

Artful: Art and dementia

A report on a three-year
pilot research program

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Forewords

Elizabeth Ann Macgregor OBE
Director, Museum of Contemporary Art Australia

In 2012, the Museum of Contemporary Art Australia (MCA) opened a new extension that included our National Centre for Creative Learning (NCCL) – a space dedicated to creative learning for audiences of all ages. This initiative provided a range of spaces that enabled us to continue and grow our work with many groups (schools, early learning, individuals of all ages with a disability, young people, adults), but we didn't have a dedicated program for older audiences.

In that year, we delivered a small two-month trial program in collaboration with Dementia Australia that explored access to the Museum for people living with dementia for 12 participants. This trial opened up new approaches and audiences for the MCA. There have been many other programs and studies that have proven the importance and vitality of the arts in improving wellbeing but there remains a lack of scientific research on whether the arts can impact or slow down the markers of this disease. A grant in 2015 from the Vincent Fairfax Family Foundation led to the development of the Artful: Art and dementia program (Artful). The grant allowed for three years' funding of a pilot feasibility research study that targeted people living with dementia and their caregivers. The MCA worked with the Brain and Mind Centre, University of Sydney, to ask: Can a creative art program enhance wellbeing and markers of neuroplasticity in people living with dementia?

Professor Sharon Naismith and her team at the Brain and Mind Centre used a randomised controlled design to test the feasibility of the program on participants. Across three years, the team conducted 32 pre- and post-program interviews with Artful participants. This methodology enabled this research study to be one of the largest and most robust of its kind; it will inform the design of future work in this field. Along with the support and advocacy of Dementia Australia, this innovative program has aimed to make a difference to participants by creating new connections and experiences through creative engagement with contemporary art, while contributing to new research in the art and health realm.

We are delighted to publish this report, which contextualises the MCA's approach to deepening engagement and meaningful participation with contemporary art. We'd like to acknowledge the work of both the Brain and Mind Centre and Dementia Australia and thank them for their passion and commitment across the past three years as well as the Vincent Fairfax Family Foundation for making this project possible. The outcomes of this program highlight the need to support further funding in this vital area of work and the incredible impact creative learning can have on people living with dementia, as well as their care partners and networks.

Barbra Williams
General Manager Client Services, Dementia Australia

Dementia Australia is very pleased to have worked with the MCA and the Healthy Brain Ageing Clinic over the past three years as part of the Artful: Art and dementia research trial. Through this innovative program, people living with dementia have had the opportunity to find new and meaningful ways to engage with creative arts, providing many positive benefits including social inclusion, improved relationships, positive emotional responses and improved self-esteem.

While Australian and international research strongly suggests that creative art plays an integral part of enhancing the lives of people living with dementia, there has been little scientific research examining the impact on the brain. Dementia Australia would like to acknowledge the MCA for their

commitment and creative approach to leading this research and shining a light on art and dementia and the positive benefits of such an inclusive and engaging program for people living with dementia and their care partners.

We welcome the publication of this report and its findings. We hope that, as a result of this research, more people living with dementia will have the opportunity to experience the positive benefits of participating in art programs, both nationally and internationally.

Thank you to the MCA for their commitment and continued support of people living with dementia through engagement with the arts.

Professor Sharon Naismith, MAPS, CCN
Brain and Mind Centre and Charles Perkins Centre
Leonard P Ullmann Chair in Psychology, University of Sydney

On behalf of the Healthy Brain Ageing Program of the Brain and Mind Centre, I am thrilled that we have had the opportunity to be key partners in the design and evaluation of the research framework of the Artful: Art and dementia study.

At all stages of the research project, I have met with dedicated, passionate MCA artist educators, and have been impressed with the outstanding commitment of the Museum to make its environment and staff dementia-friendly. People living with dementia are treated with the utmost dignity and respect at the MCA; the artist educators have a unique ability to connect with participants and their care partners through their warmth, vibrant smiles and capacity to draw out such inspiration and imagination from people living with dementia. In addition, I have witnessed a sparkle in the eyes of many people living with dementia as they engage in artmaking, enabling them to discover parts of their brain that have likely laid silent for some time.

This program has provided a solid foundation for a wonderful interdisciplinary relationship with the MCA and Dementia Australia. Though we come from different fields, we collectively strive to innovate and improve the wellbeing of people living with dementia. As detailed in this report, our findings have given us so many new ideas. When coupled with iterative refinement and advances in research tools and methodology, these are fundamental to scientific progress and discovery and what may ultimately determine two areas of inquiry: first, why the Artful: Art and dementia program is so appealing and rewarding for those who choose to participate in it; and, second, what brain processes are benefited by this program.

Beyond the science, I would be delighted to know that Artful could be offered to people living with dementia more broadly, including those living in the community and within residential aged-care facilities. It is critical that we think constantly about enriching the lives of people living with dementia – and being creative is a good place to start!

Acknowledgement



The MCA acknowledges the Gadigal people of the Eora nation, the traditional owners of the land and waters on which the MCA stands, and pay our respects to their elders past, present and emerging.

The MCA extends its sincere gratitude to the Vincent Fairfax Family Foundation who provided the funds to make this research project possible. We also extend our deepest thanks to the many colleagues with whom we have collaborated and learned from throughout this project at the Brain and Mind Centre and Dementia Australia.

We acknowledge the deep connection and passion that the two MCA Artful: Art and dementia coordinators, Michelle Heldon and Clare Thackway, have brought to the program, along with the wonderful MCA artist educators and gallery hosts. We are thrilled to acknowledge the sponsorship from Platypus Asset Management to the Artful program (2018–2020).

We also acknowledge the immense courage, warmth and commitment of all the participants involved.

A research collaboration with:
Brain and Mind Centre, University of Sydney
Dementia Australia

Supported by:



Background: Why was the research needed?

It's waking up something that maybe went to sleep ... I have never been artistic, but it inspires me to do something new.

— Maria, Artful: Art and dementia participant



Artful participant taking part in a watercolour and music workshop, MCA, 2017, photograph: Michelle Heldon

Background: Why was the research needed?

The museum context



The MCA is Australia's leading museum dedicated to exhibiting and collecting contemporary art and interpreting the work of today's artists. The MCA believes that art is for everyone, and the Museum is part of a global shift within the museum and gallery sector. It positions itself as having a key role in contemporary society as a catalyst for intercultural dialogue, learning, exchange and training. Museums play an important role in lifelong learning, social cohesion, wellness and sustainable development and, in this sense, are accountable to society.

The Artful: Art and dementia program, launched in 2016¹, has coincided with a three-year pilot research project looking at how regular art activity can impact on both wellbeing and markers of neuroplasticity in people living with dementia. Across the 34-month period of study, from 2016 to 2018, quantitative research was undertaken by researchers at the Brain and Mind Centre, University of Sydney. Researchers attended the MCA to conduct detailed assessments of those individuals who agreed to be involved in the formal research trial, both before and after participation in the ten-week Artful program.

In addition to the formal research trial, qualitative research was also conducted by the MCA and included multiple avenues for participants to provide both formal and informal feedback separate to the research. This was important to ensure that the MCA consistently learned from the participants and could alter and adapt the program to their needs. This included feedback forms accompanying each 'Artful at home' activity pack, which were distributed to each participant to extend creative engagement in between each Museum visit; a questionnaire given to participants and their care partners at the end of each ten-week program; and a reflective diary, in which artist educators wrote a reflection at the end of each session and the Art and Dementia Coordinator would add observation notes and photographs of the session.

A lot of significant learning came from these various resources. Often participants appreciated having multiple ways to share with staff their experience, both verbally and in written form. The feedback questionnaire was informal in tone, with a mixture of both quantitative and qualitative questions (see appendix p 37). Through the reflective diary kept by the staff, insights into how participants were responding to the program from week to week allowed for better understanding of how to structure each program as well as reflect on what had worked and what had not.

1. Previous to 2016, a small pilot program was offered in 2012 in collaboration with Dementia Australia where 12 people living with dementia were offered tours of MCA exhibitions by MCA artist educators.



Top & bottom: Artful participants taking part in a gallery experience, MCA, 2017, photograph: Alex Creig. Featured artwork: **Dale Frank**, *Every time I glance it's just not me*, 2014, installation view *Today Tomorrow Yesterday*, MCA, varnish, lighter fluid on anodised plexiglass, wood, Museum of Contemporary Art, purchased with funds provided by the MCA Foundation, 2014, image courtesy and © the artist

Background: Why was the research needed?

Some tailoring of the program was required in terms of the needs of the research. The timeframes for interviews with research participants were modified to avoid large gaps between the program and the interview, and 'Artful at home' packs were created to offer consistent weekly engagement with participants across the 10-week program; however, the focus was to create the best experience for those who enrolled in the Artful program. There are many similar programs in cultural organisations across Australia and the world, including MOMA, New York; Dulwich Picture Gallery, London; National Gallery of Australia, Canberra; and the Art Gallery of New South Wales, Sydney. These examples provided initial learning in the creation of Artful: Art and dementia program at the MCA, in terms of different ways to engage this audience with contemporary art and potential wellbeing outcomes.

So much was learned about the value of contemporary art for this program – its ability to offer new ideas, explore issues of the world around us, be fun, unusual, and ignite the senses. The MCA collects work by living Australian artists who use various means to explore their ideas, meaning that Artful participants experienced a wide range of contemporary practice, including video, painting, installation, sculpture and performance.

The content in the Artful program was rich and varied and involved participants looking, talking and making. Making art is an opportunity for self-expression, an important act for someone who might be looking for a sense of who they are, especially for those dealing with a loss of ability to do things for themselves; it can promote a feeling of achievement, offer hope, wonder and joy, and even a new outlook on life. In this sense, the Artful program experience has been transformational for some participants.

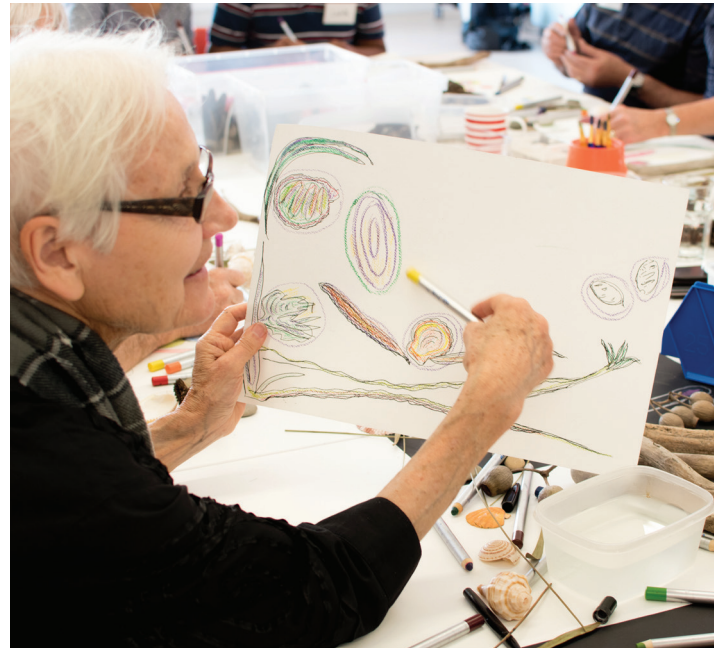
Artful participants received access to artists, working alongside artist educators who deliver the MCA's creative learning programs. These educators have their own artistic practice as visual artists, writers, performers or musicians. MCA artist educators use creative learning strategies that are unique and bespoke, and the Artful program enabled the team to assess how successful those strategies could be for people living with dementia.

There is strong evidence to support the benefits of an active social life and mental stimulation in delaying or attenuating the onset of dementia. Medical research has indicated correlations between art programs and changes in cognition, sustained attention, self-esteem, increased socialisation, and sense of wellbeing for people living with dementia; however, there is an acknowledged need for further research in this area.²

Around the world, there is a shift towards creating 'dementia-friendly communities' – environments and workplaces that support and create a welcoming experience for people living with dementia.³ The Artful program is an opportunity for people living with dementia and their care partners to step into a vibrant cultural institution and feel that it is a place for them.

2. Francesca Rosenbom, Amir Parsa, Laurel Humble & Carrie McGill, 'The MoMA Alzheimer's Project: Making art accessible to people with Dementia', 2009, p 58, momamuseum.org/shared/pdfs/docs/meetme/Perspectives_MSano-MSewell.pdf.

3. Alzheimer's Disease International, Principles of a dementia-friendly community, retrieved July 2019, [alz.co.uk/dementia-friendly-communities/principles](https://www.alz.co.uk/dementia-friendly-communities/principles).



Museums are often cold places, but here everything is living. I feel like I belong ... and I belong in a creative place!

— Iona, Artful: Art and dementia participant

Background: Why was the research needed?

Dementia in Australia

As of April 2019, there was an estimated 447,115 Australians living with dementia, with an estimated 250 people joining the population with dementia each day. It is a relevant condition for our time and one that affects many Australians and their families. Dementia is the second-leading cause of death in Australia and the leading cause of death among Australian women. Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the third-leading cause of disability burden overall.⁴

Dementia prevalence in Australia is expected to triple to almost one million people by 2050. It is well recognised that provision of programs that promote wellbeing in people living with dementia are required. If such programs are also able to improve memory and thinking skills and are beneficial for wellbeing and for care partners, they will be invaluable.

Dementia is not one specific disease. Dementia is a broad term that encapsulates many different forms of brain disease and brain injury; each has its own causes and symptoms. Someone living with dementia may experience a loss of memory, intellect, rationality, language, social skills and/or physical functioning. It affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

The most common types of dementia are Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies and Frontotemporal Dementia (FTD). Dementia can happen to anybody, but it is more common after the age of 65; however, 'younger onset dementia' (affecting those under 65) is also increasing. Twenty percent of Artful: Art and dementia program participants had been diagnosed with younger onset dementia.

The sense of loss that comes with being diagnosed with this disease can be enormous: loss in terms of grieving for the person they once were, along with coping with life changes, the loss of friends and existing networks, feelings of disempowerment and the loss of sense of self. For those with younger onset dementia, unplanned loss of income can be a huge stress, along with a loss of self-esteem and purpose in one's life.

Some people living with dementia can become isolated and secluded as day-to-day tasks become more and more challenging to manage. It can take a lot of courage just to get out of the house. People often look to their care partner, if they have one, to make choices on their behalf. Life can also become isolating for the care partner as their loved one becomes more dependent upon them and the activities or tasks they used to do together are no longer appropriate or manageable.



In Australia, there appears to be a lack of programs and activities that create a welcoming, safe atmosphere in addition to being fun and stimulating, and not degrading for both the person living with dementia and their care partner. Care homes and social clubs can often be geared towards an older generation or for people with later stage dementia and may not be places some people living with dementia, particularly with younger onset, want to go.

4. Dementia Australia, Dementia statistics, retrieved July 2019, dementia.org.au/statistics.

Artful participant and care partner taking part in a workshop, MCA, 2016, photograph: Michelle Heldon

Background: Why was the research needed?

The research context



There has been growing international interest in using art as a therapeutic strategy for people living with dementia. Using largely qualitative research findings, art and dementia programs have been linked to improvements in mood, socialisation and reminiscence, and quality of life. Many gallery-facilitated art programs are designed to enhance artistic skills or aesthetic appreciation; however, this research study, designed with the Brain and Mind Centre, is distinct in three ways:

1. Inclusion of art creation in the Artful program: Many prior studies of art programs for people living with dementia have largely focused on gallery viewing with an emphasis on recollection and memory. This is important since the viewing of art activates distinct brain regions including the 'pleasure centres' of the brain; therefore, this may be a pathway by which art promotes wellbeing. However, recent research has shown that the 'creation' of art (not simply the viewing of art) is linked to changes in brain structure and function. Therefore, engaging in art through 'creation' may be critical to neuroplasticity (that is, the strengthening of connections between brain cells). This study wished to combine both art viewing, conversation and artmaking for people living with dementia and their care partners.
2. Cognitive outcomes: Although it has been shown that art programs can enhance wellbeing, it is currently unclear whether art programs can improve aspects of memory and thinking functions in people living with dementia. In particular, the study looked at possible benefits for visuospatial skills and memory.
3. Randomised controlled design: Few studies that evaluate the efficacy of art programs for people living with dementia use a 'randomised controlled design'. This type of study design randomly assigns participants into a control group, whereby they receive the treatment or control condition. As such, the two groups should be equal on everything except the intervention, so the outcome variable can be more easily aligned with the intervention. Since large-scale randomised controlled trials are extremely expensive, require five-plus years of research and do not necessarily translate well in non-medical environments such as a Museum, the researchers for this study conducted an initial 'pilot feasibility trial'⁵; this pilot will thus inform future iterations of the program as well as other large-scale research.

This report aims to supplement existing discussion and research.

5. Pilot feasibility trials are small-scale studies meant to assess whether something can be done and, if so, how, before embarking on a larger definitive randomised controlled trial.

Artful: Art and dementia program

At this stage in my life, you lose networks or access to networks. Here, I've been able to meet people and hear what they are doing, make new connections and community.

— Narelle, Artful: Art and dementia participant



Artful participant taking part in a gallery experience, MCA, 2018, photograph: Jacquie Manning. Featured artwork: **Lara Merrett**, *Paint me in* (detail), 2018, synthetic polymer paint and ink on canvas, steel, commissioned by the Museum of Contemporary Art Australia for the Jackson Bella Room, 2018, image courtesy and © the artist

Artful: Art and dementia program

Overview

The Artful: Art and dementia program offered people living with dementia and their care partners an intimate and multi-faceted art program structured over a ten-week period at the MCA. Small groups were supported by MCA artist educators to engage in gallery experiences and participate in artmaking sessions, as well as home-based activities.

The Artful pilot research program ran between March 2016 – October 2018 working with 124 participants travelling from all over Greater Sydney and as far as Kiama, Blue Mountains, Newcastle and Bowral (see appendix p 49). The structure evolved from some key research design elements, whereby groups of six to eight people and their care partners came to the MCA fortnightly for five two-hour sessions over a ten-week period.

The 'Artful at home' packs were created out of the research requirements which necessitated participants and their care partners to engage in a weekly interaction with art over the entire ten-week program. Four packs were designed and given to participants during the alternate weeks of the fortnightly program to extend the creative experience beyond the onsite visits.

The packs included artmaking materials, an artwork image card, which acts as the reference point for each weekly activity, and a set of simple instructions. By providing the tools and structure, artmaking could easily be added to the participants' home routines. Although the packs began as a necessity for the parameters of the research study, their impact has been profound, for both the person living with dementia and their care partner (see 'Care partners', p 28).

Participants

Anyone with a diagnosis of dementia was eligible to participate in the program. However, given the required seven visits to the MCA (five Artful program sessions and a pre- and post-program interview), the program was particularly suited to individuals living at home and being cared for by family members or support providers. Priority was given to individuals interested in the research component of the program. A wait list was made available to others in the event that a placement become available due to a change in circumstances, or due to the randomised structure of the research (see 'Control arm', p 19).

People living with dementia and their care partners are affected by social isolation and a reduction in meaningful engagement. There can be so much pressure on the care partner to be everything for the person living with dementia, and opportunities for new enriching stimulus and

connection can be difficult to access and, in particular, for both parties to attend. Although individuals from residential aged-care centres were eligible to participate, it was generally noted that such centres do not have the resources to facilitate multi-visit opportunities for their residents; therefore, early on in the development of the Artful program, these centres were found not to be ideal sites to recruit participants.

Over the three-year research project, 124 people living with dementia and their care partners participated. Artful participants were most often individuals with early- to mid-stage dementia (though participants with severe dementia were eligible and did participate). The program targeted people with early- and mid-stage dementia due to the requirement that participants were able to travel to the MCA fairly easily. In addition, it was expected that there may be more capacity for meaningful engagement and participation from people in earlier stages of the disease, even if the participants were non-verbal or had other barriers. There tends to be more barriers for attendance at later stages in dementia, including declining physical function and extra personal care support needed.

Participants were not required to provide medical confirmation of their dementia subtype. However, we did ask participants or their care partners about their diagnoses. Participants were not required to be formally diagnosed to participate. Various diagnoses of dementia were reported, including 29 participants with Alzheimer's disease, 17 with younger onset dementia, eight with Vascular dementia, six with Frontotemporal Dementia and two with dementia with Lewy bodies. Some participants were included who showed early signs of brain degeneration, for example those with Mild Cognitive Impairment (MCI).

The recruitment process to take part in the research component was lengthy. The first step was an informal phone interview. The MCA Artful program coordinator would speak to the person living with dementia or their care partner to find out their current diagnosis and how they were affected personally, their interests, their former vocation, any barriers or concerns about coming to the Museum, and what they and their care partner hoped to get out of the program. Often participants expressed anxiety for several reasons, including never having visited the Museum before; not having prior experience with or interest in contemporary art; fear that the person living with dementia may have a negative reaction to the experience; concern about meeting new people; and concern about the research requirements (that is, the pre- and post-program assessments and questionnaires). Making the participants feel comfortable was key and often included several phone calls, emails and preliminary visits to the Museum to meet the staff. It often took several weeks to build a rapport with the participants to ensure that the program and the research component was a good fit for them.

Artful: Art and dementia program



The power of contemporary art and artists

The role and approach of the MCA learning team is significant to the program. Within the MCA's National Centre for Creative Learning, artist educators work with a creative learning manifesto (see appendix p 42) that takes its cue from contemporary art itself and sets out an approach that works across all MCA learning programs. Our philosophy is that art is for everyone. This manifesto offers a unique model for engaging with people living with dementia and their care partners. Participants are encouraged to bring their own story and discover multiple meanings within the artworks they are looking at, as well as to look and think in new ways. The gallery experience is based on conversation and exchange rather than a tour; the MCA uses the phrase 'gallery experience' rather than 'gallery viewing' as it emphasises the act of participation and interaction with the artwork. During artmaking in the studio, the artist educators emphasise that the process is often more meaningful than the finished product and that there is no right or wrong way to experience and make contemporary art.

Contemporary art is a powerful starting point for people living with dementia to engage and express themselves. There is no fixed meaning within an artwork, which means the viewer can bring their own emotional response and understanding to the work, enabling an ongoing process of open discussion and curiosity about the world today.

Creativity is often thought of as the domain of the young, but, through creative learning, the MCA aspires to encourage and change the way people view dementia. We aim to transform reticence into confidence, demonstrating (and celebrating!) individuals living with dementia have the capacity for learning, critical thinking and intellectual engagement. We also advocate for the proven health benefits of these activities, of wellbeing, self-esteem and social inclusion, and, most of all, the potential to attenuate the onset of dementia.

The approach of the Artful: Art and dementia program was not focused on activating participants' memories, but on rebuilding connection and cultivating a space for new experiences. The program was hands-on and responsive to the moment; it invited people to embrace wherever they were at on the given day with confidence and creativity. Importantly, this was not art therapy; the facilitators are not art therapists but practising artists. While creating art can bring therapeutic outcomes, this did not drive the design of this program. The creative artmaking experience was incorporated to open a space for expression, rather than as a facilitation tool for accessing particular emotions or memories. This approach is key to all MCA programs and is inspired from learning theories such as constructivism and active learning.⁶ Through the MCA creative learning manifesto, the staff ensured that the program was participatory, inclusive and accessible for all participants.

6. Key leaders in developing constructivism learning theory which have been influential in the creation of MCA learning programs include John Dewey, Jean Piaget and Lev Vygotsky. Influential active learning theorists include Charles Bonwell, James Eison and Mihaly Csikszentmihaly.



Top: **Tjanpi Desert Weavers: Nyurpaya Kaika-Burton, Ilawanti Ungkutjuru Ken, Niningka Lewis, Mary Katatjuku Pan, Tjunkaya Tapaya, Carlene Thompson, Yaritji Young, Minyma Punu Kungkarrangkappa (Seven Sisters Tree Women)** (detail), 2013, installation view *Today Tomorrow Yesterday*, Museum of Contemporary Art Australia, 2017, native grasses (minarri and ilping), found fencing wire, aviary mesh, textile, acrylic pillow stuffing, yarn, string, twine, raffia, plastic bagging, feathers, wool, tree branches, foam, piping, Museum of Contemporary Art, purchased 2013, image courtesy and © the artists, photograph: Anna Kučera
Bottom: Artful participants taking part in a creative strategy in our Galleries, MCA, 2018, photograph: Jacquie Manning. Featured artwork: **Julia Gorman, The Forties** (detail), 2016, installation view *Today Tomorrow Yesterday*, MCA, acrylic sheeting, wood, MDF, polypropylene, acrylic sheet, light bulbs, acrylic on linen, wooden board, adhesive vinyl, commissioned by the Museum of Contemporary Art Australia for the Inside/Out Room, 2016, image courtesy and © the artist.

Artful: Art and dementia program

Program structure



The standout for me was the first day, because we were so late and you were so welcoming, it was such a relief. I remember the atmosphere you created here, the welcome, understanding and the care was an integral part of it. It would be very different if we felt you were just doing your job.

— Sandra, care partner

Introduction and orientation

At the start of each session during the ten-week program, the program coordinator and artist educators would meet the group at a particular spot, the MCA entry foyer, where they would deliver an introduction and a brief orientation. This was vital to establish trust and a safe space where participants felt comfortable and willing to return. The group would then be led to a creative studio for refreshments. There, further introductions were made within the group and name tags given out, with staff checking to see that everyone was comfortable to wear them. The name tags made it easier for staff to remember individuals and address them by name. It also helped the participants to use each other's names and develop a sense of familiarity. Over the course of the program, the name tags removed the potential for anxiety for not remembering someone's name.

Re-orientation was used at the beginning of each visit with the participants. Often, the creative studio was set up differently to the previous fortnight, and even those who could remember the prior visit needed encouragement and prompting to feel confident and safe. This meant encouraging everyone to sit down, before the artist educators welcomed everyone back, named the program and the week it was up to, as well as reviewed what had been done the fortnight before.

Using photos and images from the previous fortnight helped to trigger a connection to the ongoing nature of the program. Even if participants did not remember the previous session, they would often feel a sense of connection when the team shared their previous accomplishments such as artworks made or discussions had in the galleries. The participants would also receive a written reflection after each session via email, of images of the artworks they had seen in the gallery and the artmaking they had participated in. This also assisted with linking and reorientation for each visit since it offered a record of their journey through the Artful program.

Gallery experience

Following the introduction, the group would split into two groups: those living with dementia visited the exhibition space with the artist educators; and care partners remained in the creative studio with the program coordinator.

There are two reasons for this division. Firstly, to keep the gallery experience intimate, enabling everyone to have an opportunity to engage and share within the group. It has proven integral that groups remain intimate in order to foster long-term and meaningful relationships. Numbers are limited to a maximum of eight participants (in addition to their care partners) in order to offer an opportunity for everyone to contribute to a discussion and to participate in artmaking without becoming overwhelmed.

Artful participants taking part in a gallery experience, MCA, 2016, photograph: Alex Creig. Featured artwork: **Stuart Ringholt, *Untitled (Clock)*, 2014**, installation view *Today Tomorrow Yesterday*, MCA, clockwork, tubular bells, world globe, steel, glass, electronics, Museum of Contemporary Art, purchased with funds provided by the MCA Foundation, 2014, image courtesy and © the artist

Artful: Art and dementia program

Secondly, for those living with dementia, the time away from their care partners was in many cases empowering; it enabled greater opportunity for self-expression and a breaking down of inhibitions. People living with dementia can often look to or rely on their 'support person' to make sure they are saying 'the right thing'; care partners also acknowledged that they often jump in to finish sentences for their loved one. This also offered an important moment of respite for care partners.

In the galleries, the group usually begins by sitting on comfortable chairs in a semi-circle to look at artworks and are prompted to engage in dialogue by the artist educator. Everyone has a voice in this setting, as it is not a tour.

When looking at artworks, not only did the Artful participants find and discuss different meanings, but the artworks themselves were often re-activated by this particular audience through non-verbal responses. These responses ranged from very small and subtle movements, such as a nod of the head with a smile, to more dramatic gestures, such as a participant who spontaneously started to drum; his care partner reported back that he had continued drumming throughout the week. Another participant, without being prompted, responded to the Tjanpi Desert Weavers' life-size woven figures in the MCA Collection, titled *Minyma Punu Kungkarangkalpa (Seven Sisters Tree Women)* (2013) through movement. In front of the sculptures, he smiled, lifted his arms and began to move around the work, stopping in front of each figure. When this story was shared with his wife, she was taken aback, saying that self-initiation was rare for him. Many participants used their bodies instinctively to have a 'conversation' with contemporary art, which the artist educators encouraged. Although most non-verbal responses to artworks were often subtle in nature, these examples offer an important recognition of what can occur when participants are given a supported space for self-expression and creativity.

Creative strategies were employed in the gallery to allow everyone in the group to feel comfortable, to connect and find their own meaning in the works. This could take the form of textural objects relating to artworks that could be felt and passed around the group. Line and pattern were explored by using a ball of wool on the gallery floor in front of the artwork *OMG* (2014) by Kerrie Poliness, or by rearranging wooden sticks into a pattern in response to *Piece to Walk Around* (1981) by Rosalie Gascoigne. This transformed the gallery experience into a participatory one rather than a tour, and the 'active' element helped to trigger the memory of the artworks when back in the creative learning space more so than simply a discussion.

For care partners, this time was used as an opportunity to connect as a group, share experiences from the program, and offer support and encouragement to each other within a safe space. Initially structured as a moment of respite, an unexpected outcome was the importance of this time for care partners to connect as a group and was built upon as the program progressed. The Artful program coordinator tailored the experience for each particular group of care partners and eventually offered them a separate gallery experience, building their confidence by providing tools and ideas for creative engagement and initiating some 'me time'. This shift in the program had positive repercussions for the person living with dementia. For example, some care partners gained more knowledge and understanding about contemporary art practice and began to initiate and explore new interactions with their loved one at home with the 'Artful at home' packs (see p 16), while others learned to step back from their partner living with dementia during the onsite sessions, giving them more time and space to explore in their own way.



Hands-on artmaking

Participants returned to the original creative learning space following the gallery experience. They were reunited with their care partners and encouraged to relax and have a cup of tea or coffee. This simple act of a tea or coffee break was important for the group to feel re-connected. It encouraged reflection, as some participants – without any prompting by MCA staff – were eager to share what they had done at home with their 'Artful at home' packs. This sense of pride and excitement in their achievements grew from week to week as they continued to gain confidence in their artmaking. Through sharing the actual artworks produced, care partners would sometimes prompt or stimulate a memory of the at-home experience with the person living with dementia, but often the artworks were passed around – this provided an opportunity not just for reflection but for new responses from those living with dementia to be heard.

Taking the program from a gallery experience to actual artmaking was an important aspect. Though the gallery experience was often interactive, making art offered a next step in the creative process, a participatory action bringing with it rewards and achievements. Moving from seeing work by artists in the gallery to expressing one's own creativity offered an even deeper engagement with contemporary art, as well as a connection with the artworks through a relationship with materials and processes. The artmaking activity was always linked to what had been seen in the gallery, allowing participants to have a greater understanding of contemporary art and creativity. The physical act of making art saw some participants come out of their shell and start interacting, laughing and conversing more with the group.

It was important to create activities that everyone could have some kind of 'success' with. Everyone learns differently – some people like to move their bodies, others like to look, others like to listen, others like to talk things through. Being aware of the different barriers that a person experiences which could inhibit their participation, such as a sensitivity to sound or a dislike of dark spaces, was important.

Artwork by an Artful participant, MCA, 2016, photograph: Michelle Heldon

Artful: Art and dementia program

Many of the artmaking activities had a collaborative component, bringing the group closer together. This took the pressure off each individual and allowed for supportive and encouraging language in response to the final result, rather than allowing a space for self-critical responses that are common for people who are new to artmaking, or whose cognitive and physical abilities are in decline. It was a way to value all contributions, no matter how small. Very quickly, a feeling of being part of a community was created and participants (especially care partners) began meeting on their own time outside of the Artful program for lunch or an outing.

Allowing the group to have access to a range of quality materials (such as watercolour paper, sketching pencils and clay) was important to not only allow them to feel valued but also to see appealing results. The workshops were not presented as 'arts and craft' but artmaking, which is an important distinction. The materials were carefully chosen to link to the artworks seen in the gallery; in this way, the work created by the participants was validated as contemporary art in their eyes.

The program consistently explored a variety of mediums and subject matter to allow for choice and to cater to the variety and ability of individuals. Some people took to using clay and three-dimensional forms, while others enjoyed drawing, printmaking or painting on silk.

Utilising technology in the sessions also brought great responses and results. Some Artful participants did not consider how technology could be an art medium and, for many, this brought a new dimension to their lives. For example, making simple stop-motion videos of drawings on iPads, linking to the drawing process of MCA Collection artist Joan Ross, drew forth a sense of wonder and appreciation, alongside a sense of achievement and possibility to do this at home with their own iPad.

Another success was an introduction to printmaking – the process was simple and produced impressive results. Having a variety of options for materials catered for different needs and abilities. One participant, who had higher needs, produced a beautiful print of a hot air balloon using soft foam. He exclaimed 'Wow!' when the print was revealed and was delighted to know it was his own work. He was then invited to add to his creation with watercolour paints.

All the participants enjoyed seeing the fruits of their labour. Being able to produce multiple prints in a variety of colours also meant that participants could see several iterations of their work and stay engaged for the entire session.

Balancing levels of risk with the opportunity for meaningful engagement needed to be thoroughly considered. Tools are often sharp and can be dangerous if not used correctly, so this was taken into consideration by MCA staff, who tried to not always default to the safe option.

Starting an artmaking activity can often be daunting for participants when deciding what they want to create. Over time, it was found that visual references and images really helped as a starting point. People instantly engaged with these references and began having small discussions. Images of a place, for instance, can trigger memories, a desire for travel or thoughts of other physical sensations, such as walking through a park on a warm day.

Gentle music was all that was needed for a drawing session using wax crayons and colourful watercolours. Having colour options allowed participants to choose their own association between colour and music. The artist educators gave simple, minimal instructions that prompted participants to repeat patterns and gestures first in the air, then onto their

piece of paper. The second part of the exercise involved swapping their drawing with a partner to add a watercolour wash. This was a challenge at first for those who were attached to their drawing, but it really helped those who needed a new step to stay engaged or who needed reference points. A few participants added washes to their partner's drawings that closely followed the existing marks in some way, either tracing directly on top, circling elements, or colouring within a pattern. This exercise was relaxing, slow and meditative and allowed participants to enter a 'zone'. Although there was not much speaking involved, everyone seemed to understand the activity intuitively. Due to its success, this format was often used by artist educators to create tangible artmaking activities alongside external stimulation (visual references, music) that provides a starting point for participants.

An awareness quickly grew among the staff members who worked on each program to make space for different kinds of engagement during an artmaking activity. If someone wanted to only observe, have a chat or make a single mark, it was always welcomed and never viewed negatively. Knowing that participants may have harder days than others, or simply not connect with a specific activity, the team would support participants to take whatever approach made sense to them that day. This was sometimes hard for care partners, who worried that there was a 'right' way to engage in an activity – but letting go of expectations was key to creating a safe space that fostered creativity.

'Artful at home' packs

The 'Artful at home' packs were developed to allow participants and their care partners a weekly interaction with art outside the MCA over the entire ten weeks. This began as integral to the research as a way for participants to remain engaged beyond the fortnightly onsite sessions. The packs include artmaking materials; an artwork image card which acts as the reference point for the activity; and a set of simple instructions. By providing the tools and structure, artmaking became something that could be added to the participants' home routines. Leon, a participant, says, 'I love the experience of coming to the Museum so much. It makes me so happy to be here, so taking something home meant that I was taking some of that happy feeling with me too.'

The instructions inside the pack were crucial as many participants and their care partners expressed concern about creating art without the support of the MCA artist educators. Therefore, the instructions considered a holistic experience for participants. Some of the prompts and tools included clearing a space to work; spending time enjoying the process by sharing stories; and using exchange by passing things backwards and forwards or reflecting an action or comment made. Emphasis was put on sharing or building a collaborative experience. Mikaela, a care partner, reflects, 'Doing the 'Artful at home' packs together was a wonderful idea because it made us connect more.'

The 'Artful at home' packs were challenging for some. Care partners, in particular, needed a lot of support to build confidence in facilitating this experience as many had little to no experience creating art. In making the packs, it was necessary to create activities that were rewarding and enjoyable, rather than something perceived as a test or homework or even child-like, similar to colouring pages.

The packs were received positively even when accompanied with challenges, and participants and care partners spoke of the enjoyment of taking something home with them. Feedback from care partners focused on how the packs allowed time for them to connect with their loved ones in new ways by engaging in something new together. Conversations

Artful: Art and dementia program

would take place that would not have happened otherwise. Words like ‘calming’, ‘settling’, ‘refreshing’, ‘playful’ and ‘thought-provoking’ have been used to describe the experience.

Case study: Jamie and Zara

Jamie came to the Artful program reluctantly. He ran a family business and spent his later years on a farm, so he was more comfortable outdoors than in a gallery. He came to the MCA for the sake of his daughter Zara, who was doing a fine art degree, but art wasn’t really him. His head was down, and he spoke quietly.

Jamie, who had been diagnosed with younger onset dementia with frontal lobe brain damage, was 62 years when he joined the Artful program in 2016. His wife, who still worked full-time, was his main carer. His days were spent in front of the TV mostly. Not long into the program, however, Jamie began to surprise himself and his family. He started to really engage with artmaking, taking to painting and developing his own unique style of mark-making. His focus changed and so did his body language and self-confidence. He became more animated, responding more to the artwork in the gallery and jumping right into the artmaking activities. His family reported that he could remain focused making art at home for hours. It became a new opportunity and vehicle for which Zara could connect and communicate with him. She cherished this time, as she had mentioned that she was previously feeling more and more isolated from him. This brought them back together in a new and enriching way.

Four years on, Jamie is still making art at home. He now has an Instagram account and is supported by Zara to continue his artmaking practice. It is now part of his everyday routine. Although Jamie has changed significantly since taking part in Artful, his connection to art has continued to grow and has allowed him to connect with his family in a new way.

In late 2018, his daughter shared the following update with us: ‘The world has become a strange and disorienting place for Dad. Seeing him discover painting in the past few years has been a beautiful thing to witness. The concentration and focus that come back to his face when

making is baffling. Because of painting, Dad is still able to engage deeply with something outside himself. He has really taken off with his art. I must thank you again, as it all started with your wonderful program.’



Left: Artful participant taking part in a printmaking workshop, MCA, 2016, photograph: Michelle Heldon
Right: Artful participant and care partner seeing the results of their printmaking workshop, MCA, 2016, photograph: Michelle Heldon

Artful: Art and dementia program



Celebration and exhibition

At the end of each ten-week program, a celebration took place that included a small exhibition of the artwork produced during the Artful program. Family, friends, MCA staff and general visitors were all welcomed. Originally organised to bring people together for their post-program research interviews, these events quickly expanded as they had huge benefits; they:

- showed the participants they are valued, as are the artworks they produce
- allowed them to publicly stake their claim as an artist
- enabled interaction with the public
- built confidence in their own abilities
- encouraged exchange, reflection and sharing
- raised awareness and interest in future programs
- bridged generational gaps
- challenged public perception and stigmas toward people with living dementia
- gave people who are often voiceless a voice in their community
- offered evidence that art is a powerful tool for social change.

These celebrations turned into a seasonal Artful Community Day, an opportunity for past, current and future participants and support networks to be regularly engaged with and invited to the MCA. It allows for people to access a space, maintain connection and build new support and social networks within the museum environment.

Albert, a participant who attended an Artful Community Day, says, 'I did not even realise how much I was learning [in the program] as I was having so much fun.'

Care partner support

Care partners have gone through their own journey during the Artful program. Many have learned what contemporary art can be. Some struggled with the pressure to perform or to see their loved one perform, particularly with the 'Artful at home' packs, where they took on a role of initiator at home and wanted to see results. Through dialogue in the closed care partner sessions, the emphasis was on taking the pressure off them and acknowledging the importance of the small achievements in the process, such as a short one-minute conversation with their loved one about the artwork image card or playing with the materials provided but not necessarily following the instructions. Time was made during every session at the MCA for the care partners to share how their at-home session had gone and what they may or may not have been able to manage to do with the 'Artful at home' pack. This sharing became integral to the program. It opened new possibilities for the individuals in the group to try new things. It also allowed the care partners to feel like they were not alone in their struggle. It became a time for them.

One participant, Marc, reflected on the value of the program for his care partner: 'I think it is good for my wife to see me doing things like this... she has to do a lot for me. This is something I can do myself.'

Case study: Narelle and Leonie

Narelle is the former principal of a theological college for women. Her diagnosis of dementia had left her feeling that everything was a test, bringing with it a fear of failing and a loss in confidence. She was not motivated to get out of bed and had become socially isolated. The Artful program had a big impact on her wellbeing, enabling her to see a 'wider possibility for existence'.

Narelle says, 'If anyone is hesitant about this [program], don't be. It is just fantastic. You can just be yourself. It is more than fantastic, I just can't think of the word... At this stage in my life, you lose networks or access to networks. Here, I've been able to meet people and hear what they are doing, make new connections and community.'

Leonie is a high school teacher and shares a home with Narelle and another friend, with whom she shares the responsibility of being Narelle's care partner.

Leonie says, 'For me, it's interesting to see how people respond differently [to contemporary art] and the fact that there's no right or wrong. Everything's okay, so [the approach to] "go for it" takes away the fear. I feel as if it's had a big impact [on us], because it's so positive and nourishing and so we both look forward to coming. Everything has run with so much joy and gentleness.'

When asked what three words she would use to describe the Artful program, Leonie says, 'Challenging, stretching and joyful.'

Artful: Art and dementia program

Being aware of barriers

In creating programs for and working with people living with dementia, the MCA was aware of the many barriers such participants face when participating in any program. It was important to attempt to find different pathways that would reduce these barriers, knowing that this was not necessarily always possible.

Some of the key barriers that arose during this program include:

- multiple barriers for participation including time, travel, intellectual and physical access
- the unpredictable nature of the disease
- the potential rapid decline of participants due to the disease which may impact their ability to participate in the full ten-week program
- the impact of loss and grief and the emotional state to participate
- the availability of care partners to support their loved ones
- a program which needs to be inclusive of different abilities.

We also acknowledge that contemporary art and creative learning can be complex, complicated and challenging. However, we have seen that it is also an ideal way to counter conventions, stimulate critical thinking and foster innovation.

In working closely with the team at the Brain and Mind Centre over the last three years on the structure of the research component of the program, the MCA has learned an immense amount in regards to what it means for an arts program to meet ethical standards and procedures for research, as well as the barriers in applying scientific research structures to an arts program. With initial goals to reach over 200 participants in this research trial, we quickly came to understand the complexities of why someone may not want to, or be able to, contribute to research.

A key part of the MCA's interest in collaborating with the Brain and Mind Centre was to see how research into an arts program could move beyond measuring impacts on wellbeing to that of cognitive and behavioural functions in the participant. Although many of the Brain and Mind Centre's research results remain inconclusive due to the small sample size of this feasibility study (see 'Research findings', p 20), we believe it is vital to share them as they offer important insights to guide and refine future large-scale studies which could have a significant impact on the field.

This report also shares insights on one of the few art and dementia research studies which has used a randomised control trial methodology. This was important to the approach of the study to offer scientific advances through a clinical investigation instead of a purely qualitative approach often used by arts programs. However, this also led to further barriers in participation such as: rigorous inclusion and exclusion criteria; extensive cognitive



interviews which were sometimes challenging for participants; and many participants not wanting to be randomised into the control arm (waitlist control condition).⁷

With such barriers kept in mind, we share the clinical results of this study as well as its qualitative research findings conducted by the MCA staff (see 'Qualitative learning and unexpected outcomes', p 26) to provide a full analysis of the program which offers transparency on the complexities and nuances of research.

7. A review of 24 Alzheimer's disease clinical trials using randomised control in the UK found that only a third of the programs were able to recruit sufficient participants within a year. This was often due to potential participants' lack of understanding of trial processes such as randomisation, patient preference for particular treatments, cognitive decline and ill health and/or carer burden. Grill, Joshua D & Karlawish, Jason, 'Addressing the challenges to successful recruitment and retention in Alzheimer's disease clinical trials', *Alzheimers Research & Therapy*, vol 2.6, 21 December 2010, p 34. Clement, Clare et al. 'Challenges to and Facilitators of Recruitment to an Alzheimer's Disease Clinical Trial: A Qualitative Interview Study.' *Journal of Alzheimer's disease*, vol. 69.4, May 2019, pp 1067-1075.

Research findings

I have witnessed a sparkle in the eyes of many people living with dementia as they engaged in artmaking [at the MCA], enabling them to discover parts of their brain that have likely laid silent for some time.

— Professor Sharon Naismith, Director, Healthy Brain Ageing Program, Brain and Mind Centre, University of Sydney



Artful participant and two care partners collaborating in a workshop, MCA, 2016, photograph: Michelle Heldon

Research findings

About the study

Brain and Mind Centre, University of Sydney
written by Professor Sharon Naismith

Study aims

In this pilot feasibility study, the Brain and Mind Centre researchers aimed to determine the suitability of assessment tools and the magnitude of change associated with participating in the Artful: Art and dementia program in the following areas:

1. Cognitive functions, including visuospatial cognitive skills, memory and speed of processing information for the person living with dementia (see glossary p 41).
2. Quality of life, wellbeing and mood for the person living with dementia.
3. Memory and behavioural function, as noted by the caregiver.
4. Carer burden, and quality of life for care partners.

In addition, we used a semi-structured questionnaire (see appendix p 44) to measure satisfaction with the program.

Research participants

In order to participate in the formal research pilot feasibility study, there were specific rigorous inclusion and exclusion criteria.

To be eligible for inclusion, participants needed to be prepared to be randomised into either a ten-week waiting list or ten-week active program group and to complete research assessments, before and after the ten-week period. In addition, the research component did not include individuals if their primary language was a language other than English (due to the requirement to complete certain cognitive tests), a history of other significant neurological disorder (for example, stroke, epilepsy or head injury), a history of severe mental health disorder (such as schizophrenia), diagnosis of drug- or alcohol-related dementia (such as Korsakoff's syndrome) or current drug or alcohol dependence.

Of the 67 participants living with dementia (not including the 54 care partners) who took part in the Artful program over the three years, 53 expressed interest in the research component. Of these, 16 did not meet the above eligibility criteria on initial screening. A total of 37 participants were formally assessed for eligibility and 32 were eligible and randomised into the formal study.

Study design

This pilot study was a single-blinded randomised control pilot study. 'Single-blinded' means that the participants were aware of the group they were assigned to, but the research team was unaware. The participants in the study were randomly assigned to one of two conditions:

Intervention arm

The Artful participants assigned to this condition completed five fortnightly face-to-face gallery-facilitated sessions (approximately two hours per session) at the MCA, alternated with five fortnightly at-home sessions (approximately one hour per session), over a ten-week period. At-home sessions were directed by the participant via the 'Artful at home' packs provided by the MCA, which contained creative and discussion exercises using varied materials. Care partners, family members and support providers were encouraged to engage and make art with participants as well. Gallery sessions were facilitated by artist educators and gallery staff; this occurred in small groups. Sessions included both art viewing, participation and creating art with mixed media.

Control arm

The participants assigned to the waitlist control condition did not participate in the art program immediately, rather they were instructed to continue their 'life as usual' for a ten-week period. Following the completion of a follow-up research assessment, they were invited to attend the next available Artful program intake.

At the beginning and conclusion of the ten-week period, each participant was assessed by clinical neuropsychologists from the University of Sydney. As noted, to prevent bias, assessors were not aware of which condition the participants had been assigned to.

Ethical conduct

The research study was approved by the Human Research Ethics Committee of the University of Sydney.

Research findings



Outcomes of the study

Of the 32 participants living with dementia enrolled in the pilot randomised controlled trial, 19 were randomised to the control arm and 13 to the intervention arm. On average, the participants had moderate dementia. The study included some participants with severe dementia, making the assessments difficult to complete and in many cases invalid, resulting in higher-than-expected incidences of missing data. Three participants from the control arm and two from the intervention arm did not return following the ten-week intervention period. Specifically, two were lost to follow-up, one voluntarily withdrew and two withdrew due to ill-health following randomisation. Overall, 16 participants from the control arm and 11 from the intervention arm were included in the final analysis.

It is important that the results of this pilot study be interpreted with extreme caution given the small number of individuals that participated in each condition, the missing data and variability in the data.

Changes in cognition, including visuospatial tasks, memory and processing speed

The research found that there were no statistical differences between those participants who were assigned to the Artful program and those in the waitlist control condition for any tests of cognition. On tests requiring more sophisticated visual (visuospatial) skills, there were no statistically significant differences between groups. However, those in the art program tended to show large improvements on a test requiring high-level integration of visual material (see 'Researcher's comments', p 24).

Changes in wellbeing, mood and quality of life for the person living with dementia

After ten weeks of participation in the Artful program, the researchers found that there were no statistical differences between those participants who were assigned to the Artful program and those in the waitlist control condition for all measures of quality of life, wellbeing and mood.

Changes in memory and behavioural function, as noted by the care partners

There were no statistical changes in carers' observations of the participants' memory or behaviour.

Changes in care partner burden, and quality of life

There were no statistically significant effects on measures of care partner burden or carer quality of life. This is not unusual, since this kind of program is often associated with extra care and effort for care partners.

Benefits of program

Anonymised questionnaires were completed by both care partners and the participants living with dementia. Using a rating scale of 1–5, where 5 is highest, the following results were found:

- 100% of respondents found the Artful program to be very beneficial
- 97.5% of respondents found the Artful program to help improve quality of life
- 71.1% of respondents found the Artful program to help improve relationships
- 95% of respondents said they would recommend the program to another person
- 92% of respondents said they would return to the MCA for other events.

Artful participant taking part in a painting workshop, MCA, 2018, photograph: Jacquie Manning

Research findings

Researcher's comments

On the study's results

While the overall results show that the Artful: Art and Dementia program was not associated with statistically significant effect on a participant's cognition, wellbeing and mood, the study was a pilot feasibility trial and included a small sample size, significant heterogeneity in the sample, and inclusion of individuals with severe dementia. In some domains, there was evidence of substantive (statistically large 'effect size') changes, such as in participants' visuospatial skills and memory; that is, there was a suggestion of a large improvement associated with the Artful program on tests requiring sophisticated visual (visuospatial) skills. However, the magnitude of change on tests of verbal learning suggested that the participants randomised to the intervention arm also tended to be a little worse in their ability to learn new verbal material.

Overall, these results suggest that, in a full-scale definitive trial, the Artful program may demonstrate the largest benefits for visuospatial skills. These are critical cognitive skills involved in higher-level tasks such as navigation, perceiving complex visual material and reading maps, for example. This hypothesis would be aligned with the notion that participants are engaging in visual tasks as part of the program, thereby likely to be using those parts of the brain that are required for visuospatial processing. However, in the absence of statistically significant benefits, this hypothesis remains speculative. This would now require rigorous evaluation with large numbers and different tests to ensure that any benefits are not accompanied with a slightly lower verbal memory ability.

In this pilot study, we also did not find significant improvements on participants' mood, wellbeing or quality of life, nor on care partner burden or care partners' quality of life. However, the participant and care partner questionnaire ratings were extremely positive. This suggests that our instruments may lack ecological validity, as they are not yet capturing the essence of the positive feedback.

On the interpretation of the study overall

The results are aligned with prior studies of art engagement for people living with dementia in demonstrating subjective improvements in relationships and quality of life. However, it is important to note that this is the first study to subject such interventions to a formal randomised controlled trial conducted in the museum environment.

Overall, the study has been critical to inform further work in this field; namely, to consider carefully the outcome measures, sample and sample size that will be required. An important initial finding from this feasibility trial was that less than one half (32 of 67, or 47.7%) of the participants enrolled in the Artful program would agree and be eligible for the research component. In turn, the final research study sample may not be representative of the entire sample. For ethical reasons, we could not collect and report on these data. In future studies, it might be important to include a 'control' condition that still offers some form of engagement (for example, gallery visits), or structure the research to compare the impact of art viewing versus art making.

In addition, there was 16% attrition, meaning that five participants withdrew from the research. This number is not unusual in studies of older people including those living with dementia, and roughly equal numbers withdrew from the control and Artful intervention arms. The research tests were also primarily designed for those with mild to moderate dementia. Since on average the Artful participants had moderate dementia, and some cases were quite severe, many participants were too impaired for



the tests that were administered, resulting in large amounts of missing data, and it is possible that participants were performing at 'floor' levels on the tests, meaning that they tests were not a valid indicator of their true capacities. It may also be the case that those with more severe forms of dementia do not benefit from the Artful: Art and Dementia program (and, therefore, influence or 'washout' the results when averaged) or that the tools used for assessing improvements were not sufficiently sensitive to detect change.

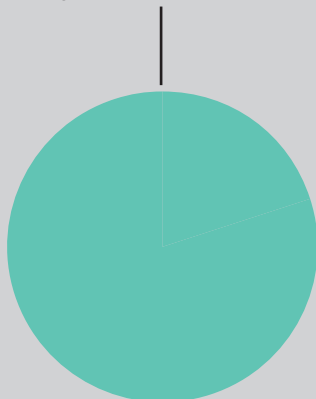
Future studies may therefore wish to also restrict the range to only those with mild dementia, or even mild cognitive impairment, where the opportunity for an intervention to improve cognition may be greatest. Even so, given that few interventions have the capacity to change or improve cognition in individuals with a clear dementia diagnosis, it is prudent to acknowledge that such programs may not yield measurable change in memory and thinking skills. Thus, a ten-week program may be too short to result in formal improvements, especially in the context of an underlying neurodegenerative disease, with a variety of dementia diagnoses.

Finally, there is some suggestion within the scientific literature that brain change may precede any observable/measurable benefit to cognition. If this were the case, inclusion of neuroimaging (that is, brain scans) and much longer follow-up periods would be required in the design and interpretation of future research trials. Given that the feedback of art programs is extremely positive, definitive future trials would ideally be double blind and would include an active control group that is matched on social contact. This would enable researchers to ascertain whether the Artful program itself is truly associated with perceived benefits or whether the general engagement in the social art environment is stimulating and sufficient to be associated with improvements in perceived wellbeing.

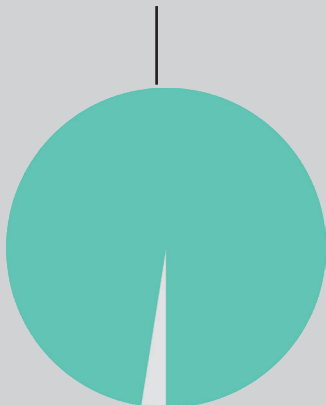
Importantly, there were no adverse events associated with being in the program, meaning that the Artful program is safe, and if perceived to be of benefit, there is no suggestion from this preliminary trial to suggest that the program is harmful. Finally, given that there were marked benefits reported in association with Artful in response to the satisfaction questionnaire, further studies should incorporate formal qualitative research methods (e.g. focus groups) at the conclusion of the program.

Artful participant and care partner enjoying the view of the harbour, MCA, 2017, photograph: Alex Creig

100%
of respondents found the Artful
program to be very beneficial.



97.5%
of respondents found the Artful program
to help improve quality of life.



71.1%
of respondents found the Artful program
to help improve relationships.



**Artful participant
feedback
March 2016 –
October 2018**



95%
of respondents said they would recommend
the program to another person.



92%
of respondents said they would return
to the MCA for other events.

Qualitative learning and unexpected outcomes

The MCA has been a safe place for us to come and be able to join in, participate and interpret and feel a part of something beautiful, satisfying and healing.

— Vivienne, care partner



Artful participant and care partner collaborating in a workshop, MCA, 2019, photograph: Maja Baska

Qualitative learning and unexpected outcomes

Overview

In addition to the cognitive research developed with and analysed by the Brain and Mind Centre, the MCA also gathered its own qualitative data from feedback, surveys and reflection diaries on each program and participant; measured the levels of participant engagement throughout the program, including responses to program activities and the 'Artful at home' packs; and conducted post-program follow-up surveys on the impact the program had on participants' lives. This ensured the program was evaluated in a holistic manner, allowing for improvements to be made after each session. While we were focused on markers of wellbeing and social connection, we saw many unexpected outcomes and identified key tools that led to the success of the program and reflect the unique approach of Artful.

Care partners

Although the program began with an interest in working with people living with dementia and providing respite for care partners, we soon began to see the immense impact the program had on the family and support people who attended. Previous research in the sector had focused similarly on the potential role of the arts for individuals living with dementia; therefore, this was how the research on the program with the Brain and Mind Centre had been structured.

Through our survey results, we saw that 100% of care partners responded positively to the question, 'How beneficial was the MCA Artful program for you (personally)?' During the first year of the Artful program, we saw the importance of the program for care partners in terms of their individual growth and their relationship with the person for whom they care. The program has allowed for new connections to be built between the participant and their care partner, encouraging meaningful encounters that allow them to find new means of communication and to see each other for who they are outside of the disease. For many care partners, their relationship with their loved one is one of loss and grief for the person they were prior to the onset of the disease; they must deal with these changes from day to day. Creating new connections allows carers to feel hopeful about forming a positive relationship in a new reality, rather than trying to connect with what has gone.

In our survey to all 57 participating care partners, 71% reported that the program had had a positive impact on their relationship with their family, peers and significant others. Many care partners who attended the Artful program spoke about feeling lonely and lost, and in need of new, engaging and appropriate activities for people living with dementia; they wanted to find something to do together and had not had much success. Care partners reported that the Artful program often gave the person living with dementia a new lease on life and a new sense of self.



It's quite isolating and your world shrinks substantially living with dementia. This opened a world at the MCA and at home. The homework triggered us to talk so much more on a day-to-day level. It was a privilege.

— Paula, Artful: Art and dementia participant

Artful participant and care partner taking part in a workshop, MCA, 2016, photograph: Alex Creig

Qualitative learning and unexpected outcomes

Through observation and feedback, we have seen some participants have personal breakthroughs during the program that have surprised even their care partners: dancing and singing to various degrees in response to artworks; an increase in writing for individuals who had not written in some time; an increase in speech and confidence when making decisions and participating in activities. These examples were often possible only when care partners stepped back in order to see their loved one try something new, take a risk, speak for themselves and engage independently. While this was very challenging for many care partners, it has also been transformational for their relationship. Even for the many participants who did not experience these significant physical and visible changes, the shift in relationship between the care partner and individual living with dementia from one of dependency to a creative collaboration during something together outside of the disease which was so important to both participants.

A big part of the journey for many care partners was gaining confidence in their ability to contribute to conversations about and the creation of art. For many care partners, the program was their first foray into contemporary art and they arrived to the program with similar anxieties to the participants living with dementia. Over time, they learned that there is no right or wrong approach to contemporary art, and that the process of artmaking is more important than the finished product. These insights helped change the way they engaged with the 'Artful at home' packs, allowing them to enjoy the experience in a new way and let go of any preconceived 'rules' or expected outcomes.

Karina, a care partner, says, 'The 'Artful at home' pack would sit open on our kitchen table during the week with the materials laid out ready for my husband to engage. I would find myself walking past it some days and it would call me to sit down and dabble. Even if it was just for a moment, it was a little time for me during the day and it brought a little sense of calm and relaxation and then I would get back to things.'

Through Artful, care partners had the opportunity to learn something new for themselves and spend time doing something unrelated to caring for their loved one or thinking about the disease. Their active engagement in the program meant that they were as much a participant as the person living with dementia. Their own demeanour and ways of engaging with their loved one changed as they saw the benefits of the program both for their loved one and for themselves.

The artmaking was an opportunity for care partners to not only step out of a 'care partner' role and do something that brought enjoyment and self-expression, but it also provided a space to connect in new ways with their loved one. Many care partners claimed to have run out of ideas for fun and engaging activities they could do with their loved one. It was also a time for care partners to be given permission to play and to build confidence by being a part of the group and observe the different strategies used by the artist educators. There could be a new creative dimension to their role as care partners, as well as to themselves. Many reported a feeling of relaxation and enjoyment when sitting and being creative.

Case study: Vivienne and Johanna

At the beginning of the ten-week program, care partner Vivienne shared that she was quick to tell her mother Johanna, who presented with Frontotemporal Dementia, to be quiet as an attempt to protect her from saying anything embarrassing. Her feedback at the end of the program expressed a shift in their relationship; Artful had had a flow-on effect to other areas of their relationship and communication in day-to-day activities.

Vivienne says, 'The art class taught me as a care partner to be able to let go and express myself as well as allowing Mum to be herself and not have to be perfect. It has helped us grow closer and I have learned to take a back seat as a daughter and care partner and tend to observe Mum more and enquire and ask her for her input and interpretation. I have learned to allow Mum



Artful participants with an MCA artist educator taking part in a gallery strategy, MCA, 2019, photograph: Maja Baska. Featured artwork: **Dale Frank**, *Every time I glance it's just not me*, 2014, installation view *Today Tomorrow Yesterday*, MCA, varnish, lighter fluid on anodised plexiglass, wood, Museum of Contemporary Art, purchased with funds provided by the MCA Foundation, 2014, image courtesy and © the artist photograph: Alex Creig

Qualitative learning and unexpected outcomes



to be able to express herself without criticism and judgement. The MCA has been a safe place for us to come and be able to join in, participate and interpret and feel a part of something beautiful, satisfying and healing.' Her mother Johanna says, 'It has made us feel happy together.'

Impacting the day-to-day routine

Created initially as a short-term tool to keep participants engaged in between their fortnightly visits to the MCA, the 'Artful at home' packs quickly evolved into a long-term tool for meaning-making and relationship building, which could be integrated into participants' day-to-day lives. The packs also became something that the MCA team could continuously learn from, build upon and transform.

For the person living with dementia and their care partner, working on the 'Artful at home' packs often sparked connections to memories, in addition to creating new experiences. The artmaking process triggered conversations and collaboration – not, as one person described it, the typical home routine of 'sitting and looking at a blank screen'. Each person developed new skills over time and they learned together, instead of one teaching the other. The packs contained the potential for light-bulb moments (new learning) and the freedom for each party to be who they are.

Responding to the question, 'How beneficial did you find the take-home activities?', 75% rated them as beneficial or extremely beneficial. The 'Artful at home' packs became a cherished resource for the participants who expressed a lack of activities and ideas of things for them to do at home which could be both fun and meaningful. Often the only resource they could compare it to were mindfulness colouring-in books, which often lack in creative openness and variety and do not offer resources for conversation. Other resources were also often child-like in nature or lacked scaffolding options.

Although the 'Artful at home packs' were not always completed collaboratively as originally intended, feedback showed that it became a meaningful activity for both the care partner and individual living with dementia to do independently, either in tandem or collaboratively depending on their preference, mood and schedules.

I think we both surprised ourselves. I was amazed at my husband's interactions and what he could do creatively. I learnt so much while enjoying myself at the same time.

— Phoebe, care partner

Family dinner on Monday night has now been programmed to include a creative art class with [my] mother as the head pupil.

— Edmund, care partner

For the care partner, they needed to be supported to change their perspective of the pack as 'homework' with expected outcomes; instead, they learned to remain open to see what may or may not happen when a space is offered and creative invitations are made with prompting and encouragement. Our survey results showed that 26% of care partners experienced art-related challenges as part of the program. Once they began to feel comfortable with this aspect, they shared that they experienced more talking, laughing and connectedness with the person living with dementia. Artmaking also helped them transition from passive viewers to artists themselves, and saw each of them thinking and problem-solving. Some commented on an increase in participation and self-initiation for the person living with dementia after participation in the 'Artful at home' pack. One care partner shared that her husband, whose ability to make everyday decisions such as taking a shower or getting dressed had diminished, was less likely to need guidance or prompts after a session of artmaking. For her, she felt that the packs helped to initiate this, as it was consistent with the days she laid out the activities for him to engage with.

When sharing and reflecting on their at-home activities and artworks during the onsite program, the participants supported and encouraged one another, contributing to the sense of pride in their accomplishments. Responding to the survey question, 'How much did you enjoy the artmaking component of the program?', 75% responded with positively; there were zero negative responses.

Many previous participants have kept in touch with the MCA team over the years to share the different ways that they have incorporated artmaking into their daily lives following the Artful program. For example, researching art classes to attend near where they live; starting their own art practice at home; setting up a ritual of other family members taking part in weekly collaborative artmaking; borrowing new books from the library about art; and finding opportunities to collect objects for creative engagement on nature walks or other excursions. The integration of artmaking into the daily home routine has derived from the 'Artful at home' pack experience; it shows that engaging with contemporary art and creative practice is not something that necessarily needs to occur at a museum or gallery, but could take place in one's own home.

Artful participant at home using an Artful 'At home' pack to create an artwork, 2017

Qualitative learning and unexpected outcomes

Scaffolding creative risk

The ten-week structure allowed for an ongoing connection between the group to build community and social engagement. Connection was key for the participants to feel comfortable and safe, and this feeling was integral to the program. Participants in the program often expressed surprise, not only at the type of activities they were being exposed to but also at their ability to participate in them. In receiving this feedback, the MCA team started to form an understanding of the importance of challenging participants in the program and offering them opportunities for growth within a safe space – something they may otherwise not experience in their day-to-day lives.

The Artful program provided multiple opportunities for people living with dementia and their care partners to learn, to face new challenges, and to grow, both in confidence and in the development of new skills. Offering a challenge enables a sense of achievement for many people. In building the activities, the staff ensured they were simple and achievable, but not childish or dumbed down. There was always an openness for self-expression and never an attempt to prescribe or teach art.

One participant reflected at the end of a program, 'While I needed help for some activities, it showed me that I could still do different things ... it gave me a sense of pride.' By building confidence and trusting relationships over several weeks, both participants and care partners felt they had a support system at the MCA that enabled them to move out of their comfort zone, confront potentially challenging activities and learn new things. This is significantly different to other programs which are drop-in in nature and may not build long-term relationships between participants and staff. The MCA also ensured that the staff was consistent throughout the length of each ten-week program in order to build these relationships further.

Artful participants were each recognised for their achievements and contributions, something that can become a rarity in their lives due to the disease. As one participant said, 'It allows us to continue to live, giving hope for the future.'

A wide range of tactile tools and creative strategies were used throughout the program, enabling participants to not worry about getting it 'right', but to explore new ways to express themselves creatively through making marks, gestures or moving their bodies. This can be particularly useful for those with reduced language, for example those experiencing Frontotemporal Dementia – the body becomes the means for expression. It can give a person a new lease on life, especially when facing so many barriers in their daily routine.

Atmosphere and pace became very important to the format of the program. First impressions can make a big impact and stay with a person, affecting the entire experience. The MCA artist educators placed an emphasis on establishing a warm, welcoming and relaxed space, which was maintained throughout the ten-week program. The mood was light-hearted; the sessions were filled with laughter and connection. The pace was slowed right down, compared to how other MCA learning programs might be delivered. Plenty of time and space was allowed for the group to settle in and a quiet private space was provided to return to when needed. Yet, even within this format, the artist educators talked about the importance of risk-taking and providing small challenges.

The artist educators allowed plenty of time for participants to speak, think or just be. All reactions were encouraged and valued – not only verbal ones. Sitting down next to a participant could be vital in making them feel comfortable and supported. During an artmaking session, sometimes



participants may not make a mark at all and simply hold materials or mention some words or stories triggered by the activity. This was always acknowledged as a valid contribution to the program.

To create a safe space for the group, the artist educators would offer the participants prompts. This would include simple demonstrations; images of artworks they may have seen in the gallery to help trigger memory; a repetition of instructions; non-verbal gestures; options to help scaffold the activity so that individuals could either do the first step or move through each step; reminding the group that they could not get it 'wrong' (to avoid a sense of failure); and encouragement to enjoy the process and utilise collaboration and sharing to ease expectations and pressure to perform.

Gentle guidance and scaffolding from the artist educators could come in the form of placing a new art material in the person's hand and encourage them to repeat an action; quietly sharing a technique by simply making some unassuming marks alongside them; or exchanging materials back and forth, creating a conversation and opportunity for engagement.

Even finding the right chairs to sit on in the gallery proved to be an important aspect of helping participants to feel safe – to literally support the group. Typical gallery fold-out stools do not have a back and arm support and can be unsafe and confusing for someone living with dementia to try to sit on as it does not have clear visible markers of which side is the front and which side is the back. After much research, ten bright orange chairs with backs and armrests were purchased. These new chairs were recognisable as a functional chair, easy to see and use, and comfortable and manageable to get up and down from. They also suited the practical needs of being able to be folded and moved around the gallery.

The artist educators approached risk-taking in a number of ways: by experimenting with unconventional art materials, pushing participants' comfort zones as to what art could be, performative processes, dancing and moving to be creative and using new technologies, for example a green screen. These methods allowed the artist educators to open up an unknown world for some of the participants through a range of completely new experiences; there were many unknowns regarding what this might mean for people living with dementia.

Artful participant taking part in a workshop, MCA, 2018, photograph: Jacquie Manning

Qualitative learning and unexpected outcomes

A good example of risk-taking is a collaborative painting activity that took place in response to artist Lara Merrett's *Paint me in* (2018), an installation work commissioned for the MCA Bella Room. Firstly, the group explored the artwork, which consisted of three hanging painted drop sheets that could be sat or lay in, or moved on a pulley system. For many, it was a new experience to interact with an artwork in this way – to be encouraged to touch and become a part of the art. Not only did it challenge the participants' ideas of what art could be, but it broke down barriers for engagement. With little to no verbal instructions, and regardless of physical or intellectual challenges, the group took to it like a playground – laughing, dancing and relaxing in the hammock-like artwork, responding to each other and coming together to move or shift one another. An 80-year-old participant with limited movement sat carefully in the fabric grinning from ear to ear, while a participant in his sixties living with younger onset dementia rocked the older gentleman from side to side. In the responding artmaking session, the artist educators spread out a large sheet of canvas so that it draped across the tables and onto the floor. The participants were then given rollers and brushes attached to sticks and invited to add paint to the surface. The sticks reduced their control and the canvas was expansive and not conventional. This wasn't a 'safe' activity and it pushed people outside their comfort zones to not only embrace what art and painting could be, but to let go of expectations and control.

Many other organisations often speak about dementia programs in terms of how to avoid and manage risks. Although the MCA agrees that risk management is key in terms of safety and wellbeing, creative risk-taking became an important content planning tool for staff on the program. We began to see large shifts in participant engagement, as risk was scaffolded into each session. The artist educators planned the program to scaffold the creative risk whilst also having adaptable options that kept in mind's each participant's needs. In response, the sense of accomplishment from participants was overwhelming – they expressed surprise, pride and joy. Participants also became more open as the program continued to take on more creative risks and introduce new activities and materials.

Play

Play is something we associate naturally with children. We forget how to play as we get older; being given permission to play is highly liberating, and sometimes even intimidating.

Being allowed or invited to play became a vital part of the program. Many people who join the Artful: Art and dementia program have little to no art experience. We often heard the sentence, 'I haven't picked up a pencil or paintbrush since I was a kid.' Participants who left the artmaking sessions often said, 'I haven't had this much fun in years!'

The gallery experience can bring out surprising new interactions when the group feels safe, and able to interact with the artwork. There can be lots of impromptu small body movements and dancing. One care partner talked about her husband feeling a sense of freedom from his disease by being given the permission to play.

We have seen how contemporary art is key to audiences finding a sense of freedom. The MCA collects work by living Australian artists who use various means to explore their ideas, meaning that Artful participants experienced a wide range of contemporary practice, including video, painting, installation, sculpture and performance. For many, it opened up a whole new world: an opportunity to find enjoyment while making new meaningful connections, discover new forms of self-expression, and explore new ways to communicate and play – to play with materials, language and ways to move one's body. Admittedly, the 'play' within the Artful: Art and dementia program was highly

structured. The artist educators created a framework of creative learning strategies that enabled fun and the development of new experiences and skills to take place. It is play with a purpose. It is play that encourages confidence and an opening up. It is play that promotes a sense of freedom!

We witnessed many moments of joy – laughter and camaraderie – and learned the value of acknowledging every person's point of view. In addition to verbal feedback, the artist educators observed feelings of joy among the participants during activities, which highlights the value of shared experience. When asked, 'Did the Artful program help improve your overall mood?', 92% responded positively.

Being given 'permission' to play is also an avenue to joy. For those who have lost language, finding expression through moving the body is an important aspect of retrieving a sense of personhood, and a different form of communication. Play is also seen as a form of exchange and activation within the Artful program – the participants' varied responses to the gallery experience reactivated and 'brought to life' the artworks within the gallery.

Language and terminology

Identity, or personhood, is often seen as one of the most important aspects of psychological wellbeing. People living with dementia are often immediately labelled as 'someone with dementia' and that alone. The stigma of this label plays out in terms of a removal of choice, autonomy and dignity. To lose identity is to lose the fundamental essence of quality of life.

One of the most important approaches within the Artful program has been to work with the person and not the disease. The individual is viewed as a person in their own right, and the program works from where they are, meeting the person at that particular time and place. It is essentially linked to the present and to being mindful – to operate in the here and now. There is a mirroring effect on the care partner, who is labelled a 'carer' once their loved one is diagnosed.

Through the program, we adapted our use of language in terms of the often-used umbrella terms 'people with dementia', 'carer', 'care giver' and 'support person'. The current terms we use are 'individuals or person living with dementia' and 'care partner', but we found that any label is disempowering and can take away agency, so we focused on referring to everyone solely by their first names.

Any label associated with dementia is often reminder of the disease, a loss of independence and of self. For those who choose to identify, they may choose not to be described as a 'person living with dementia', but with a more specific type of dementia, for example, Lewy body disease. It is more empowering to be able to say 'I identify as ...', as opposed to a term being given to you by others. Although we use 'care partner' in this report as a blanket term, we have learned in the program to say 'spouse', 'sister', 'brother', 'friend', 'daughter', et cetera. We saw ourselves using fewer terms that referred to the disease and instead focused on each individual. For many participants, the program became a space where they could forget about the disease and be valued for who they are instead of only being seen or defined by the disease.

The language and instructions used by the artist educators were delivered in a manner that always maintained respect for the participants. So often group activities for people living with dementia can become patronising if the individuals are spoken to as children or as if unable to understand. Engaging participants with respect and dignity was key to building a strong sense of trust. Language and tone are therefore important in creating a space that inspires and where all participants feel valued and respected.



Artful participants taking part in a gallery experience, MCA, 2018, photograph: Jacquie Manning. Featured artwork: **Lara Merrett**, *Paint me in* (detail), 2018, synthetic polymer paint and ink on canvas, steel, commissioned by the Museum of Contemporary Art Australia for the Jackson Bella Room, 2018, image courtesy and © the artist

Qualitative learning and unexpected outcomes

Perspectives on wellbeing

Dr Allen Power is a renowned American geriatrician who specialises in dementia care. In 2016, a report by Alzheimer's Australia, 'Living Well with Dementia', drew on his seven domains of wellbeing as described by people living with dementia to attempt to reframe the conversation around dementia to be more positive and empowering. The seven domains are:

1. Identity
2. Meaning
3. Connectedness
4. Growth
5. Security
6. Autonomy
7. Joy

The Artful program is an example of how museums can be safe spaces, contributing to wellbeing for those living with dementia and their care partners. In our survey results, responses to the question, 'Did the Artful program improve your overall quality of life?', 97% responded positively. Building on Power's seven domains, the Artful program addressed ways to become a dementia-friendly museum by training staff across multiple departments and keeping this audience in mind when considering other aspects of the Museum, such as wayfinding, seating and lighting.

The freedom to make choices is a human right. Decision-making can be challenging for people living with dementia, which can be perceived to be a negative for both the individual and their care partner. Throughout the program, however, we began to see participants making small choices and finding their voice. Comments on what they did not like about the program, or did not want to do, were received positively; it illustrated a capacity to form an opinion and be heard. Therefore, it was important to create a balance of decision-making requirements within the structure of the program. The artist educators found strategies to reduce the need for decision-making that may overwhelm participants, while ensuring they felt empowered throughout the program. Often this balance would change with every session depending on the activity, the group and how each individual was feeling that day. Not expecting prior experiences with each individual to inform future ones became an important lesson for the artist educators.

The length of the program, ten-weeks with each group, was pivotal for the MCA staff to gain a greater understanding of the needs and interests of individuals and the group as a whole. A few participants in each group tend to only come out of their shell after two to three sessions. For example, Ben, a former medical doctor with no knowledge of art, was very quiet and reserved in the first few sessions he attended. His wife shared that he had a fear of failure and was not used to working with unknown outcomes, and he was intimidated by the open-ended nature of the artmaking activities.

Initially, his wife was concerned the program was not suitable for him but was encouraged by the Artful coordinator to stay with it. After the third session, Ben began to sing spontaneously during the artmaking session, having been reminded of a song he liked from an artwork he had seen in the gallery that day. Staff found the song online and played it to the group to enjoy. Over the ten-weeks, he opened up immensely and started relating artworks to memories of his childhood and offering insightful reflections in the group discussions. Music became a key part of the program due to Ben's interest and was integrated into the rest of the activities. At the end of the program, his wife said, 'Everything we do in life is prescriptive. There are a list of instructions and you complete them. This has really been different for us, learning there is no right or wrong way. Ben has really come out of his shell. This program has made a real impact on our lives ... Thank you for bringing back the smiles.'

Ben says, 'The Artful program has opened my understanding of the need to view things in a wider perspective. At first, I found it took me a while to settle down if there were things distracting me. It was better if I had some quiet music as background. I found it good to look at other items nearby and imagine what might work for me. It usually took about half an hour before I could settle on what I wanted to do and I think this is the most important factor, for sure. I really enjoy the atmosphere and comradeship of the friends I have met during the program.'

This balance in being led by participant's interest and tailoring the program became a vital way of working with participants. Through tailoring the program we saw participants grow in confidence and be empowered to take creative risks.

Qualitative learning and unexpected outcomes

Case study: Norman and Nanette

Norman attended the Artful program independently. Sometimes he had notes in his wallet to remind him of the date or what train he had to catch home. He struggled to remember some things and could get flustered if he was running late, or if things were busy and stressful at home.

Norman came to the program soon after being diagnosed with Alzheimer's in 2015 at the age of 65. He was a geologist and metallurgist and had opened a new engineering business in Sydney. He had always had an interest in art, although he had never done artmaking before. He was also a keen surfer, walker and traveller.

Norman says, 'Art has helped me to settle down. Yes, I forget people's names but when I'm doing art I am suddenly in a different environment. It is all calm and I can think. The stress just dies away.' Since the Artful program, Norman has maintained his own art practice. He sought out art classes in his local area and often attends more than one a week. He has developed his own particular painting style – a repeated motif of colourful flowing shapes with faces or text appearing in the painting. The titles of his artwork are important to him and are poetic in nature, for example, *The river of dreams* and *The person inside*.

His wife Nanette says, 'I did not have a direct involvement with Artful, but I have seen the positive impact it has had. Norman always came home excited about what he had done, showing or explaining what he achieved and being so proud of his work. He always looked forward to attending. Norman was very fond of the artist educators and always had something to tell me. The program offered Norman a new insight into achieving something that he feels confident about and an ease with the [Museum] and surroundings. I cannot thank you enough.'

This program ticks all the boxes [Dementia Australia] says for you to do. One: get out of the house; two: socially engage and connect; three: stimulate your brain in new ways. We just want to keep doing it.

— George, care partner

We need to change our minds about people whose minds have changed.

— Dr Allen Power M.D.



Top: Artful participant and MCA artist educator taking part in a workshop, MCA, 2020, photograph: Jazz Money
Bottom: Artwork by an Artful participant, *People Together*, 2019

Qualitative learning and unexpected outcomes

Impact on artist educators



As an educator, the program provided an amazing emotional experience for me. I was able to invest much energy into relationships and connections with participants, which isn't possible with single visits from groups.

— Athena, MCA artist educator

The Artful program is delivered by MCA artist educators, who have been specifically trained by both Dementia Australia (formerly Alzheimer's Australia) and the National Gallery of Australia (NGA) outreach program to work with people living with dementia.

Dementia Australia is an organisation of experts and leaders in dementia care, and its staff delivered specifically tailored training and support to select MCA staff before the program's launch in 2016. This included a full day of training with an introduction to dementia, practical workshops and a series of demonstration tours. Denise Herman, Coordinator of Social & Therapeutic Programs, Dementia Australia, was present to support the MCA team to take a small group of people living with dementia through our galleries. The NGA outreach program is delivered throughout Australia and draws on the NGA's experience of running a dementia program over ten years in Canberra. The NGA's Program Coordinator Adriane Boag provided the MCA team with initial guidance and support then delivered training to the staff to build further confidence and understanding once the Artful program was underway.

Having worked on the Artful program, the artist educators have developed many new skills and report being impacted both personally and in their own creative practice. Cindy, an MCA artist educator, says, 'Being a part of the Artful program has greatly increased my awareness and understanding of the variety of audiences who respond positively to creative artmaking. This has created a deeper purpose for my art practice and a stronger sense of the contribution I can make to the broader community. It has given me a sense of connection to people that I didn't have before.'

The Artful program is one of the few MCA programs that includes multi-visit sessions; over time, the artist educators and participants built incredibly meaningful relationships, which meant it was often hard to say goodbye to groups at each program's end. Artist educator Brook says, 'It has been extraordinary to see the development and changes in confidence in some participants. The atmosphere and group community dynamic has been incredibly warm and supportive with participants encouraging, complimenting and sharing ideas with one another. I have seen friendships form and felt such joy hearing stories and memories from each participant. It has been a joy to be a part of this program.'

The program has also informed how the artist educators approach other programs that they deliver for groups across all ages. 'Working on the Artful program was really affecting,' says artist educator Harriet. 'I became very aware of the different ways to deliver information in different formats as appropriate to people's communication needs and feeling more comfortable to really spend a long time talking about particular things.'



Artful participant and care partner enjoying morning tea, MCA, 2019, photograph: Maja Baska

Conclusion

We like coming here and being opened up to these creative processes and its [something] that you can't quantify. It's like travel. You experience it, it changes you, but you can't say in what way it's done that.

— Josephine, care partner

Conclusion

The next steps

Over the last three years, we've seen the importance of our holistic approach. Artful: Art and dementia differs from other art and dementia programs in many ways, including:

- a focus on a variety of contemporary art mediums
- a combination of gallery experience with hands-on activities
- a multi-visit structure delivered with consistent staff which establishes connection, warmth and intimacy
- a program being delivered by trained artist educators
- the use of professional and high-quality art materials
- the inclusion of 'Artful at home' packs
- the closure of the ten-week program with a celebratory event and mini exhibition
- a focus on creating new experiences
- the creation of a safe space, enabling expression, creativity and creative risk-taking
- the research and involvement of the Brain and Mind Centre.

The MCA has learned an immense amount from this program, from both the participants and their care partners, about how to remove the multiple barriers that exist for this audience. We have since ensured that all of our programs are created with consideration for people living with dementia to take part. This is helped inform MCA's approach to ensuring that art is for everyone. This includes being committed to taking a lead on best practices for dementia-friendly museums. We've seen this slowly take shape as we have developed new strategies for creative learning and implemented different communication techniques specific to this audience, in addition to purchasing new equipment and offering training to our staff.

We have received many enquiries from across the globe expressing great interest in our unique approach. However, we have restricted external observers having access to the program and participants. It would not only shift the ratio of participant to non-participant, but would affect the intimacy of the program. This has led us to explore professional development opportunities in order to share our expertise with others. Through two-hour evening workshops, we have shared our knowledge and insights with professionals who may benefit from our approach, including teachers, museum and gallery staff, and employees from the aged-care and support sector.

During these workshops, we have also invited participants living with dementia to share their experience of their program. This has proved to be incredibly meaningful and empowering for participants in being acknowledged as valuable contributors.

Following the research trials and its associated learnings, the Artful program re-launched in 2019 with a new structure: a six-week program offering weekly



sessions accompanied by the 'Artful at home' packs as well as quarterly Artful Community Days – an expansion of the celebration days which offer a space to exhibit participants' artworks and for previous participants to attend and stay connected. This revised structure for the program was created based on participant feedback and has been extremely well received (it will also run in 2020). It continues to integrate qualitative and quantitative research surveys and staff diaries to ensure the program improves and evolves based on participant experience and feedback.

With every program we continue to meet incredible participants whose contributions inspire us. The Artful program is a direct result of their openness and spirit. We look forward to seeing how this program will evolve as we continue to learn from each other and contribute to new research. We urge others in the field to continue to innovate and work towards a common goal of making all programs and spaces dementia-friendly, as well as working towards continued collaboration between the arts and health sectors.

Artful participants and MCA artist educators taking part in a painting workshop, MCA, 2016, photograph: Michelle Heldon

Glossary and appendices

Glossary

‘Artful at home’ packs	An activity pack created to offer fortnightly artmaking experiences at home to Artful participants. These were given fortnightly as part of the 10-week program. Packs include: an artwork image card from the MCA Collection, which offered inspiration for the activity; an instructional step-by-step activity sheet with tips and open-ended questions to prompt conversation; a list of materials required, which could be easily found in the participant’s home; and an array of professional artmaking materials needed for the activity. Each activity encourages the person with living with dementia and their care partner to collaborate, but also allows for individual contributions if preferable.
Artist educators	Practising contemporary artists trained by MCA staff to lead creative learning programs for all ages.
Care partners	This term denotes an agreement between the person with a chronic condition and their loved one(s) to be partners in care as best they can. Care partners can be wives or husbands, brothers or sisters, children, aunts or uncles, and/or friends.
Creative learning	An approach to learning and inquiry which uses creative processes. It prioritises open-mindedness, constructive inquisition, harnessing the imagination, collaboration and experimentation.
Dementia	Dementia is not one specific disease. Dementia is a broad term that encapsulates many different forms of brain disease and brain injury; each has its own causes and symptoms. Someone living with dementia may experience a loss of memory, intellect, rationality, language, social skills and/or physical functioning. It affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person’s normal social or working life. The most common types of dementia are Alzheimer’s disease, Vascular dementia, Dementia with Lewy bodies and Frontotemporal Dementia (FTD). Dementia can happen to anybody, but it is more common after the age of 65; however, ‘younger onset dementia’ (affecting those under 65) is also increasing.
Neuroplasticity	The brain’s ability to reorganise itself by forming new neural connections throughout life. Neuroplasticity allows the neurons (nerve cells) in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment. Research suggests that dementia is associated with the decline in neuroplasticity.
Neuropsychologist	A psychologist who studies the relationship between an individual’s brain and their emotional, physical and social behaviour.
Randomised control trial	A study in which people are allocated at random (by chance alone) to receive one of several clinical interventions. One of these interventions is the standard of comparison (or control). The control may be a placebo (‘sugar pill’), or no intervention at all.
Scaffolding	Scaffolding is a teaching method that enables an individual to solve a problem, carry out a task, or achieve a goal through a gradual shedding of outside assistance. Like physical scaffolding, the supportive strategies are incrementally removed when they are no longer needed.
Visuospatial cognitive skills	Visuospatial ability refers to a person’s capacity to identify visual and spatial relationships among objects (for example, judging vehicle distance and speed accurately). Visuospatial ability is measured in terms of the ability to imagine objects, to make global shapes by locating small components, or to understand the differences and similarities between objects.
Wellbeing	Wellbeing is a concept that reaches beyond health status, cognitive or functional ability. There are many good models for wellbeing, but the one we refer to is Dr Allen Power’s seven key ‘domains’: identity, connectedness, security, autonomy, meaning, growth and joy. These seven aspects of wellbeing are important to everyone, regardless of age, culture or ability.

Appendices

Appendix A: MCA creative learning manifesto

Our creative learning manifesto is a set of values and concepts that guide the development and delivery of all learning programs that we offer.

Art is for everyone	Art does not discriminate. Art reaches beyond age, ability, experience, education, gender, culture and language.
Artists at the heart	Artists are experts in their field. When it comes to imagination, risk-taking, skills and ideas, an artist's practice makes a remarkable model for creative learning.
Look and think	Artists invite us to be creative and critical thinkers, to understand art, ourselves and our world in exciting new ways.
Colour outside the lines	Contemporary art gives us an opportunity to step outside of our comfort zone, to rethink the rules, take risks and imagine the impossible.
Play with process over product	Art-making is a space for playing and experimenting with materials, techniques, ideas and possibilities. The process itself can be more engaging than the final outcome.
Bring your own story, take fresh meaning	Everyone brings their own story to art, making connections to their own life experience.

Appendix B: Staff diary/weekly program reflection (example)

Session notes	Artist educator notes	Coordinator notes
Week 3: 24 April 2017	<p>Today in the gallery we looked mostly at the artwork of Rose Nolan. Everyone seems to feel comfortable sharing their ideas and associations freely. Again, Lianne's enthusiasm and charisma is encouraging and imaginative. Grace is happy to take lead when she is given the space to discuss her ideas. Nick needs one-on-one support to share his ideas as his voice is softer and needs a little encouragement before sharing. He seemed confident this week to share his views on some of the artwork including that he politely wouldn't look at some of the artworks more than once and had a good discussion with the Educator about what we consider art to be. I think it is encouraging for Nick to share his views on the artworks and hope this suggests his comfort in doing so. We also met Lara this week and she seemed particularly engaged in the artworks and had a lot to say about what she saw.</p> <p>We noted that it takes a lot of time to leave the gallery as participants are very engaged in their conversations and might even need extra time when returning to the studio as they pass the other artworks in the gallery and people.</p> <p>The workshop extension seemed to work well with most of the participants choosing to make their own extension to the threading activity. After seeing the resulting works, I wondered if the activity was challenging enough for the participants and thought it might be a good idea to have an extension to the studio activity if needed.</p> <p>Lara seemed to settle in well despite a rough start to the morning arriving late and with no support person.</p> <p>Many participants are sharing their knowledge and expertise in their experience of the arts and spending time acknowledging this expertise is important to the group. Educators have made great observations that the group are really articulate and enjoy discussing the artworks at length and strategies were not needed to aid the discussions. Often, they might instead interrupt the flow of conversations as participants focus on the doing.</p>	<p>Harriet made the comment that Nick started thinking everything was art.</p> <p>Commenting on a table in the NCCL, 'I wouldn't have done it like that.' He said really beautifully, 'There is art, and there is nothing. This is something in between.'</p> <p>Threading was difficult for some. Lianne mentioned that she felt like she was failing at it. She drew on the circles and I thread them for her.</p> <p>Lara joined us this week. Her driver said it was too hard to get to the city, so he didn't come. She was quite stressed by this and wasn't sure how she was supposed to get home.</p>

Appendices

Appendix C: 'Artful at home' pack (example)

ARTFUL

– At home pack

Museum of
Contemporary
Art Australia

HELLO!

This Artful at-home pack contains some creative activities for you to explore together. We encourage you to share with each other your thoughts and experiences.

This program is supported by Vincent Fairfax Family Foundation and is created in collaboration with The Healthy Brain Ageing Program, The University of Sydney and Alzheimer's Australia NSW.



INCLUDED IN THIS PACK IS:

- Artwork image card
- An art-making activity
- Carer feedback form
- Any materials you may need

TO HELP YOU ALONG YOUR WAY:

- There is no right and wrong in art. Explore and find your own meaning
- Before you begin, set up a comfortable space (for example, clear a table of all items)
- Give yourself plenty of time
- Don't be afraid to stray from the brief if something becomes more interesting
- Process is more important than the end product
- Enjoy yourselves!



Appendices

Appendix D: Participant feedback form (example)

Our creative learning manifesto is a set of values and concepts that guide the development and delivery of all learning programs that we offer.

1. How beneficial was the MCA Artful program for you?

Not at all

Very

2. How beneficial do you think the Artful program was for the person you attended with?

Not at all

Very

3. How much did you enjoy the artmaking component of the program at the Museum?

Not at all

Very

4. How beneficial did you find the take-home activities?

Not at all

Very

5. How much did the program help improve your overall quality of life?

Not at all

Very

6. How much did the program help improve your overall mood (e.g. happier?)

Not at all

Very

7. How much did the program help improve your relationships with family, peers and significant other?

Not at all

Very

Appendices

8. How likely would you be to recommend the program to others?

Not at all

Very

9. How likely would you be to return to the MCA for other events?

Not at all

Very

10. What were your reasons for wanting to participate in the MCA Artful program?

11. Were your expectations met at the end of the program? Why/why not?

12. What were the challenges you faced when attending the MCA Artful program?

13. How could the MCA Artful program be improved?

Appendices

Appendix D: Program feedback form (example)

ARTFUL
– Feedback form

Museum of
Contemporary
Art Australia

We would love to hear a little bit about your at-home experience

On a scale of 1 to 10, how engaged were you both during the activity? (please circle)

Not engaged 1 2 3 4 5 6 7 8 9 10 Very engaged

What do you think contributed to this level of engagement?

Did the activity spark any discussions or change in behaviour?

Overall, how long did you spend together with this pack?

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Appendix E: Program logic slide

With thanks to Diana Ferner, Director, Consulting of Social Ventures Australia who ran a workshop with us on this approach.

VISION

The MCA's vision is to take a leadership role in shaping an Australia that values contemporary art and artists. We exist because contemporary art matters: it stimulates the imagination, creatively engages our aesthetic senses and has the power to transform lives. Contemporary artists address complex ideas and challenge us to think and see the world differently to inform our outlook on life and society.

ISSUE

We believe that the MCA and contemporary art are for everyone. Contemporary art stimulates the imagination, creatively engages our aesthetic senses, and has the power to transform lives. Contemporary artists address complex ideas, they challenge us to think and see the world differently to inform our outlook on life and society. However, there are many barriers to accessing contemporary art including awareness, cost, travel and a lack of confidence and/or knowledge about art.

ACTIVITIES

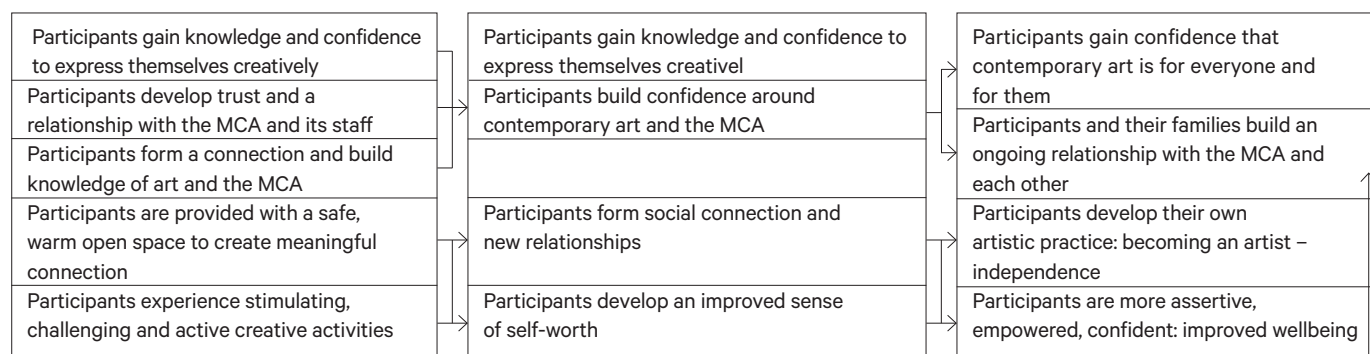
The MCA works with people with dementia, care partners and their support networks to provide them with:

- opportunities to engage with artists and contemporary art in the MCA Collection
- opportunities to learn and develop new ideas, skills and experiences through creative hands-on artmaking, both at the Museum and at home ('Artful at home' pack)
- social connection and community

OUTCOMES

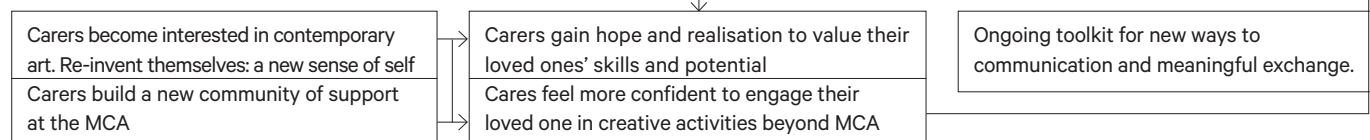
People living with dementia

Various diagnosis



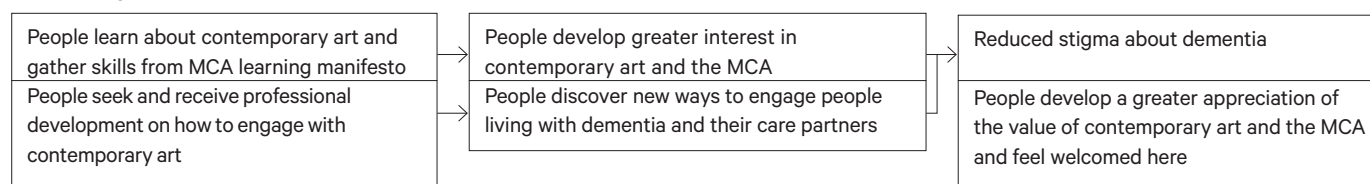
Carer giver

Partners/family members/care workers



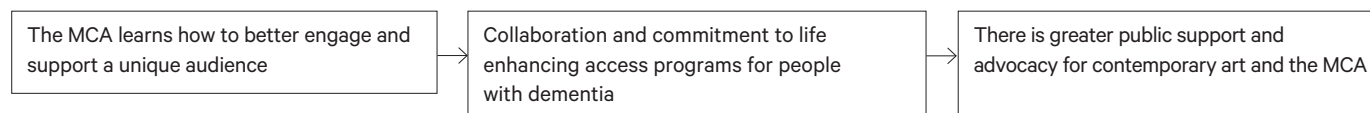
Art and health sector

Galleries, aged care, health care



MCA and partners

MCA staff, Brain and Mind Centre, Dementia Australia



Appendices

Appendix F: Artful program participant profile

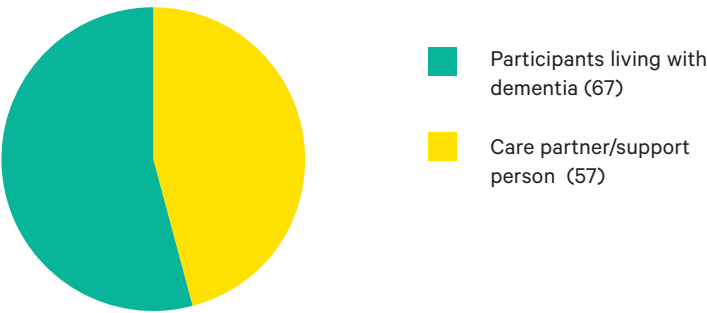
3 years. 16 programs. 124 participants, 1 research project. From 2016–2018 the program has engaged with 124 individuals (participants and their care partners) over 16 ten-week programs.

Occupation

Participants from Artful came from varying cultural and geographic backgrounds. Participants came from diverse areas of professional experience including: health and medicine, accounting, banking, business, sales, law, education, science, technology, industrial relations, human resources, engineering, diplomacy, military, administration, building, town planning, farming, sport and homemaking, among other things. Not all had experience or prior interest in the arts although we did have participants with experience in dance, design, fashion, music, visual arts and conservation.

Participants and care partners

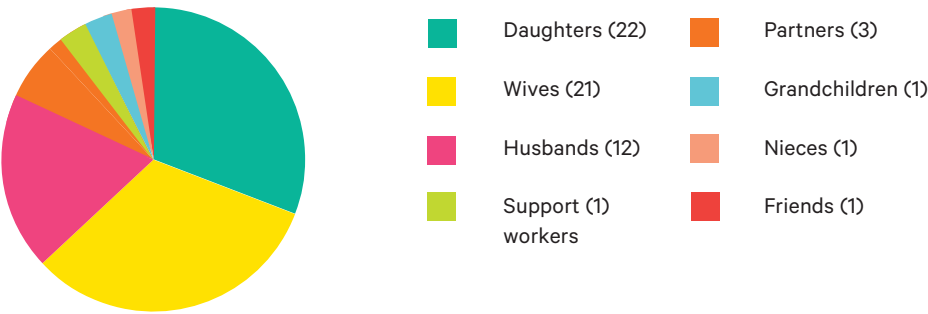
Participant breakdown



Care partners

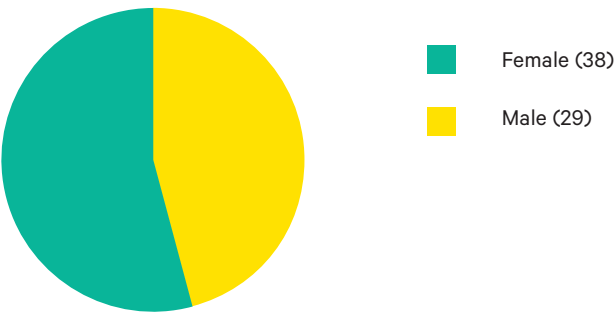
Relationship to participant

*5 participants attended the program independently



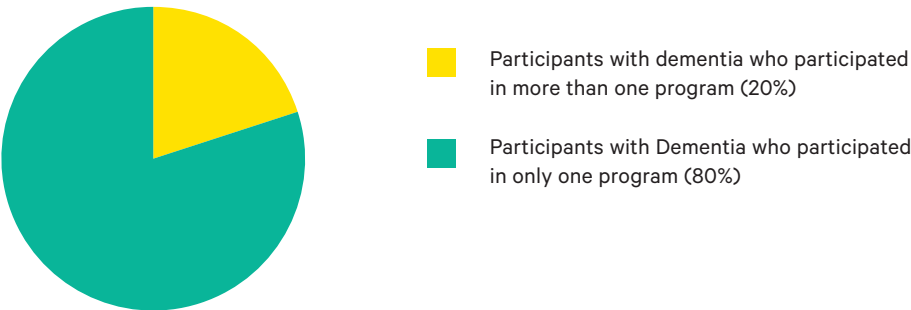
Participants living with dementia

Gender breakdown

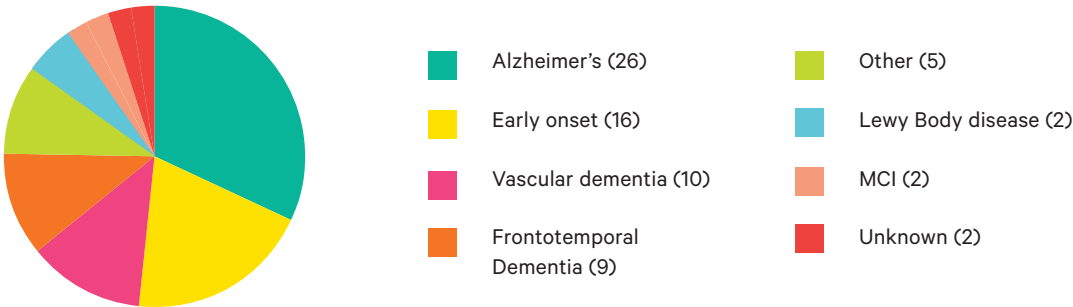


Appendices

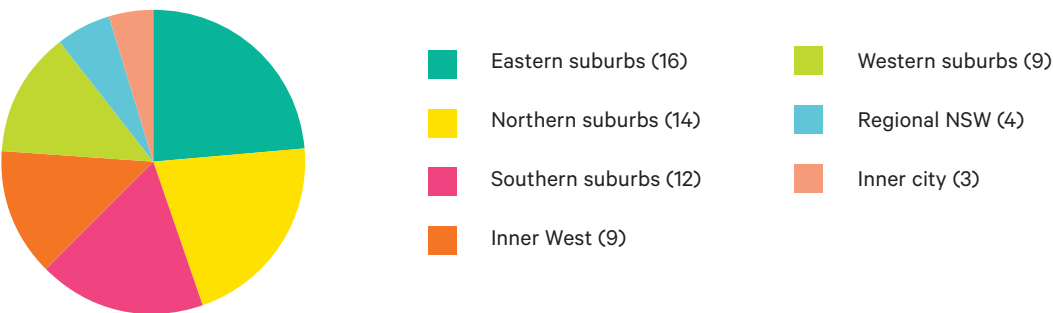
Participants living with dementia
Participation



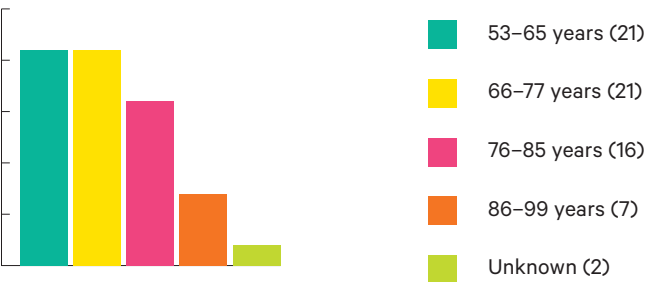
Participants living with dementia
Diagnosis



Participants living with dementia
Regional postcode



Participants living with dementia
Age



Appendices

Appendix G: Report contributors

MCA staff

Alice Blandeau-Thomas, Art and Dementia Coordinator (2019-)

Yaël Filipovic, Public Engagement Manager

Michelle Heldon, Art and Dementia Coordinator (2016-)

Gill Nicol, Director, Audience Engagement

Clare Thackway, Art and Dementia Coordinator (2017)

MCA artist educators

Athena

Brook

Cindy

Clare

Ella

Giselle

Giulia

Harriet

Katie

Liam

Sarah

MCA Hosts

Alice

Floura

Francesca

Georgia

Lee

Marietta

Brain & Mind Centre, University of Sydney

Amelia English, Senior Project Officer, Healthy Brain Ageing Program

Prof Sharon Naismith MAPS CCN, Leonard P Ullmann Chair in Psychology, NHMRC Dementia Leadership Fellow,

Director, Healthy Brain Ageing Program

Stacey West, Clinical Trial Coordinator, Healthy Brain Ageing Program

And the Neuropsychologist team

Dementia Australia

Denise Herman, Coordinator, Social & Therapeutic Programs

Sian Larkin, Group Facilitator, Early Intervention

Anne Lunnon, Manager Support Services

Susan McCarthy, Executive Director, Client Services and Education

Indigo Melrose, Younger Onset Key Worker

Barbra Williams, General Manager Client Services

Artful: Art and dementia program supporters

Vincent Fairfax Family Foundation 2015–2018

Platypus Asset Management 2018–2020

Appendices

Appendix H: Where can I learn more about this study?

You can find more information about this study on the websites listed below. When a full report of the study results is available, it can also be found here.

– <http://www.anzctr.org.au/> Once you are on the website, type “ACTRN12616000100493” into the “Search Now” box.

The researchers will be writing up an article to be published in a scientific journal. When this article is published it will be made available on the website.

Full trial title: A randomised controlled trial to assess whether a 10-week combined gallery-facilitated and at-home art program, ‘Art & Dementia’, can affect changes in neuropsychological markers of visuospatial functioning, as well as improvements in ratings of quality of life, mood and carer burden, in older adults with dementia.

ART & DEMENTIA Protocol number: 2016/003

The University of Sydney sponsored this study, and full ethics approval was obtained through the Human Research Ethics Committee (HREC) of the University of Sydney. Its headquarters are at Level 6, Jane Foss Russell Building University of Sydney NSW 2006. The study was conducted in compliance with all stipulations of the study protocol, the conditions of ethics committee approval, the NHMRC National Statement on Ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice. (CPMP/ICH-135/95).

Museum of Contemporary Art Australia

For any questions, please contact the MCA Art and Dementia Coordinator: mail@mca.com.au or +61 2 9245 2400.


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Heldon, M, Filipovic, Y, & Nicol, G, 'Artful: Art and dementia program: A report on a three-year pilot research program at the Museum of Contemporary Art Australia', Museum of Contemporary Art Australia, Sydney, 2020.

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