

## An Art Gallery Access Programme for people with dementia: ‘You do it for the moment’

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**Objectives:** People with dementia often have decreased opportunities to engage in higher level intellectual or sensory activities. This programme investigated the effect of taking people with dementia to discuss artworks at the National Gallery of Australia (NGA).

**Method:** Fifteen people from the community and eight from residential care attended the gallery once a week for 6 weeks. They discussed artworks with NGA Educators trained in dementia skills. Sessions were filmed and the level of engagement analysed using time sampling methods. Focus groups with participants, carers, and educators provided qualitative data.

**Results:** Participants were engaged from the outset and remained engaged. They became animated, gained confidence and were able to discuss and interact with the artworks and the social process. This included the more impaired RACF groups, who were more withdrawn or behaviourally disturbed in their usual environment, raising the concept of *excess disability*. In focus groups these participants had impoverished memory for the programme but community participants remembered it with pleasure and wanted it to continue. Carers confirmed these sentiments but reported no lasting change in participants. Educators spoke mostly about what they had learned, including new ways to present to other clients.

**Conclusion:** The programme went beyond many dementia activities. Despite no evidence for lasting effects, all involved wanted the programme to continue. A carer quote: *You do it for the moment* encapsulates a sense that an activity is worthwhile even if it gives benefit only whilst running. The programme is continuing and expanding.

**Keywords:** activity; quality of life; psychosocial intervention; excess disability

### Introduction

The multiple cognitive and functional losses associated with dementia lead to reduced independence and quality of life (Kolanowski, Buettner, Litaker, & Yu, 2006; Logsdon, Gibbons, McCurry, & Teri, 2002; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004). Poorer quality of life in people with dementia is associated with lack of social contact and activity (Burgener & Twigg, 2002; Logsdon, Gibbons, McCurry, & Teri, 1999). Unfortunately, there is often a paucity of meaningful activity available to this population. Observational studies in residential aged care facilities (RACF) find residents with dementia spending only 10% of their time in therapeutic or leisure activities (Chung, 2004; Ice, 2002), even less if they have severe cognitive or functional impairments (Buettner & Fitzsimmons, 2003; Kolanowski et al., 2006). Voelkl, Fries, and Galecki (1995) found that 40% of RACF residents with severe dementia did not participate in *any* activity other than routine care over a 1-week period.

Similarly low levels of activity occur in the community, with frail older people spending more than 50% of their time alone (Pruchno & Rose 2002). People with dementia still at home report that their needs for social participation and activity are largely unmet (Meaney, Croke, & Kirby, 2005). In addition,

programmes which *are* available often underestimate the remaining abilities of the person with dementia, resulting in tasks with little intellectual stimulation or sense of achievement (Perrin, 1997). For example, Buettner and Fitzsimmons (2003) found that, for the 12% of a residential care sample who did have access to activity, it was inappropriate based on the individual's interests or level of functioning. This raises the concept of *excess disability*: ‘The discrepancy that exists when a person's functional incapacity is greater than that warranted by the actual impairment.’ (Chung, 2004, p. 23).

The excess disability literature points to a tendency to overemphasise deficits associated with dementia and suggests that carers and health professionals neglect to recognise and promote residual strengths and abilities (Malone & Camp, 2007). For example, Sabat (1994) reported functional and behavioural differences between two settings. When at home, the caregiver would assume dysfunction (e.g. inability to cut their own food, follow instructions or make decisions), and report that the person with dementia was withdrawn and ‘did nothing’. Conversely, staff at a day centre reported that the same person was ‘extremely helpful’, providing assistance to staff and other residents. Excess disability is a reversible phenomenon and can be reduced under circumstances that promote

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independence (e.g. Baltes, Neumann, & Zank, 1994; Rogers et al., 2000).

### **Aim**

The main purpose of this project was to determine whether participants could significantly engage in an activity which, while normal for unimpaired populations, is at a higher intellectual and sensory level than programmes often provided to people with dementia. It was based on work by Artists for Alzheimer's (ARTZ) in the USA (Zeisel, in press), which aims to promote quality of life for people with dementia by providing an intellectually stimulating environment in which they are actively engaged with other people and with artworks. The programme is said to improve the wellbeing of people living with dementia (and by extension, their carers) and reduce negative symptoms such as withdrawal and agitation, though these claims have not been formally evaluated.

### **Method**

#### **Ethics**

The study was approved by the Greater Southern Area Health Service Human Research Ethics Committee.

#### **Design**

Baseline demographics and characteristics of the sample were collected and a mixed-subject design was used to examine engagement during the National Gallery of Australia (NGA) sessions. Focus groups were held post-programme.

#### **Participants**

Seven people with dementia still living at home and eight from residential care took part. Community participants were recruited through the local Alzheimer's Association. RACF participants were recruited from two facilities, both with dementia-specific units. Criteria for inclusion were: (1) diagnosis of dementia, (2) people whom staff believed would benefit from the programme, and (3) able to hold at least a simple conversation. Informed written consent was obtained from all participants, supplemented by carers/guardians where appropriate. There were four groups: one all male and one all female community group and one from each of the residential facilities. Six NGA Educators who had expressed interest were involved, with two facilitating each group.

### **Measures**

#### **Participant characteristics**

A pre-programme questionnaire was completed for each participant by either a family member

(community participants), or with the assistance of RACF staff. Apart from basic demographics, the *Clinical Dementia Rating Scale* (CDR) (Morris, 1993) was used to assess level of impairment. The CDR assesses cognitive and functional capacity across seven domains of functioning. Algorithms produce a single grading to denote symptom level, ranging from none to severe.

To assess difficulties in caring, family carers or care staff reported on behaviours associated with dementia which caused them stress (e.g. calling out; repetitive questions, violence), using a validated instrument devised by Bird, Llewellyn-Jones, Korten, & Smithers (2007). They rated the frequency of that behaviour over the preceding 2 weeks on a 7-point Likert scale, and how much stress it caused them on a similar scale.

#### **Programme effectiveness**

**Behavioural analysis.** Sessions were filmed by an NGA volunteer. Two independent raters observed the films and coded participant activity, arriving by consensus at operational definitions for a range of behaviours as indicators of affect, for example enjoyment. Because we were interested in change over time, Weeks 1 and 5 were coded using time-sampling methods whereby raters had 5 seconds 'on' (watching the participant) and 5 'off' (coding the predominant behaviour from the previous 5 seconds). Similar observation-based methods have been used to objectively assess engagement and affect in people with dementia (Judge, Camp, & Orsulic-Jeras, 2000; Lawton, Van Haitsma, & Klapper, 1996).

**Focus groups.** Following the programme, focus groups were held for participants, carers, and NGA Educators to examine perceptions and experience of the programme. There were also informal discussions with RACF staff. Transcripts were analysed by two raters independently using grounded theory (Henwood & Pidgeon, 2003), which involves open coding of the material to identify core categories (themes) and the properties of those categories (sub-themes). Themes are not specified prior to coding. There was a high level of agreement; disagreements were resolved by consensus discussion. All themes included in the results were expressed by two or more people in the group.

#### **Procedure**

The six NGA Educators were given training by staff from Alzheimer's Australia and Dr John Zeisel (founder of ARTZ). Content included: what dementia is, symptoms, impact on quality of life, and how to facilitate group tours with people with dementia (e.g. style of presentation). One of the authors (MB) provided support and advice as required through the programme.

Educators facilitated discussion on approximately four artworks each week from the Australian collection for a total of 45–60 min. They were pre-selected by NGA staff, initially based on advice to use fairly straightforward works, though they soon found that some abstract works were acceptable. To promote consistency and predictability, groups ran at the same time each week, and the same educators facilitated the same group across the 6-week period, meeting participants as they arrived. RACF participants were brought by one or two staff, community participants were accompanied by an Alzheimer's Australia volunteer.

A bench was placed in front of each artwork before the session, and participants sat in a row. After the first week, when anxious RACF staff attempted to interpret what educators were saying to their charges, they were asked to sit out of sight so that participants interacted only with the artwork, the educator and each other. Staff assisted with moving residents onto the next artwork, and were available should participants become too agitated.

## Results

### Participant characteristics

Table 1 presents basic demographics, showing that RACF participants were more impaired and older than community participants.

Behaviours which stressed community carers included repetitive questions, forgetfulness, delusions, losing items, inability to follow instructions and reduced capacity for communication. They ranged in observed frequency from one to two times per week (e.g. requesting to visit deceased mother) to several times an hour (e.g. difficulty communicating). These behaviours were associated with a moderate amount of stress by carers, though one carer reported no challenging behaviours or stress.

For RACF participants, behaviours which stressed staff included repetitive questions, calling out, moving furniture, resisting personal care – sometimes violently, shadowing people, reduced ability to communicate, and repetitively seeking comfort. Frequency ranged from 'several times per week' (e.g. resisting care) to 'several times per day' (e.g. asking to go home). All staff reported at least a moderate level of stress due to these behaviours, one recorded extreme stress (7 on the stress scale). That is, the RACF sample included

participants who manifested significant challenging behaviours in their everyday life. Despite the stated selection criteria, two RACF participants were severely aphasic, one normally unable to produce coherent sentences or understand other than simple speech, the other somewhat able to understand but incapable of producing other than grunts or, occasionally, *Yes* or *No*.

### Behavioural observations

Because of the small sample, it was necessary to collapse the rich observational data into four categories: *negative* (e.g. withdrawn, distracted, fidgeting); *neutral* (unclassifiable behaviour such as being distracted by personal carer; talking to self – operationalised as repetitive mouth movements with no direction of speech); *engaged* (e.g. showing interest in guide/artwork/other participants; talking; looking at artwork) and *highly engaged* (e.g. laughing; smiling; gesturing; active listening – operationalised as nodding while listening to another group member or leaning towards them to hear better). An acceptable level of agreement was found between the two raters (Kendall's tau-b = 0.72,  $p < 0.01$ ).

Three participants were excluded from the analyses because they did not attend Session 1, leaving 12. Results are reported in Table 2 as proportion of total time in each behavioural category, with means and standard deviations. It can be seen clearly that, for the sample as whole, there was a high level of engagement from the outset, with 84.4% of observations classified as *engaged* or *very engaged* at Time 1. Less than 10% of the observed time was spent in withdrawn or neutral behaviour, and this did not change.

Mixed design analyses of variance (ANOVA) were conducted on the proportion of *very engaged*, *engaged*, *neutral* and *negative* observations. The between-group variable was *type of participant* (two levels: community, RACF). The within-subject variable was *session number*, with two levels (Time 1 – Session 1, Time 2 – Session 5). All assumptions were satisfied.

For the *engaged*, *neutral*, and *withdrawn* observations, there were no significant main effects for type of participant or session, and no significant interaction effects. For the *very engaged* observations, though there were no significant main effects for *participant type*,  $F(1, 10)=2.37$ ,  $p > 0.05$ , or *session number*,  $F(1, 10)=0.06$ ,  $p > 0.05$ , there was a significant interaction between these two factors,  $F(1, 10)=12.35$ ,  $p=0.01$  (Figure 1). Contrast comparisons showed that, for RACF participants, observations suggesting they were *very engaged* in the sessions significantly increased from Time 1 to Time 2,  $t(7)=2.70$ ,  $p=0.03$ . There was no significant difference in the level of *very engaged* observations from Time 1 to Time 2 for the community group,  $t(3)=2.70$ ,  $p > 0.05$  but, during the first session, they showed a greater proportion of very engaged observations than RACF participants,

Table 1. Participant characteristics.

	Community groups	Residential care groups
Mean age (range)	70.8 (56–80)	86.6 (80–93)
Clinical Dementia Rating	4 mild 3 moderate	4 moderate 1 moderate to severe 3 severe

Table 2. Mean (SD) proportion of observations by time and participant type.

	Community ( $n=4$ )		Residential care ( $n=8$ )		Total ( $n=12$ )	
	Time 1	Time 2	Time 1	Time 2	Time 1	Time 2
Withdrawn	0.02 (0.04)	0.02 (0.03)	0.11 (0.03)	0.08 (0.02)	0.08 (0.09)	0.06 (0.05)
Neutral	0.01 (0.07)	0.01 (0.05)	0.10 (0.05)	0.08 (0.04)	0.07 (0.14)	0.06 (0.10)
Engaged	0.59 (0.07)	0.69 (0.07)	0.61 (0.05)	0.58 (0.05)	0.60 (0.14)	0.61 (0.14)
Very engaged	0.38 (0.06)	0.29 (0.06)	0.18 (0.04)	0.26 (0.05)	0.25 (0.15)	0.28 (0.12)

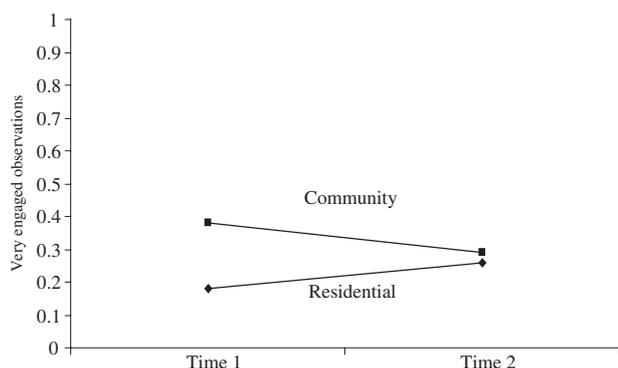


Figure 1. Mean proportion of very engaged behavioural observations over time by participant type.

$t(10)=2.65$ ,  $p=0.02$ . At Time 2, there was no difference in the proportion of very engaged observations between these two groups,  $t(10)=0.35$ ,  $p > 0.05$ . Findings must be interpreted with caution because of the small sample size, but they do provide tentative evidence that community participants were highly engaged from the outset but that the more impaired RACF participants took time to catch up.

### Focus groups

Results are presented by group (RACF participants; community participants; carers; Educators). Issues raised by RACF staff are also discussed. Results for each group are subdivided into themes, with illustrative quotes in Tables 3–5.

### RACF Participants

Participants were approached 2–3 weeks after the programme, with an NGA Educator attending as a memory prompt. Of those capable of conversation, one had clear memory of the programme, two had some recollection when prompted (e.g. shown prints of artworks they had seen<sup>1</sup>, one had flashes of memory with much prompting, and two had no apparent conscious memory of the programme. The content of the focus groups was impoverished, apart from those who remembered the tours – when they remembered – saying they had a good time, and commenting on how good the ‘girls’ (educators) were. Accordingly,

qualitative themes from residential care participants are not further explored.

### Community participants

At 6-week follow-up, all community participants who attended the focus group remembered the programme and some of the context. For example, one participant recalled correctly that on their last day they looked at carvings and statues rather than paintings, while others spontaneously recalled the NGA volunteer who filmed the group.

Comments were positive, with the most frequently reported theme enjoyment of the programme. All participants described the programme as a *wonderful, great, entertaining* experience: *It was such a buzz!* Other themes were as follows.

*Engagement and intrinsic benefits independent of having dementia.* Most participants indicated that the programme had deepened an existing interest in art or sparked a new interest. These comments could be typical of any group regardless of whether they had dementia though, consistent with the quantitative data, such comments show their engagement in the programme (Quote 1, Table 3).

*Normalisation and discovery of residual abilities.* Specific to dementia, participants recognised that the programme was different from their routine experience, *A whole – just another world.* It was intellectually stimulating and encouraged them to think and learn: *It makes me feel a bit intelligent.* Participants also reported that they were treated as normal, rather than people with dementia (Quote 2, Table 3). They also noted the sensitivity of the educators in this respect (Quote 3, Table 3)

While discussion included comments about living with cognitive impairment and associated problems, including concerns about *making an idiot of myself*, a strongly related theme was that the programme showed participants they still had capacity to do things despite dementia (Quotes 4 and 5, Table 3). Some comments showed remarkable insight into the nature of memory in dementia, including depth of processing (Quote 6, Table 3).

Table 3. Quotes from community participants.

1	Well it was an awakening for me. I've always gone to galleries. I've always looked at pictures but then when I was in the group, you know, the ladies [educators] . . . they talked about who the painters were and various things and so and it was truly, it was just like something new.
2	Facilitator: Do you mean the educators were making allowances for the fact you had dementia? Participant 1: I don't think so, not for me. Participant 2: I never felt that at all.
3	They (educators) were the shepherd. Sometimes I would like to say what I would like to [do], and they would say . . ."Was that . . .?"
4	We sort of think to tend about the things that we can't do but it [the programme] aims to sort of expose you to something, to show that you can still do something.
5	We did achieve something out of it. Isn't it good? At least we can do something worth while.
6	When I became part demented I lost a lot of it, but I'm finding now that I have a selective . . . I can recall some of the artwork because it sort of imprinted itself in my mind . . . if things make an impression I can remember
7	It got me sort of getting out there, having to see more people.
8	Different people see a painting in a different light. We were all seeing different you know.
9	It just wasn't long enough.
10	I wish it was going on you know. I enjoyed it so much.

Table 4. Quotes from carers.

1	When we went to the gallery, cause we go to the gallery often, . . . he would point out the things or would not necessarily point out, but would know that he had seen it before and he would discuss it.
2	There was another Drysdale in Adelaide and I'm sure it's the same woman. And he recognised that.
3	[He was] going to the cupboards to find some art books, sketching books to get out. Of course it had to be all sorted in anticipation of the work and what they were going to do there . . . he was doing beautiful work.
4	He enjoys talking and seeing things . . . as long as he's got someone to talk to. He's probably more interested in the talking to other people possibly than the [actual pictures].
5	Once you galvanise into action, once the clothes are out, and the breakfast, and he . . . knows he's going on another outing and it's quite good cause he knows that I enjoy the break without having to worry about him.

*Social aspects.* Another important theme was the benefits of social contact and discussion. One member had previously spent most days since his diagnosis walking by himself, avoiding social contact. Another described himself as very shy. Despite this, all members reported becoming at ease with one another and that they enjoyed the increased social contact (Quote 7, Table 3). Part of the social enjoyment was the variety of ideas when presented with the same artwork. Participants recognised that this presented the opportunity for discussion and a broadening of ideas (Quote 8, Table 3).

*Future of the programme.* Participants made repeated comments about wanting the group to continue. These comments were unsolicited by the interviewer, and for the purpose of evaluation, reflect the value of the programme to those who took part (Quotes 9 and 10, Table 3).

#### *Community carers*

*Recall.* Despite all community participants at the focus group remembering the programme, two spouses felt they had no memory for it. It is possible that more recall prompts were available in the focus group, including the presence of their fellow participants. By contrast two other carers reported instances where their partner recognised something from the group on subsequent art gallery visits. In one this was

recognition of a previously seen picture (Quote 1, Table 4), and in another striking instance, a participant recognised a model used in an NGA painting in a different portrait in Adelaide (Quote 2, Table 4).

*Enjoyment, social aspects, and lasting change.* In the main, carers confirmed participants' enthusiasm for the programme, and some reported positive effects at home (Quote 3, Table 4). Another participant theme reported with equal strength by carers was the social interaction aspect of the programme (Quote 4, Table 4). Despite this, carers consistently reported that there were no lasting changes. Their partners' behaviour and demeanour was the same as it had been prior to the programme. It is best encapsulated in the comment of one carer: 'You do it for the moment'.

*Logistical issues and improvements to the programme.* Most felt it was not a challenge to get their partner to the group each week, as the household already had established routines to assist with daily activities (Quote 5, Table 4). The only criticism was the few occasions where NGA staff did not give participants prints of the works they had seen, making it difficult for carers to engage with their spouse about the experience. Consistent provision of prints of all artworks seen was the only improvement they could suggest.

Table 5. Quotes from educators.

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1	I was wondering how I was going to have these conversations... How we would keep them going?... I wasn't sure what their memory would be like even for one sentence or for one discussion to the next.
2	What hit me was how diverse they all were. The thing that touched me was the courage and the good humour... And their generosity of spirit. They were actually very tolerant of us and our ignorance about a lot of things to start with...
3	And the most amazing, amazingly sensitive comments that, you know, we've been here for many years and we've not heard... So for me it was actually very enlightening.
4	[About someone with aphasia] I learnt that you can't assume that because they are not speaking that they are not communicating.
5	Well, we do [other groups] in a, in a much more intellectual challenging way... concentrating on knowledge and facts and intellectual rigour. Where this is a more sensual and experiential relationship to the painting.
6	I have learnt to be patient and to listen.
7	We had to really work to... get them to understand what they were contributing was really important and valuable and that took a while. [Confidence] had kind of diminished
8	I did notice... with them getting in the taxi and people became hesitant about why they were there again. So while they were looking at paintings and talking they were all in a different world and then you come back to 'do I get into this taxi to go home or not?' So... you'd be chatting along and forgetting [that they have dementia] and then suddenly remember that you have to say: 'well this driver is going to take you home'.
9	Even though when I was at the nursing home they didn't recognise me, when they arrived on the bus [to the gallery] they were recognising me.
10	Once they came into the space and remembered where they were it was almost they picked up where they left off last week
11	All her art background came back. She started talking about the composition and perspective and colour. Things like the John Brack Dancers... We chatted for ages about how she used to get the buses to the dance and a whole lot of stuff.
12	It was a strain when we had some carers there at the last programme, each of the participants tended to refer back to their carers a bit and they weren't as spontaneous. [When carers were absent] their confidence changed, people became more vocal... otherwise they depend on the carer
13	... when XX came in with his family. We went for coffee and we had gone for tea with him before and the group had got their own tea and we didn't take much notice of them... when his daughter was there she took over his feeding. She thought he'd forgotten.
14	I walked in [to the nursing home] and I was amazed at how flat they all were. They were totally flat. They had no animation at all... When they come to the gallery they arrive they're excited, they get hyped up, their brain is actually tweaking a bit more and you get them in and they respond where as there it was extremely difficult to get them to respond.

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### *RACF staff*

During the RACF focus groups, we talked informally with staff who had helped prepare residents, or who had accompanied them to the NGA. A consistent comment was about how much preparation it took to get residents ready early so that they left at the same time each week in the RACF bus. Finding the time of day that was optimal for both the RACF and the gallery required negotiation. In some cases considerable cajoling was required to get them out of the door because residents did not remember the programme and did not want to go out, though they brightened up once at the NGA. Staff did not feel that any residents had been changed by the programme though, in both facilities, staff who travelled on the bus reported that some residents, normally withdrawn, were very animated and talkative on the way back from the NGA.

### *Educators*

*Initial expectations and subsequent experience.* Educators had little previous experience of dementia and they reported great anticipatory anxiety about, for example, what participants would be capable of (Quote 1, Table 5). Anxiety did not last long, as the educators were exposed to people with dementia: *It was just a joy.* Their comments showed considerable insight about diversity and residual capacity in dementia, such that: *Almost anything was possible.* This included

recognition of participants' humour, ability to communicate and individuality (Quotes 2–4, Table 5).

*Gaining skills.* The educators were particularly vocal discussing what they had learned from the programme about presentation style, changing from providing education to helping people experience the artwork (Quote 5, Table 5). They reported a slower and less directive style that allowed participants time to reflect and contribute (Quote 6, Table 5). One educator reported transferring these new skills to other gallery groups.

*Effects on people with dementia.* There were two sub-themes under this heading: *Enjoyment/confidence*, and *memory stimulation*.

Educators repeatedly spoke about the obvious enjoyment and enthusiasm of group participants: *They did light up when that bus pulled up.* All felt that participant confidence was heightened during the programme, though that it had taken some work (Quote 7, Table 5). They also reported that within the gallery they would sometimes forget that individuals had dementia (Quote 8, Table 5).

*Effects on memory.* Educators noted frequent evidence of memory stimulation within the group. This included recognition of other participants, educators and the

programme itself. Sometimes, recognition was only within the gallery context. For example, participants did not recognise an educator when she arrived at their nursing home (Quote 9, Table 5), or could not recall where they were until they were in the Australian Collection (Quote 10, Table 5). Educators reported a great deal of satisfaction watching artworks stimulate memories (Quote 11, Table 5).

*Excess disability.* Educators were struck by the way the presence of carers impacted on participants, noticing that outside of the group context some participants became less confident in their opinions and actions, and even showed reduced capacity for self care (Quotes 12 and 13, Table 5). They also observed *excess disability* in practice, contrasting the demeanour of participants in the gallery and in the RACF (Quote 14, Table 5).

*Logistical issues.* The final theme was logistical issues in running the programme and potential areas of improvement. The educators noted that success is dependent on a number of factors, firstly routine *outside* the programme (e.g. getting participants to and from the group, accessing the building in predictable and routine ways and ensuring wheelchair access, ensuring benches are placed in front of artworks before participants arrive). Commenting on one unsuccessful session where RACF staff forgot participants' glasses and hearing aids, they noted that if people are unable to hear discussion or see the artwork engagement is impossible, irrespective of a diagnosis of dementia. Secondly, processes *within* the group need to be thought through, including size. They felt four was the maximum because of the variety of cognitive impairment and personality type. Four was also the maximum number of artworks; enthusiasm from participants and educators occasionally lent itself to covering more material, resulting in time pressures and diminished quality of discussion.

## Discussion

The Art Gallery Access Programme was a pilot study run to determine whether people with dementia could engage with and enjoy activity demanding a higher level of intellectual engagement than many activities offered to this population, and also to explore measurement issues for future studies. It included an RACF sample somewhat more impaired than is normal with such a project. It had more ramifications than expected, including illustration of *excess disability*. Outcomes are discussed with respect to effects on participants with dementia and the NGA Educators. Methodological limitations and issues are also discussed.

## Outcomes for people with dementia

Overall, the programme achieved its aims. Quantitative findings, based on coding of participant behaviour, showed that engagement was high for all participants from the outset. Eighty-four percent of observations in week one were classified as *engaged* or *very engaged*. It could have been expected that educator and participant anxiety and unfamiliarity would present difficulties in the first week and there is tentative evidence that the RACF groups, much more impaired, did become more engaged over time. There was a significant increase from week 1 to week 5 in the number of *very engaged* observations. However, this could be an artefact of the criterion used to divide engagement into two levels, basically level of animation when demonstrating positive affect. The main point is that, for the sample as a whole, level of engagement started high and stayed high. Only a small proportion of observations were negative or neutral.

Comments by people with dementia, carers and educators confirm the quantitative data, and provide a much richer source of experiential information. Community participants recognised residual capacities as a result of the programme, several reflecting that they were surprised by what they had achieved. Other benefits reported by participants and/or educators included memory stimulation – recalling past events and stories from discussion of an artwork and increased confidence and animation, though only during the sessions. Participants reported that they were treated with dignity, felt a sense of achievement and appreciated the chance to socialise in a shared activity. Two had previously been very withdrawn.

On the other hand, participant behaviour appeared different within the group than elsewhere. In the presence of carers, or away from the programme, participants seemed to lose confidence. When engaged with the artworks, the educators, and each other, they showed more capacity and positive affect than was normally apparent. The concept of *excess disability* has particular salience here. These observations support the notion that under circumstances which promote independence, even people with moderate to severe dementia can achieve more than is typically observed in their daily interactions. This highlights the importance of developing psychosocial interventions and activity programmes which optimise opportunity for people with dementia to use their residual skills and abilities.

There was no evidence that the programme produced longer term effects for people with dementia, though we did not formally measure affect or behaviour pre- and post the project. For our sample, no carers or staff reported cognitive, behavioural or social improvements as a result of the programme. A community access programme, although stimulating, is not likely to produce lasting reversal of symptoms that occur as a result of the disease process, though it may lift participants to what may be their

real potential whilst it is going on. This does not obviate the value of the programme. For the period participants were engaged in it, they enjoyed and valued what they were doing, and showed more capacity and positive affect than normal. This is best encapsulated in the carer comment: *You do it for the moment.*

### **Outcomes for national gallery educators**

Comments by educators were rich and enthusiastic. Initial anxiety about running the groups was quickly replaced by confidence. The most common comment was how much they had learned, even about artworks they already knew. They reported improved knowledge and understanding of dementia and its impact, and improved skills for working with people who had dementia. These included patience, less 'intellectual' and more 'sensual' approaches, less talking and leading and more listening, slowing down the educating process, not being frightened of silence. These skills had been transferred to other age groups by at least one educator. Educators repeatedly commented on the residual capacities of people with dementia, demonstrating not only their initial underestimation of participants' abilities, but their subsequent recognition of the diversity still evident in this population. That is, long term benefits of the Art Gallery Access Programme may include increased insight into dementing illnesses, reduced stigma, and recognition of the residual personalities and capacities of people diagnosed with dementia. This would be a valuable outcome of any community programme.

### **Methodological limitations and issues**

This was a pilot programme, mainly determining whether such a project was logistically possible. Results are limited by small sample size and failure to formally measure, at baseline and post-programme, behaviour and affect in participants, family members and RACF staff. Future evaluations should include these measures with larger samples and with a wait-list control group. Two other possible measures are, firstly, forced choice recognition using prints of artworks seen and not seen, based on our experience in a focus group where even people with no conscious memory for the programme were able to discriminate with some accuracy. Secondly, based on comments from RACF staff, that normally withdrawn residents were animated and talkative on the way home, we suggest monitoring behaviour for a defined period before and after each gallery visit. This would help determine whether the change in behaviour truly is *for the moment* or whether effects, positive or negative, last longer.

We did establish a method to measure our main interest for this pilot – whether participants engaged in the programme. Observation of facial expressions and behaviour is a commonly adopted partial solution to

the problem of determining the internal states of people with dementia (e.g. Lawton et al., 1996), where direct measurement of subjective experience is limited by impairments in cognition. Two researchers worked independently on the behavioural coding, and the final system bears striking similarity to observational measures developed by other researchers in this field (e.g. Judge et al., 2000). Like these authors, we collapsed very rich behavioural observations into somewhat prosaic categories for the purposes of statistical analysis. *Engagement* completely fails to capture phenomena such as participants dancing with educators in front of 'Latin American Grand Final' (John Brack, 1969), or one of the normally aphasic residents suddenly beginning to explain, with some fluency, the way the artist had constructed a painting as a series of rectangles.

### **Conclusion**

The Art Gallery Access Programme went beyond many activities commonly available to people with dementia. It made allowance for dementia but it was a much more mainstream activity, in which participants were able to hold their own such that some educators would forget that dementia was an issue. A critical issue highlighted by this study is the ability of psychosocial programmes to maximise the residual capacities of people with dementia. That is, the excess disability observed external to the programme was not an issue within the group context. This, in turn, reinforces the importance of providing interventions that promote 'normal' higher level activities for people with dementia.

The NGA has continued to run the programme, with new participants, and negotiations are in train for expanding it to other Australian galleries.

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## Note

1. In one facility, we had prints of artworks they had seen and some they had not seen, and an informal trial suggested that even participants with no conscious memory of the programme could fairly reliably discriminate. This suggests an obvious memory prompt for future programmes, as well as a possible outcome measure in future evaluations.

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