cognitive and physical activities including reading, writing, doing crossword puzzles, playing musical instruments, dancing, walking, tennis and swimming on dementia risk reduction. Dance was the standout activity – the authors' found that regular dancing reduced the risk of dementia by 76%, twice as much as reading.⁴⁴

When you consider what the activity requires, this is not surprising. Dancing involves cognitive stimulation (learning new steps and routines), physical exertion and social engagement, incorporating multiple measures for dementia risk reduction. Interestingly, not all forms of dancing offer the same cognitive benefits. Working on memorized sequences might improve performance but does not create new neural pathways whereas dancing that involves spontaneous responses in the moment was the most beneficial.

As Associate Professor and Dementia Australia honorary medical advisor Michael Woodward has noted:

“Dementia risk reduction essentially begins in your 30s and 40s, so don't wait for your 70s; join sequence dancing, line dancing or anything, as early as possible.”⁴⁵

Conclusion

“

Everyone is creative. Finding ways to express our creativity in dozens of different ways is part of being human. Some people enjoy cooking, others planting gardens, choosing clothes, arranging rooms, or inventing things. Some sing or play music. Others express their creativity with paints or pastels, in poetry or prose.⁴⁶”

Dr Pat Baines, Dementia Art Therapist and Dementia Australia Community Development Officer, Dementia Friendly Communities Program

Australian cultural policy emphasises the fundamental value of the arts and specifically identifies the importance of supporting people living with dementia to participate in arts-based activities.

As the extant studies, observations and initiatives from people living with dementia, family members, carers, researchers and practitioners make clear in this paper, engaging in the creative arts can and does make a critical contribution to supporting wellbeing for people living with dementia, and their family members and carers.

Article 27 of the United Nations Declaration of Human Rights Act (1948) states that “Everyone has the right to freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits”.⁴⁷ As individuals and a community, we must collectively commit to supporting people living with dementia to exercise that right.

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About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the the more than 400,000 people living with dementia and the more than 1.5 million Australians involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers. We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

National Dementia Helpline

1800 100 500



For language assistance
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