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For all who work with people with dementia

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The Big Picture in dementia research

SPECIAL ISSUE

Celebrating and showcasing
10 years of achievements and
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Viewing art brings ‘in the moment’ pleasure

A recent evaluation of the Art and Dementia program at the Art Gallery of NSW shows that viewing art brings ‘in the moment’ pleasure for people with dementia, as well as opportunities for storytelling, reminiscence and conversation with friends, family and carers. **Gail Kenning** reports

Dementia impacts cognitive functioning, and so memory and judgment may be impaired. However, consciousness and emotional memory persist and so even in the later stages of dementia, people are able to feel pleasure and joy (Cohen 1988; Cohen-Mansfield *et al* 2012; Guzman-Velez *et al* 2014; Sabat 2006; Zeisel 2009).

Having a good quality of life and experiencing pleasure are key motivations for many people (Maslow 1970). Social engagement and leisure activities are not only pleasurable; they have been shown to impact on positive well-being (Cutler 2009; Kenning 2015; Renshan *et al* 2012).

Many people spend their leisure time in the company of others visiting art galleries. They enjoy the familiarity and challenge of viewing artworks and the social interaction that occurs in the gallery environment. In 2005/2006 almost one quarter of Australian adults visited a museum or art gallery (ABS 2005-6). Similarly for people living with dementia, having something to do and opportunities to meet and talk to others can contribute to a fulfilling life and alleviate feelings of stress and depression that so often accompany a diagnosis of dementia (Lipp 2003).

Increasingly, art access programs are being established worldwide that provide opportunities for people living with dementia to experience ‘in the moment pleasure’ through engaging with cultural artefacts and in social and cultural activities in gallery spaces.

‘Opening people’s eyes and minds’

The Art Gallery of New South Wales first ran a pilot Art Access Program for people with dementia not long after the successful launch of the Meet Me At MOMA program at the Museum of Modern Art (MOMA) in New York in 2006. The MOMA program drew on the growing understanding of the beneficial impact of



Participants in the Art and Dementia Program at the Art Gallery of New South Wales. Photo courtesy Art Gallery of NSW

engaging with artworks for people with dementia (Zeisel 2009) and informed the development of similar programs internationally (Basting 2009 p118).

Australia has been at the forefront of providing opportunities for high-quality engagement and interaction with artworks in Sydney (at the Art Gallery of New South Wales) and Canberra (at the National Gallery of Australia). The Art Gallery of New South Wales’ Art and Dementia program was developed in consultation with MOMA and the National Gallery of Australia and adapted to suit local conditions, the works available in the gallery collection and touring exhibitions, and the expertise of its gallery staff and volunteer guides.

The program aims to provide opportunities to “open people’s eyes and minds to the wonder, richness and sheer pleasure of art” (Art Gallery of New South Wales 2015). It provides people with

dementia, families, caregivers and care staff guided access to Australian masterpieces and international touring exhibitions (such as *The greats: masterpieces from the National Galleries of Scotland*, and *Matisse and the moderns*).

The program allows people with dementia and their carers to view three to four artworks under the expert guidance of volunteer guides. These guides have an in-depth knowledge of the artworks being viewed and have received specialised training from Alzheimer’s Australia NSW, Danielle Gullotta (the Art Access Program producer at the Art Gallery of New South Wales) and Adriane Boag (National Gallery of Australia Program Coordinator). It is a structured experience using a conversational approach to enable participants to reach their own interpretation of the works of art through observation, discussion and by making associations with their own lives.

Participants may recall stories of the past, talk about present experiences with the guides and other participants, or quietly enjoy looking at the artworks.

Danielle Gullotta explains: "We aim to talk to the person first. Dementia is just a condition they have. It is important that people are given the opportunity to see things they love...and to have opportunities for new experiences" (personal communication, July 4, 2015).

Focus on the 'here and now'

When facilitating arts engagement for people with differing cognitive and physical abilities, and in introducing new audiences to art and the gallery, special requirements must be met. Simply getting people living with dementia in the same space as the artwork in order to experience it first-hand takes organisation and dedication on the part of many people.

The Art and Dementia program primarily focuses on the 'here and now'. While some people with dementia may not be able to recall the art they have viewed or artists they have discussed, a day or even in some cases only an hour later, this does not diminish the potential for the 'in the moment' pleasure of experiencing artworks.

Steven Sabat, Professor of Psychology at Georgetown University, suggests that positive emotional experiences, like viewing art, can have an ongoing impact on people with dementia. He argues that a "person may not be able to recollect consciously some previous experience, but his or her actions will reflect a memory of that previous experience nonetheless" (2006 p11). Therefore, positive emotional experiences can contribute to people's overall well-being (Cohen *et al* 2006; Cohen-Mansfield *et al* 2012).

Evaluating the Art Access Program

Researchers at the University of Technology Sydney (including this author) recently evaluated the Art Gallery of New South Wales Art Access Program to examine its impact on people living with dementia, their family members and carers. The Arts Engagement For People With Dementia study, which began in October 2015 and was completed mid-2016, was commissioned by the gallery. It used a mixed methodology approach involving qualitative and quantitative research. Approval for the study was granted through the Human Research Ethics Committee of the University of Technology Sydney (HREC 2015000330).

The primarily qualitative study followed four groups as they viewed four paintings under the expert guidance of program facilitators. It engaged with participants'



Enjoying *Joie de Vivre* at the gallery.

Photo: AGNSW

family members, care staff and facilitators before and after the gallery visit. The study used a range of research approaches including observation, interviews and surveys of those involved in arranging, delivering, and experiencing the program in the gallery space, and drew on best practice evaluation of music, drama, and the visual arts and social science methods (Flatt *et al* 2014; Killick 2013; Mittelman & Epstein 2006; Thomson & Chatterjee 2013). Accordingly, this evaluation used the following methods with analysis based on triangulation of data collected through:

- Ethnography incorporating both personal and video observation.
- Interviews (formal and informal) with carers and gallery staff involved in the program. This provided a level of expert review; and
- Pre- and post-visit survey questionnaires.

This study did not seek to show the long-term impact of engaging with artwork, although there is need for further research in this area, but instead focused on evidence of 'in the moment pleasure'. In addition, the study examined:

- The extent to which the Art Access Program provided pleasure and enjoyment and positively contributed to the well-being and quality of life of people with dementia.
- What pleasure, joy, and mental and emotional stimulation that contributed to the quality of life of people living with dementia could be observed 'in the moment'.
- What learnings can be gained from the

Art Access Program in relation to care, well-being, and quality of life for people with differing needs.

The participants

The groups of participants taking part in the study were from a community centre with a dementia care program, a residential aged care facility, and a government-funded program for people with younger onset dementia, in Sydney.

The participants ranged from 46 years of age to 92. Some were mobile and active, showing only mild symptoms of dementia, being able to engage in prolonged relatively sophisticated conversations about the artworks before their memory issues became apparent. Other participants were more severely impaired by their dementia; three people were aphasic, two were aphasic and had little ability to communicate through facial expression or gesture, and several participants had comorbidities such as Down syndrome and depression.

Observations and interviews

Researchers observed participants as they travelled to the gallery, moved through the gallery space, and viewed the artworks. They noted participant responses consistent with the behaviours of people enjoying the experience. This included smiling, laughter, animated chatter, pointing and looking at the artwork, and engagement with program facilitators, their peers, or care staff.

Researchers also looked for reactions that suggested participants were not enjoying the experience. These included behaviours such as fidgeting, negative comments, crying out, sleeping, yawning, shouting, or walking around.

All participants, care staff, and program facilitators were audio and video recorded to allow for further analysis to be conducted by researchers after the gallery visit. Unstructured interviews were carried out with care staff, family members, gallery staff, and program facilitators and they were all also asked to complete survey questionnaires. These included questions about their overall quality of life and their experience in the gallery on the day of the visit.

A total of 35 people with dementia attended the access program during the four days of the evaluation and completed questionnaires. Of those, 21 people were observed closely. Ten program facilitators were interviewed and completed questionnaires about their experience of delivering the program, and 11 care staff accompanying the participants completed questionnaires and spoke about their experiences.

Key findings

While there are methodological challenges in evaluating the cognitive, affective, and conative impact on people with dementia of participating in art access programs, this intensive period of study and analysis led to three key findings:

- Art access programs provide opportunities for **normalcy**.
- The **context** of the visits to the gallery is an important aspect of the art experience.
- Social support or '**scaffolding**' can enable people with dementia to undertake new experiences and build on existing capabilities.

Normalcy

In brief, normalcy results in each individual being treated with dignity and respect and accorded the rights and privileges of all citizens regardless of ability (Chenoweth *et al* 2009; Killick 2013; Kitwood 1997; Treadaway *et al* 2014). This does not mean that there is a 'norm' or 'standard' approach to be conformed to, but recognises individuals as being different, having different interests, needs and capacities and wanting different experiences. It recognises that although dementia is a degenerative condition all individuals have potentiality and possibility.

Context

The importance of context is a key finding of the study. Factors such as the length of the journey to the gallery, the atmosphere on the bus or other transportation used, the seating of the chairs in front of the artworks, noise levels in the gallery, etc can cause discomfort, confusion, or even rejection and withdrawal by participants. Such factors can mean that individuals may not arrive in the gallery space in a condition to engage with the artwork.

Social scaffolding

Social scaffolding refers to the individual's support framework and how collaborative

and social experiences impact on people's ability to achieve (Bruner *et al* 1976; Hyden 2014; Rogoff 1990; Vygotsky 1978). For example, individuals can be supported in achieving a greater understanding of artworks through a relaxed environment, interaction that models normalcy, and the creation of an inclusive environment. Such an environment welcomes and accepts all responses to the artworks and proceeds with an expectation that all attendees have something to contribute – regardless of the stage of their condition. Social scaffolding is a key aspect of enabling individuals to gain the most from their experience.

A positive experience

In evaluating the impact of the Art Gallery of New South Wales Art Access Program for people with dementia, this study looked broadly at the context in which the programs took place. It considered the physical, social and cultural influences on people with dementia attending the program; recognised the importance of how the gallery as an organisation responds to people with differing abilities; sought to gain an understanding of who was attending the program; examined how attendees arrived in the space ready to engage with the artworks and what artworks were viewed.

The study found a range of stakeholders were involved in providing a positive experience for people with dementia. These included care staff, gallery staff and facilitators, and family members and primary carers.

It highlighted the importance of organisation, structure, and planning; specialised training; and flexibility and adaptability across all stakeholders. The relationships between gallery staff, professional care staff, family members and carers and people with dementia were important for the program's success.

All attendees had a positive experience of the gallery's Art Access Program. The reactions of people living with dementia

during the gallery visits were consistent with those of other gallery-goers and included smiling, laughing, pointing and gesticulating at artworks, talking, asking questions and commenting on artworks, quietly contemplating the works, and the occasional exaggerated exclamations associated with liking or disliking the work or the gaining of new insights.

Participants gained access to material and experiences not often available in their everyday lives, including opportunities for social interaction and engagement with their peers, care staff and facilitators, and times of quiet reflection that did not focus on their everyday circumstances, health, or care needs.

The visit provided opportunities for attendees to tell stories, reminisce, and prompted moments of self-identification. Attendees showed their joy by clapping, thanking facilitators, and in commenting on how much they enjoyed their experience.

For those who remembered the visit, it provided opportunities for reflection and conversation later with their peers, care staff and family members. For those who did not remember the events in the gallery there was a lingering sense of having had a good time; as one participant, 'Jenny', commented: 'I like...but I can't remember'. Implicit memory of the experience and a sense of feeling good was, it would seem, retained even after the explicit memory of the event was gone. ■

More information

A copy of the evaluation report is now available to download from the gallery's website at <http://www.artgallery.nsw.gov.au/media-office/living-with-dementia/>.

The Art Gallery of New South Wales' Art and Dementia Art Access Program is available free for groups on any Thursday or Friday for one hour between 10.30am and midday if booked at least two weeks in advance. Sessions for individuals and their carer partners are offered on the third Thursday of the month. Details at: <http://www.artgallery.nsw.gov.au/calendar/type/art-and-dementia/>.

The gallery also offers a limited number of outreach visits to eligible community organisations who cannot access the gallery, with tailored presentations exploring selected artworks. For bookings and inquiries phone (02) 9225 1740, email pp@ag.nsw.gov.au or visit the website at <http://www.artgallery.nsw.gov.au>

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Art and Dementia Program participants with a facilitator at the gallery earlier this year.

Photo: Christopher Snee, AGNSW

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Sustaining the succe

Not-for-profit aged care provider Eldercare completed the implementation of its Dementia Excellence Program at 12 residential facilities across the greater Adelaide and Yorke Peninsula regions earlier this year. **Sarah Jamieson, Karen Parish and Sue Krake** explain how the organisation successfully overcame challenges to prove that a truly 'person-centred' approach to dementia care enhances resident well-being



Eldercare's staff now do things 'with' residents and not 'for' them. All photos courtesy Eldercare

We conceived our Dementia Excellence Program in 2010 and, six years later, believe we've learned the formula for improving the well-being and quality of life for our residents. On average, 56% of residents at our facilities have a medical diagnosis of dementia and that number has reached as high as 88% at one site (Boerth 2016). To meet the need for high-quality dementia services, we transformed our culture by replacing 'task-focused' care with a genuine 'person-centred' approach.

Promoting resident choice

Person-centred support has been defined as "treatment and care provided by health services that places the person at the centre of their own care and considers the needs of the older person's carers" (Victorian Department of Human Services 2003). The Australian College of Nursing believes 'person-centredness' is an ideology that underpins the delivery of nursing and health care generally (ACN 2014). To us, it's care that enables real resident choice. We identified five areas where residents can be empowered to make their own decisions:

- Individual hygiene preferences (when

and how a resident wants to bathe or shower).

- Mealtimes (when, how and what a resident likes to eat).
- Sleep and wake patterns (when and how a resident prefers to rise and settle).
- Meaningful engagement (which activities a resident wants to participate in).
- Preferences (how a resident likes to live, what they enjoy and what gives them purpose).

Our dementia care is now less structured. We've made simple changes to facilitate real choices. Mealtimes have become shared experiences where residents and carers eat together. Items of interest, half-completed tasks which invite engagement and books are accessible for residents to connect with any time. There is laughter, music, singing and dancing. Spontaneity is celebrated and a level of untidiness accepted as a sign of life being lived.

This article explains how we successfully introduced the Dementia Excellence Program and identifies the obstacles and challenges we have overcome to ensure the long-term sustainability of the program beyond implementation.