

Lost In Art Too.....

**An evaluation of a 10 week programme of art sessions
provided by Denbigh County Council
for people with dementia and their carers**

By

Samantha Gregory MSc

&

Dr. Gill Windle

Dementia Services Development Centre

Bangor University



Lost in Art Too at Ruthin Craft Centre

An Evaluation

'But you're not engaged in the process; and that's what makes a person human... the process' (Sterin, 2002 p.8).

People with dementia often experience poor quality of life due to reduced independence, reduced activity and, reduced social contact (Katsuno, 2005). This reduction of social contact is often the result of the stigma associated with the condition, often leading to the family and friends of people with dementia treating them differently. In one study, a participant with Alzheimer's disease felt people treated them as if they do not exist, others felt ignored, and others had had friends abandon them when they learned of the disease (Katsuno, 2005). According to the Telegraph, so bad is the stigma associated with the disease that doctors responded to a recent call by the government for General Practitioners to screen for dementia earlier by saying that the possibility of diagnosis would scare elderly patients from visiting the doctor's surgery (Adams, 2012). Dementia is also often described as worse than death (Patrick, Starks, Cain, Uchmann & Pearlman 1994), thus, it is not surprising that people with dementia feel so isolated.

An in depth personal account of living with such a label gives an important insight into the problems faced, the person with dementia is *'transformed, with the label, from the former role as a spouse, parent or lover, into a 'caregiver' one and one is never looked at in the same way again'* (Sterin, 2002 p.8). In the early stages of the disease, people with dementia are still capable of many things and yet, often people write them off due to the associations of the label. This raises the concept of excess disability, where, due to the stigma of a dementia diagnosis, the individual's incapacity is viewed as *'greater than warranted by the actual impairment'* (Chung, 2004, p.23). This means that there is a tendency by healthcare professionals, carers, and those in contact with people with dementia, to overestimate weaknesses and ignore strengths in people with dementia (Malone & Camp 2007).

In light of this, there has been increased interest into finding activities in which people with dementia can engage with and enjoy without feeling patronised or stigmatised, and which stimulate the participants both mentally and physically,

making them feel valued and deemed capable. One such activity is art. The National Gallery of Australia developed an art gallery access programme for people with dementia, some of whom were in the community, and some in residential care. The research found that the people with dementia engaged with the art, there was frequent evidence of memory stimulation, growth of confidence and the participants felt that they were treated with dignity, felt pleased with what they had achieved and enjoyed the socialisation. Though they found no long-term benefits of the programme, researchers stated that *'you do it for the moment'* (Macpherson, Bird, Anderson, Davis & Blair 2010).

Researchers in Spain, who undertook an artistic educational programme with individuals in the early stages of dementia, report similar results. Participants were committed to the activity and were eager to learn new things. The programme reinforced feelings of capacity and positive self-image (Ullan et al 2011).

Activities where the participant and carer work together can work well. For example, researchers found that engagement and attendance levels were high at a 'singing together' group. The participants with dementia's rate of decline appeared to reduce, showing a positive outcome of the activity. Carers enjoyed participating with the person with dementia. The person with dementia also greatly enjoyed the sessions (Camic, Williams & Meeten 2011).

The Lost in Art too programme at Ruthin craft centre builds on these ideas, providing an art programme for people with dementia and their carers to attend and enjoy together. The evaluation of the first Lost in Art too programme (Algar & DCC, 2012) identified a range of benefits of the programme which challenged perceptions of excess disability. These included suggested improvements in; communication, mood, and memory (for names, people and the art procedure), despite the process being a new form of learning. The evaluation of the second wave of projects will explore this in more depth. It will explore:

- The role of procedural memory within the sessions and the extent to which there may be a 'carry over' effect to tasks at home.
- Changes in communication and mood of the person with dementia.
- Attitudes towards people with dementia, and how these may be changed through the art programme (school children, attendees at the exhibitions).

Method

Participants

The service providers recruited five participants with a diagnosis of Alzheimer's Disease/Dementia (3 male, and 2 female) from the Denbighshire area. Three participants attended the sessions with family members, and two alone. Two of the participants had not previously attended Lost in Art. The other three had attended at least one programme previously.

Inclusion criteria: must be in the early stages of Alzheimer's, living in the community, able to attend the craft sessions, able to participate in the craft sessions. Exclusion criteria: unable to give consent, unable to communicate.

All participants had been diagnosed with dementia for between one and five years (2.7 years average). Participants' ages ranged from 65-86years, (73.4 years average). The participants came from a range of educational and work backgrounds and had a range of skills.

In total six carers were interviewed, due to one participant attending at different points with different family members. Fifteen year-five primary schoolchildren participated in the school visit with two members of teaching staff. The researcher interviewed the schoolchildren in two groups, one group of seven and the other eight. Two Artists worked together to facilitate the programme.

Procedure

The Education room at Ruthin craft centre was the venue for the art sessions. The room had toilet facilities and a small kitchen for refreshments. Each session was 2 hours, delivered weekly (in the afternoon) over 10 weeks. Artist Sian Hughes delivered the sessions, with support from artist Lisa Carter. The Art project was based on the current gallery exhibition at the Craft centre; 'Carving Out Space', which was wood and nature based. Artists included in the exhibition were; Gary Breeze, Warwick Freeman, David Nash, Jim Partridge and Liz Walmsley, and Guy Taplin. In week nine, a group of schoolchildren also attended the session in order to work with the group. This was in the hope of educating the children on the capabilities of individuals with dementia. An overview of each week's session is presented in table 1.

Table 1: Session Summaries

<p>Session 1 Date 21/01/13 Attendees: Participants: Full Group. Artists: Sian Hughes, Lisa Carter Other attendees: Sian Fitzgerald, Jo McGregor, Gill Windle, Samantha Gregory Summary: The facilitators introduced the evaluation and gave participants consent forms and information to take home and read at their leisure. The group then went to look at the Gallery exhibition, with focus on Guy Taplin's birds. Where the artists demonstrated a way of making foam birds, then the group returned to the workroom and the project was explained. Most people made more than one bird and some moved onto experimenting with clay.</p>
<p>Session 2 Date 28/01/13 Attendees: Participants: 1 Absent. Artists: Sian Hughes, Lisa Carter Other attendees: Samantha Gregory, Elen Bonner Summary: The group looked in more detail at the Exhibition as a whole, focussing on some of the calligraphy of local names for birds. They then returned to the Guy Taplin piece for a focussed reminder of materials and method. There was a tea break and clay demonstration then everyone worked on their own pieces – some going back to foam, some using the clay. At the end of the Session the group went over to Studio 5 to set up the ongoing display</p>
<p>Session 3 Date 4/2/13 Attendees: Participants: Full Group Artists: Sian Hughes, Lisa Carter Summary: A brief visit to the Gallery, concentrating on paint and decoration. Artists brought in books and images of bird shapes and designs as well as blank wooden bird shapes for the group to use.</p>
<p>Session 4 Date 11/2/13 Attendees: Participants: 1 Absent Artists: Sian Hughes, Lisa Carter Summary: The group started in the Gallery looking at Gary Breeze's work and making up names for birds. The artists demonstrated the cut letters that they hoped the group would use then the group returned to the workroom. The artists passed round wooden letters in small boxes that maintained the smell of the laser cutter, and the group all sniffed the scorched wood aroma. The group worked in two groups on a collaborative piece with the letters then took the art to the studio.</p>
<p>Session 5 Date 18/2/13 Attendees: Participants: Full group Artists: Sian Hughes, Lisa Carter Summary: Gallery visit looking again at Gary Breeze and taking in the made up words on paper from last week. The group then returned to the workroom for continuation with the collaborative pieces. Other group members working on separate pieces, building on work from previous weeks and starting new projects.</p>
<p>Session 6 Date 25/2/13 Attendees Participants: Full group. Artists: Sian Hughes, Lisa Carter Summary: No Gallery visit this week: Continued ongoing projects and themes.</p>

<p>Ended with everyone going over to Studio 5 to put up the pieces.</p>
<p>Session 7 Date 4/3/13 Attendees: Participants: 1 Absent. Artists: Sian Hughes, Lisa Carter Other attendees: Jo McGregor (Briefly) Summary: Went into the Gallery to focus on Warwick Freeman's pieces. Artists took in some found objects and clay and the group pointed out a range of aspects of his work. Artists showed the group how to roll a ball of clay between 2 lathes to make an even slab. It was a group member's birthday and Lisa had brought in a cake and candles – all sang Happy Birthday. Jo arrived with letters with more information on the dates and options coming up. In anticipation of using next week to prepare for the school visit, the group stayed on briefly. Outlined ideas and the group contributed.</p>
<p>Session 8 Date 11/03/13 Attendees: Participants: 1 Absent. Artists: Sian Hughes, Lisa Carter Summary: Carving out space exhibition had come down. Discussed school visit, everyone contributed ideas. Planning for the session came largely from the group.</p>
<p>Session 9 Date 18/03/13 Attendees: Participants: 1 Absent. Artists: Sian Hughes, Lisa Carter 15 school children, 2 teachers Other attendees: Elen Bonner, Samantha Gregory, Jo McGregor Summary: Children arrived in the morning for a session alone with the artists, discussed the work in studio 5, went to the work room, worked with charcoal, then went for lunch In the afternoon, the room was set up with workstations for 5 groups in total. Participants set up their workstations, bringing in things in for the pupils to work with. Carried work over to studio 5 and discussed the artwork created. Made sounds with one piece of work</p>
<p>Session 10 Date 25/03/13 Attendees: Participants: 2 Absent. Artists: Sian Hughes, Lisa Carter Summary: A small group due to the snow and transport problems. Final session, so lots of finishing off and setting up the gallery. The group collaborated with Charcoal. Lots of conversation.</p>

Data collection took place at the beginning, during and after the 10-week programme, using the following approaches:

1. Semi-structured questionnaires administered in interviews with the participants and a family member/ close friend at the beginning and end of the programme: Baseline interviews took place in the first two weeks of the project (See appendix 1), and final interviews took place as close to the final session as possible (see appendix 2). Participants were initially interviewed with the person who spent the most time with them, thus not necessarily the person that they attended the sessions with. The baseline and follow up questionnaires explored the themes of communication, mood and memory, found in the evaluation of the first Lost in Art too programme (Algar & DCC, 2012), as well as exploring changes in confidence, carer participant relationship, socialisation and enjoyment. However, not all themes were present for all participants due to each individual's circumstance.
2. A focus group with the schoolchildren: a topic guide was developed and the researcher recorded the schoolchildren's discussions in a focus group immediately after the art session they attended (see appendix 3).
3. Observation of the participants by the artists throughout the duration: The artists wrote a summary on each session, commenting on each participant as well as the general issues and positives within the session. They also filled out a small report on each participant and, if appropriate, their partner each week (See Appendix 4).
4. A focus group with the participants: After the ten weeks, a focus group with two participants and two carers was conducted.
5. A follow-up interview with the Artists at the end of the ten-week programme.

Data analysis

The researcher thematically analysed all data with the themes located at a semantic level, therefore all meaning derived from what was said at the explicit surface level. This analysis was performed both between participants to look for group themes, and within participants to look for individual development and themes. The researcher split the artist observational data into three broad areas; participant and carer interaction, participant development, and group development, then looked for themes inside these broad areas. The researcher recorded and transcribed the focus

group data then subjected it to thematic analysis. One researcher conducted all analysis, with samples checked by a second person.

Prior to the start of the programme, the service providers sent out an information sheet to all of the participants, explaining the purpose of the evaluation. Before any interviews were undertaken, the researcher ensured that the participants understood the nature of the evaluation, and sought their consent to take part. The researcher assured the participants that attending the Lost in Art sessions was not dependent on agreeing to take part in the evaluation, and they were under no obligation to give their consent. All participants were aware that they had the right to withdraw from the study without penalty at any time.

All data was securely stored in a locked cabinet in a locked office, and the electronic data was stored for use on a personal password protected University server, and not stored on the hard drive of any desktop computers. All participant data was anonymised with all identifying features such as names and occupations removed from verbatim.

Results

Part 1 - the participants and their partners/friends

All of the participants engaged fully with the sessions and expressed enjoyment. Three of the five participants attended every session, one missed the final session due to adverse weather conditions. The final participant attended just four of the ten sessions provided due to transport issues and illness.

1. Mood and Quality of Life

The baseline and follow up interviews included questions about participants' mood and quality of life. At baseline, four out of the five participants felt that they were satisfied with their life, this changed to five of the five at follow up. At baseline three out of the five said they have dropped some activities and interests since the diagnosis, however this changed to two out of the five at follow up. Two of the five would rather stay at home than go out and do things, this is stable at both baseline and follow up and is most likely due to their situation wherein they care for a sick relative, rather than the diagnosis of dementia. At baseline, three of the five participants felt that they had a good ability to do things for fun the other two feeling their ability to be poor or fair, this changed at follow up to four feeling their ability to be good, and one

to feeling it was excellent. Participants views on their own memory and on their ability around the house did not change in a particularly notable way, however, no one felt worse about their abilities in this respect and a couple of individuals felt better. See figure 1 for a visual representation of the findings.

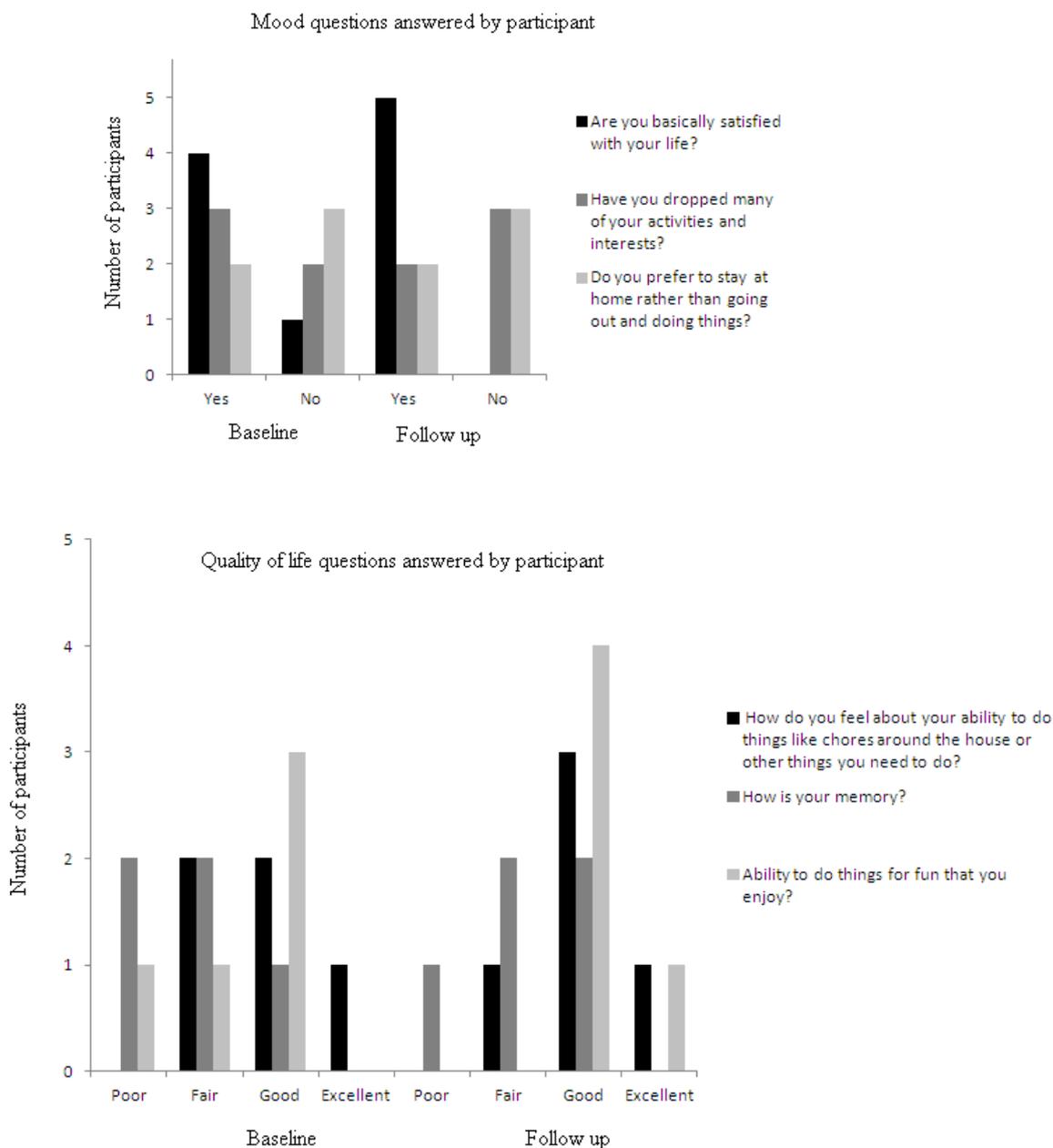


Figure 1. Mood and Quality of life data

2. Abilities

At the start of the programme the evaluation sought to ascertain the extent to which the participants were able to undertake daily functional activities, such as making a cup of tea, and the follow up interviews sought to explore examples of any changes in capabilities such as more independent action, perhaps after coming home from the Lost in Art Sessions.

One participant lived alone and was fully independent. At the outset, participant's partners were generally positive about the abilities of the participants and were encouraging of what they could do, though it is unclear whether carers overlooked further capabilities. All participants were capable of washing and dressing themselves and were encouraged to be independent to an extent, although one was described as *'not very good at starting things'* implying that some assistance was needed.

Some examples given implied that encouragement was required for independent actions:

'I get him to set the table.'

'Always sending her off to find things. It can take a while, 5 or 6 times asking, but we get there in the end.'

Other examples demonstrated that the participant was capable of independent action, and that this was encouraged.

'He goes up the garden on his own.'

'He walks to the community centre on his own.'

At the end of the programme, none of the participants were reported to have any changes in functional daily living activities, however one participant had been inspired to do more painting and drawing at home, and another *'came home thinking of ideas'*.

3. Social activities

Some of the participants had active social lives, others were less active, though none appeared lonely or completely isolated as they had family contact. Often, other aspects of their circumstances interfered with socialisation more than their diagnosis; two participants lived with sick relatives and one participant had age related mobility problems. Despite this, all of the participants went to at least one other dementia group, such as Singing for the Brain, the memory café and a community illness group. Also affecting the social lives of the participants were transport issues, as the

participants all stated that they no longer drive. One participant stated, concerning social activities, that:

'I like going out but I like being at home.'

A participant's partner described one of the many issues that are present while still trying to have an active social life and care for a person with dementia:

'We used to go out for the day but now takes a long time to get going, sort things out.'

4. Memory

At the outset, the memory issues caused some problems in the relationship, often being described as '*frustrating*', however all of the couples were, overall, good humoured about their situation. One carer commented that she was '*not a natural nurse*', which made it difficult for her to be patient with her partner's problems.

5. Memory for the sessions

Despite the memory problems faced by the participants all but one had good memory of the sessions, three could discuss the sessions without prompts, bringing things up about the session spontaneously, the other could discuss it when it was brought up to them in conversation.

One carer and participant explained that the Sunday before the session the participant spends time looking for objects to take to the sessions, showing memory not only of the theme of the project and their own work, but also memory of when the session took place.

The researcher spoke to two participants without people who had attended the sessions; they both had excellent memory for the sessions. One would often discuss the sessions with friends, the other could fluidly discuss what they had done during sessions, though they could not remember people's names.

6. Reasons for attendance

All of the participants and their carers reported attending the Lost in Art sessions for the social and fun aspect: One participant said she goes for '*friendship*', another said she goes for '*the enjoyment of doing it*', and another participant said they go to '*meet people with same problems*'. A further important reason for going, highlighted by a carer, is for the person with dementia '*to be with someone who isn't nagging*'.

7. Social benefits

Socialisation is a key part of the sessions with movement around the group being encouraged, as participants have to get up to obtain craft materials. Also, there is ample time set aside in sessions to have tea and biscuits and chat. It is good for the participants to be able to socialise with others who share their difficulties, but in a setting that displays their abilities rather than inabilities.

One participant summed up the difference between the sessions here and other dementia groups: *'I found other groups depressing but there is a good mix of people at this group, some worse than me, but some better.'*

After taking part in Lost in Art, participants and carers expressed many ways that they felt the sessions had benefited them, these were both social and personal benefits.

One carer said a key benefit was a feeling of *'being part of the team'*, another said that it *'gets you out of the house... meet others... swap ideas'*.

A feeling of belonging in terms of social benefits was apparent; a participant felt a key benefit was; *'swapping ideas with people that are better than you are and not quite as good'*, and a further participant expressed that *'we are all as mad as each other'*.

8. Personal benefits

A carer stated that the sessions were beneficial for the participant due to them being *'engaging for his mind'*.

One participant said it was *'good to be following an interest'*.

One carer said that it was good to be able to do an activity together where the participant was not dependent on the carer.

A carer felt a key benefit was that it was *'good to see him have an outlet for his creative side... good to see him get on with stuff without me'*.

A key personal benefit for one participant and their carer was that the carer found that they learnt to; *'let her do what she wants to, not trying to direct her'* which shows a positive change in their relationship.

9. Mood and confidence

Two themes noted were mood and confidence. It is difficult to extract one from the other, as raised confidence improves mood.

One participant said they enjoyed the session but *'had to come to terms with not being able to do some things'*, however they did show pride in their work, saying; *'some of the ideas I came up with I was really pleased about'*.

A carer stated that a participant's mood was lifted by the sessions, as was confidence, and though the participant comes home tired he *'enjoys it and gets a lot out of it'*.

10. The artists

Participants and carers were highly praising of the Artists, with one stating that they were *'absolutely brilliant... really inspirational...very patient'* and that they are *'good at gluing everyone together'*. However, there was a feeling from one participant that the artists time was difficult to divide between the participants; *'artists are spread thin in terms of getting everyone started'*.

11. Looking forwards to the sessions

One carer said that the art sessions were the focal point of the week, creating a structure and they looked forward to the sessions, planning, and seeking materials the day before the session. A participant and their carer said they *'miss it when it's not on'*.

12. Surprises from the sessions

A couple of participants were expecting painting or drawing and expressed initial disappointment at this, however they did enjoy it and were surprised at how much. One participant's carer was surprised at how interested the participant was. Another was surprised by how much was learnt.

One participant commented that the sessions were; *'first class'* and that they were; *'really surprised by how good it was... better than I expected... great fellow pupils, great teachers, great subjects'*.

One carer said that they were *'surprised at some of what she really enjoys and captures her imagination'*. Another carer said they were; *'surprised by the level of engagement in certain things and how much he enjoyed certain things.'*

13. Session enjoyment

When asked what he thought about the sessions one participant replied; *'I really enjoyed that'*. Another participant said that she likes telling people about what she has been doing and that the art is the best thing she has done, she also stated that she *'liked the absolute freedom, you could do whatever you wanted'*, they also; *'enjoyed the charcoal and sharing memories'*.

One participant said it was good because they are *'all in the same boat'*, and a carer said they *'enjoyed it once stuck in'* and that *'it's enjoyable, sociable and encourages you to get out'*.

Three of the participants and their carers expressed that they enjoyed the school visit;

'Really enjoyed the school visit but it wasn't long enough.'

'She did really enjoy the time with the children, she loves kids.'

'Enjoyed the session when the children came especially.'

There were some negative comments about the sessions, however all participants and carers were generally positive.

One carer commented that the participant enjoyed the sessions *'less this time than last time'*, but said that it may be the dementia worsening and that this time they had *'struggled to understand what [the artist] wants'*. Further to this, a participant said that sometimes it would be nice to be able to just sit and chat, and that they *'don't like being told what to do'*. Another participant felt that the art was not challenging enough for them; *'Art was a bit mundane... would like to do more challenging things'*.

13. Suggestions for future

When asked what they would suggest for the future the participants and their carers generally stated that the current format worked, however two participants felt that they would like more tuition and that it would be enjoyable to do some painting instead of craft, also it would be enjoyable to go on trips.

Some participants and carers would prefer not to be walking from the workroom to the gallery at the beginning, perhaps meet in the gallery, this is due to the cold weather. One participant expressed that a timetable for the students would be useful, so that they would be able to prepare in advance of sessions. Another suggested that it might be good to work on one specific piece of work throughout.

When asked if they would attend again in the future all participants and carers said yes. A carer stated that this sort of thing has *'got to be enjoyable for both carers and participants'* saying that the sessions completed were perfect in that respect, stating that the *'formula atm [at the moment] is brilliant'*.

Part 2 - The artist observations

The artists made weekly observations focussing on (if present) the carer's relationship with the participant and on the participants enjoyment and achievement in the sessions. They recorded observations on weekly assessment forms as well as writing a general weekly report. The two artists collaborated on the reports and on the weekly assessment forms. The researcher received these weekly for thematic analysis in order to generate themes from the sessions.

1. Participant and carer interaction

Three of the five participants regularly attended the art sessions with a family member. The artists assessed and commented weekly on the interactions between the couples.

At the beginning of the course, some carers had a tendency to 'take over' the participants' work:

'[Carer] appeared to take the responsibility for working for both of them.'

'[Carer] eager to finish some tasks for [Participant].'

However, as the course progressed this over involvement subsided.

'Worked well together, [Carer] supporting with her free form ideas in clay.'

'Worked separately and comfortably.'

One carer and participant couple however, did interact well from the start, and throughout, as this observation from the first session demonstrates;

'[Participant] and [Carer] interact well and companionably without [Carer] taking over.'

2. Participant development

One of the challenges associated with dementia can be a difficulty in beginning something, therefore the participants often needed help with initial ideas for their work.

'[He] needed support.'

'Initial hesitation about how to begin.'

This support can mean that the artists do not always get a chance to spend time with everyone in the session.

'Between the needs of [three participants] at various levels, felt that I had not made time for [other participants].'

3. Confidence

Confidence appeared to increase as the weeks progressed, with participants arriving eager to begin work. Participants who had needed help at the beginning were working independently by the end.

'Worked fast and intently completing his design on a piece of wood with confidence and fluidity -no hesitation.'

'Very confident and involved.'

'Eager to start: immediately took out some paints he had brought.'

'Worked astonishingly fast and confidently.'

4. Memory for the sessions

Some participants remembered the session's themes, bringing in materials to aid in the development of their work.

'Arrived with armloads of timber that he put in the car himself.'

'Bought in cards with birds on for the school children.'

'Spends the weekend 'foraging' and preparing things to bring; wood and various objects and gadgets to add to the pieces.'

5. Participant enjoyment

Participants commented each week on session enjoyment, there was only one week where a participant expressed a desire to leave early, and even here, they stayed until the end.

'Said she really enjoyed the session.'

'Said again how much he enjoys coming here.'

One participant attended another art session alongside this one and mentioned the other art class wasn't as stimulating and was not as good

Some participants seemed to experience flow (a state of complete immersion in an activity).

'Commented that the time had gone really fast.'

'Totally engaged.'

Part 3 - The visit from the schoolchildren

The participants were active in the planning of the school visit and all of them looked forwards to it. They planned the visit together, coming up with their own ideas for what to do with the children.

'We talked a little about the plans for the school at the beginning and again at the end – this is coming together from the group's skills and suggestions.'

Before the school visit, a representative of the Alzheimer's Society visited the children at their school and gave them an overview of living with dementia. The schoolchildren arrived at 10am and spent the morning looking around the galleries and doing some artwork. They spent a long time discussing the display of the participant's work in studio five. They then did a large charcoal picture in the education room before going for lunch.

In the afternoon the participants and carers arrived, some arrived early in order to prep their workstations for the session, however one participant could not make it. Everyone introduced themselves, and they all wore name badges. The children went to work with the participants and their carers in groups of twos and threes. Some of the participants worked separately from their careers and so there were six groups in total. Some groups produced work as a team, others all worked around the same concept but on individual pieces. After the work was complete, everyone went to studio five to display and discuss the work they created.

1. Nervousness of attending the session

Many of the schoolchildren acknowledged feeling nervous about meeting the people with dementia, one account summed up the general feelings of the group:

'I was worried in case I like frightened them, like scared them if they like, if I told them my name and the next thing, like after dinner time or something, they didn't know who I was and then I might have scared them. And they'll be asking a lot of questions so I thought I might get upset.'

2. Expectations due to beliefs about people with dementia:

Many of the group had prior expectations about how the people with dementia would act:

'I was expecting them to be a bit quiet and not being able to do things that we would be able to do.'

'[I thought] we were going to need to help them out a lot.'

'I was expecting them...to just put something down and just fiddle with it but not do anything with it.'

'I thought they would forget what they're doing once they start.'

Surprise at the capabilities of the participants due to the expectations held:

'I thought that the people with dementia weren't gonna be as active as they were... to make something they would just get a slab of clay, put it there and get something, poke some holes in it but they weren't... they were actually creating stuff, like cutting it up into exact slices so they could create stuff.'

'I was expecting them to be... more unbothered, unhelpful, and just wanna do nothing but they did wanna do stuff, they were active and they were helpful.'

I think [a particular participant] was quite quiet, but that's normal for people with dementia, but to see what he'd created with all the other people who were working with him was just really special basically because you'd never think that someone with dementia would include that piece of art work on, it's amazing to see.'

3. Enjoyment of working with the people with dementia

'I wish I could sleep over and do it again.'

'It was nice working with people who aren't your age, and like people who you don't really know.'

'It's been a pleasure working with the people who have got illnesses and they are different from us, they are different ages and it's nice working with people that aren't from our year group and people who we haven't met before and it's like nice to know more about them.'

'I think it was really nice from the start of the day to the finish ... working with [a particular participant], he sort of looks like a professionalist and sort of, he sort of makes stuff a professionalist would make.'

4. Attitude change

The group all expressed an attitude change towards people with dementia, all agreeing with the positive statements made by the more vocal members of the group.

'Don't judge people, don't judge them before you meet them.'

'Just because the people that you'll be working with have dementia it doesn't mean they're gonna be totally different 'cause they're really nice and kind ... as you meet them you just forget they have dementia 'cause they're so... normal.'

'They can't help having [dementia], I think it's nice for them to be interested in art and all these different, like, crafts because even if they have dementia they can't help having dementia it just comes and they don't, it's not their fault. I think more people should like, understand that because it's not all about what they look like or what they talk like.'

For the people with Dementia and their carers the school visit was an enjoyable experience. The artists also acknowledge that it *'is a vital and important part of the Lost project. The children encourage the Lost participants to tap into and find different methods of communication and physical movements that may not be part of their everyday anymore. Assuming the responsibility of explaining something to children was of obvious benefit'*.

Part 4 - Follow up focus group with participants and carers

Only four people from the group took part in the follow up focus group, just two of these being the people with dementia. Due to the small size of the group, the discussion was limited, however it reiterated many points that came up in the follow up interviews, demonstrating their importance to the group.

1. Session enjoyment

The group had very positive feelings about the sessions, with participants stating, when asked their general feelings about the art:

'Excellent'

'Very good'

'Very enjoyable'

Part of what appears to have made the group so enjoyable appears to be the social aspect, with everyone getting along well, and enjoying themselves because of this:

'I think it's a very friendly group.'

'We've all sort of worked with each other, and thoroughly enjoyed it'

'Made new friends, which has been lovely.'

Other comments made also helped to establish what made the sessions so enjoyable with participants and carers praising the way the artists encouraged and stimulated the group:

'[The artist] made sure we were always busy if we were just talking, so, well, this is good isn't it – getting the best of both worlds.'

'[The artist's] given us lots of ideas and then you could follow these ideas and do them as we wanted more as a team which was good.'

The group also enjoyed the stimulation they received from visiting the gallery each week in order to gain inspiration from the works on which they were basing their art work:

'It's given you sort of ideas where you can sort of do something, what you can do with what you have got.'

'We looked at other peoples different ideas and what they think is Art, whereas you might not, well, you don't always do you, they're completely different.'

The school visit also helped to make the experience an enjoyable one:

'I think we all enjoyed it, it was, the children were delightful.'

'They were lovely children.'

2. Encouraging activity

An important benefit of the sessions that came up throughout the discussion was that the initial step of going to the art encouraged activity for the day/ week, in both the carers and participants in attendance.

It gave the incentive to get out as well when you might have felt, ooh, it's not very nice and we won't bother, sort of thing. It gives you motivation and motivation to do once you've sort of motivated with that sometimes it rubs off on other things, probably at home.'

'And you know, you feel much better for it, getting out and doing it, then it rubs off lots of ways, doesn't it? Because, although you tell yourself you'll feel better if you have done it, you think, ah well, later.'

As discussed in the follow up interviews one participant has been encouraged, through the sessions, to take up painting again at home:

'It has encouraged [him] to do a little bit more of, I mean, not of what we've been doing here so much, but, erm, of his own art work that, he's been really making an effort and doing quite a bit of it, whereas he was a bit reluctant before, but he's really been getting on with it.'

Another participant states that going to the art has made her more active:

'It encourages me to do more work in the house and in the garden.'

Part 5 - Follow up interview with the artists

The follow up interview with the Artists touched on both organisational points and on the participants themselves. In terms of organisation, an important aspect discussed was the phone calls. These calls were to ensure participants attendance at the sessions, however the artist who made the calls found that they were used in other ways as well:

'Just by making that one call to say it's on tomorrow, you are aware aren't you? You remember the time? You could get embroiled and involved in a whole host and array of problems and situations...it's quick how you become more of the trouble shooter and as a problem solver and you can quite quickly become involved with being a support person as soon as you connect and start asking questions, you know, 'are you going to be able to come tomorrow?' well, it's not yes or no often is it? It's, 'well I could if someone can come get me...'

Therefore, there was the concern that due to the nature of the call, situations may come up that the person phoning may not be able to deal with alone:

'Perhaps somebody younger, who hadn't, hadn't actually internalised or thought clearly that some of these people's lives are very difficult and you get information that you have to process and sort and you know maybe at 20 I would have been more dramatic about it.'

However, it was clear that the phone calls were important:

'I think the phone around is a vital part of the project and not just for the organisational value....but I actually do think it's a part of the project for the participants.'

The artists also discussed the benefit of having a gallery space for the participants to use weekly to display their work. It was felt that this gave the participants a greater sense of purpose and a feeling that their artwork had a focus.

'I think it really galvanised them to make work that they felt had some kind of weight to it... They were mindful that they weren't just passing the time and making something, they were always mindful that the work was going to be seen and I think almost, that's really important because it's made the work have a significance from the off in that room. They didn't make anything flippantly, or just to fill up the hour.'

The artists were surprised by the level of commitment and engagement that came from the group

It wasn't about just, 'ooh, we're there now we'd better just do something' born out by the fact that everyone was quite committed to finishing their work, there wasn't any kind of sitting back or, 'we've done this, we had to do a bit of clay, so we have'. I was quite surprised by the level of commitment really.'

Further to this, the artists felt that all of the individuals involved in the sessions put something of themselves into the work:

'I just really didn't feel that they were ever making work because they were told to make it, it was all incredibly personal and very intrinsically linked into their past experiences, and I don't think anybody made any superficially. It really was an interpretation, of significant memory, or parts of their experiences now... It came

directly from their own experiences and/or memory, nothing to do with the fact they have got dementia or not, which is again quite unusual.'

'It was to do with exploring processes, as you say, exploring them mindfully and meaningfully... see what the processes would do.'

The artists also found that the group engaged in discussions about art itself:

'We had loads of conversations about creativity, loads of conversations about the role of artists, loads of conversations about people troubled by the idea that because a lot of the work is slightly abstract in nature. And then quite long conversations about why that was significant and important. I mean, it just didn't feel like a, I don't know, it felt like a very full and engaged group, didn't it?'

Some of the participants developed as the sessions progressed for example two of the participants gained confidence and independence:

I felt that over the last three, four weeks, he's really become very confident in what he's doing and a bit more outgoing, in the last week or two he's been quite, well, he's always cheerful, but he's been even more jolly... He became definitely more physically determined, he was moving further around the room to get at stuff he wanted to do and would stand up when he was sitting down at the beginning of the group.

[Another participant's] definitely grown in confidence and works much more independently now than he did before and seems happy with what he's creating.'

The carer/ participant dynamic in one couple also changed for the better over the course of the sessions. At the beginning of the sessions, the carer would 'step in or take over' also, the participant was 'quick to sort of feel neglect' if their carer was not paying enough attention, however, towards the end of the ten weeks this dynamic had changed dramatically:

'By the end of the sessions both of them were very settled and gave themselves nice healthy space and mutual respect about working differently and what they were good and not good at and enjoyed. They seemed to work very confidently alongside each other without being in each other's pockets. I think they, that their relationship, or working relationship, really developed.'

One participant attended with his son, and though at first his son *'was a bit uncertain of his role and a bit anxious on [his Fathers] behalf and then the first time he came he made the Heron didn't he? Then after that he didn't actually do his own work, he was quietly just enabling [his Father], so in a sense he became more relaxed in the group.'*

'[He] said that he felt that he was getting a lot out of it and he was getting a lot out of it with his father.'

One participant did not manage to attend many sessions due to transport issues and sickness, however it does appear that he got something out of the few sessions he attended. The artists relayed a conversation they had had with a support worker who had in turn spoken to the participant's wife about this participant's involvement in the sessions, stating that:

'He's a very proud man and finds it difficult to, kind of connect or settle into being guided or led, ...and kind of likes to be the one who's in control, even though, obviously, that's getting more and more difficult and he said it was quite an unusual situation that he was 1. Wanting to come to lost in art, 2. Wanting to come back and could actually remember and talk about the people connected to it, [his wife] was shocked and quite surprised.'

One of the most important sessions in the eyes of some of the participants was the school visit, and the artists' comments reflected this.

'We both felt that the school participation was incredibly significant ...the fact that the children, inspired and generated different methods of movement and communication.'

The artists' observations demonstrated how vital this kind of interaction is and how beneficial it was for the participants:

'Many of the participants were moving around the tables, reaching and stretching and bending in a way that we just hadn't seen them do, triggered by just completely different interactions, triggered by the fact they had a sense of responsibility with vulnerable being younger than them and I thought that was, well, vital. I was blown away actually.'

The artists were also impressed by how much responsibility the participants took on in terms of setting up the session as a couple of participants arrived early in order to set up, and others brought things along to use during the session;

'They took responsibility of their interaction, took ownership of it completely. It's also more than you'd ever imagine or expect of anybody to be honest.'

The artists also noticed a change in the group dynamic as a whole

'People became less introverted about their own work and became much more comfortable discussing other peoples work and sharing in it and bouncing ideas off and talking about people's work, they were very reluctant to do that in the beginning.'

Discussion

The initial plans and subsequent proposed analysis were limited due to a) the small number of participants (five) and b) to three of the participants having already taken part in the previous sessions. This is an important caveat to consider when drawing any conclusions around the benefits of this specific programme.

Nevertheless, the in-depth analysis summarises a number of useful points that suggest some of the key benefits of the Lost in Art programme, and areas of the programme that could be further developed for future service delivery. The results are now discussed in relation to the three study objectives.

1. The role of procedural memory within the sessions and the extent to which there may be a 'carry over' effect to tasks at home.

The artwork produced in the sessions was not based on a specific procedure, however it did build on, and create, skills. For example, the participants actively explored the many ways in which they could manipulate clay. One participant went from just pressing clay to creating patterns and motifs. Other participants used a glue gun, which takes a certain amount of skill, and when unable to use the glue gun themselves, for example due to shaking hands, they were the initiators of how and where the glue would go. Participants used spray paint with confidence and used charcoal. All of these materials require an understanding of the situation and the goal in order to make effective use of them (they are not, for example, items often seen in the art room of a primary school), showing that the participants were engaged in the art process. Also, the participants would often come into the workroom eager to begin,

showing that they remembered what they were doing and knew that they enjoyed it. These abilities and the enjoyment seen here correlates strongly with findings from other similar studies such as the artistic education programme in Spain (Ullan et al 2011). In the mentioned study, participants with a diagnosis of dementia learned how to use cyanotype and with this new learning came feelings of increased capacity.

From carer reports, there is no evidence that our participants demonstrated a carryover of increased capacity at home, in terms of their abilities around the house. However, one participant who lives alone did express that coming to the group encouraged more activity at home, which is a positive outcome. Further to this a carer expressed that the act of going to the art encouraged them to do other activities as it got them out, whereas they may not have left the house otherwise. This is equally beneficial for the participant, as they themselves may therefore not have gone out otherwise. An additional benefit for one participant is that they started to paint at home, something that, at the beginning of the sessions, their carer had been trying to encourage.

All of the participants demonstrated memory for the sessions. On top of this, all but one often discussed the sessions. For those participants to remember the sessions was not deemed especially surprising by carers, however, in one case, the detail at which the sessions were remembered was. In terms of carer responses to memory there can be biases in terms of them being more used, in the long term, to the participant remembering things than not. In addition, in terms of excess disability, the carers who attended the sessions were an unrepresentative sample, as the three pairs who attended as participant and carer had attended Lost in Art before and of the other two participants, one attended and lived alone, thus demonstrating high capabilities and the other cared for a sick relative.

The sessions also affected home life in that they gave participants a focus for the week. One participant spent the day before the art session gathering materials to use in the artwork, showing they remembered when the session was as well as what it was about.

2. Changes in communication and mood of the person with dementia.

Again, due to the size of the sample and the majority of the group having previously participated in the sessions it is difficult to draw full conclusions, however, confidence visibly increased throughout the sessions. Participants became more

physically confident in terms of moving around the workroom to find items they needed, participants also felt ready to begin sooner and needed less help as the weeks progressed. This again reflects the findings in Spain as the participants found they were capable of the work and proud of the outcomes, thus increasing their confidence (Ullan et al 2011).

Two of the three carers did not consider there to be any real changes in confidence, communication or mood at home because of the sessions, however the final carer felt that the sessions improved the mood and confidence of the participant. All of the participants were good communicators going into the sessions.

All but one of the participants had felt that they were satisfied with their life at baseline. The participant who was not satisfied with life at baseline was satisfied at follow up. Though there is no statistical power due to the small sample size, the sessions do appear to have had a positive effect on this person's mood and quality of life. This is extremely positive and though dementia can affect mood, as can changes in dementia medication, the weather etc., life satisfaction is something that you internalise more than a question about your mood, meaning that the answer should be based more on a general feeling over time, rather than mood on the day. This change could therefore be attributed to increased self-efficacy and a feeling that one is capable of achieving something positive despite the dementia diagnosis. This is again reflective of the findings in the artistic educational programme in Spain (Ullan et al 2011).

Session enjoyment was a key factor for all of the participants and their carers, with everyone at follow up stating how much they had enjoyed themselves. It was also clear through the weekly notes that participants enjoyed each session, often expressing their enjoyment at the end of each session. This session enjoyment can be said to contribute to putting the participant in a better mood, even if just for the time that they are participating.

3. Attitudes towards people with dementia, and how these may be changed through the art programme (schoolchildren, attendees at the exhibitions).

The focus group with the schoolchildren demonstrated clearly the kind of stigma attached to dementia. The schoolchildren reported being frightened that they might scare the participants, and that they may have to help the participants. They also expressed that they expected the participants to be very limited in what they could do

in terms of the artwork. However, once they met and worked with the participants the schoolchildren reported that they were surprised by how capable the participants were, expressing that if they did not know that they had dementia they would not be able to tell.

These initial perceptions of dementia indicate how in general, many people are afraid and misinformed of the condition. The change of these attitudes in the children demonstrate how important it is to help people with dementia integrate with people who do not have dementia and help educate them about the condition. The artists, the children, the carers, and the participants themselves viewed the session with the schoolchildren as incredibly valuable, and the reason for this lies in the positivity of the interaction. The participants were the ones in charge here, showing the children what to do and how to do it, giving them a sense of responsibility that some of them may not have felt since receiving their diagnosis. This demonstrates the power of inter-generational practice and more work like this with schoolchildren would be extremely beneficial in any programme of this nature in the future.

The artwork is displayed in a gallery room in the Ruthin craft centre. It is open to the public in order to demonstrate to people that people with dementia are capable. This also demonstrates to the participants themselves that their work is worthy of being displayed in such a way, thus promoting better self-image.

Conclusions and suggestions

Further to the initial objectives that the project set out to explore, is the idea of the art group as a place of socialisation. Many of the positive comments made by participants and their carers about the sessions related to the group being a place to socialise. However, in terms of self-efficacy the art is important as it gives the participants a sense of purpose and, ultimately, achievement that they would not have if the group were just a social situation. In order to confirm or discredit this point, and to know if this sense of achievement is necessary for the participants to benefit, further study is required wherein an art group is compared with a similarly implemented socialisation group to ascertain the unique, beneficial aspect of the art.

In terms of the future, some of the participants wished for more tutorial-based sessions, again demonstrating that they have, and most importantly, believe themselves to have, the capacity to learn. Considering these suggestions may be useful to future delivery, as one participant did not feel challenged by the artwork.

Participants and carers also had further suggestions regarding the structure of the sessions. They felt that meeting in the workroom and then walking to the gallery was a difficulty due to the weather and poor mobility, feeling it would be better to meet in the gallery. Another suggestion made by a participant was that a timetable would be useful to help them prepare in advance for sessions. It would also help those participants who had difficulty remembering the session's themes.

Lost in Art should also consider focussing more sessions on inter-generational practice, as this would help to improve the way that people with dementia are viewed as well as giving the participants the sense of responsibility discussed. A future programme could involve more groups of children and perhaps for longer time-periods, as some participants and carers felt the session was not long enough.

It is also important to broaden the scope and amount of participants involved in the sessions. However, the artists' time was limited even with just the five participants and four carers that attended, therefore it may be beneficial to have volunteer facilitators who can help participants begin work and enable them to use equipment. One way to do this would be for the carers to be involved with the general set up, or the more capable participants.

The way the group is advertised as an art group may also need revising as participants and carers pointed out the connotations associated with the word 'art' in that it conjures up images of paintings, whereas the group itself involves more craft. This may need considering when advertising for new participants in a new wave of projects.

The artists showed concern over the phone calls to the participants and carers in that they were used as more than just a functional act. The carers used the artist who phoned as a sounding board for the problems faced in their daily lives. This could in some circumstances result in the artist feeling distress over what is heard and some training and support for the person with the responsibility of the calls needs to be offered. The calls themselves are a vital part of the project as they ensure that the participants and carers are aware of, and can make it to the sessions.

Overall, the art group is a very positive environment for the people with dementia, it is somewhere that they are treated like 'normal' people. As one of the artists put it, they were a '*very full and engaged group*'. They do not get this kind of treatment elsewhere in the community, one participant expressed indignation about a task given to him at a different dementia group he attended, where the facilitator had

had him make an Easter basket of the nature a child in reception class would make. Therefore, this kind of group is an important addition to other forms of community based dementia groups. It enables the participants to express themselves and gives them a sense of achievement. Self-esteem is extremely important to people and just because a person has dementia does not mean that they should be denied this. In conclusion, it is important that people with dementia are able to take part in activities that are engaging and meaningful, and as demonstrated here, art is one of those activities with a range of potential benefits.

References

- Adams, S. (2012, December 26). Dementia screening 'will scare patients from seeing their GP'. *Telegraph.co.uk*. Retrieved May 16, 2013, from <http://www.telegraph.co.uk/health/healthnews/9756812/Dementia-screening-will-scare-patients-from-seeing-their-GP.html>
- Algar, K. and DCC (2012) Lost in Art too....? Evaluation of Art Sessions Provided by Denbighshire County Council. Bangor University.
- Camic, P. M., Williams, C. M. and Meeten, F. (2011). Does a 'Singing Together Group' improve the quality of life of people with dementia and their carers? A pilot evaluation study. *Dementia*, 0(0) 1-20. Doi 10.1177/1471301211422761
- Chung, J.C.C. (2004). Activity participation and well-being of people in long-term care settings. *Occupational Therapy Journal of Research*, 24, 22–31.
- Katsuno, T. (2005). Dementia from the inside: how people with early stage dementia evaluate their quality of life. *Ageing and society*, 25(2) 197-214. Doi: 10.1017/S0144686X0400279X
- MacPherson, S., Bird, M., Anderson, K., Davis, T. and Blair, A. (2009). An art gallery access programme for people with dementia: 'You do it for the moment'. *Ageing and mental health*, 13(5), 744–752. Doi: 10.1080/13607860902918207
- Malone, M.L., & Camp, C.J. (2007). Montessori-Based Dementia Programming: Providing tools for engagement. *Dementia*, 6, 150–157.
- Patrick, D. L., Starks, H. E., Cain, K. C., Uhlmann, R. F. and Pearlman, R. A. (1994). Measuring preferences for health states worse than death. *Medical Decision Making*, 14(1), 9–18. Doi: 10.1177/0272989X9401400102
- Sterin, G. J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia*, 1(1) 7-10. Doi: 10.1177/147130120200100103
- Ulla, A.M., Belver, M. H., Badi, M., Moreno, C., Garridol, E., Gomez-Islal, J., Gonzalez-Ingelmo, E., Belgadol, J., Serranol, I., Herrero, C., Manzaneral, P., and Tejedor, L. (2011). Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study. *Dementia* 0(0), 1-22. Doi: 10.1177/1471301211430650

Appendix 1: Lost in Art Interviews (baseline)

READ TO PARTICIPANT:

'AS PART OF THE LOST IN ART PROJECT, BANGOR UNIVERSITY HAVE BEEN ASKED TO UNDERTAKE AN EVALUATION OF THE PROGRAMME. AS PART OF THIS, I WOULD LIKE TO ASK YOU SOME QUESTIONS. THERE ARE NO RIGHT OR WRONG ANSWERS, WE SIMPLY WANT TO GAIN YOUR VIEWS AT THE START OF PROJECT. WE WOULD ALSO LIKE SPEAK TO YOU AGAIN AT THE END OF THE PROJECT.'
THIS SHOULD TAKE APPROXIMATELY 30-45 MINUTES.

Data from:	Age:	Gender:	Marital status:	Approx. when were you diagnosed with memory problems?
Participant:				
Carer/partner:				

[INSTRUCTIONS TO RA: QUESTIONS 1-6 ARE TO BE ANSWERED BY THE LOST IN ART PARTICIPANT ONLY. PLEASE ENSURE THAT THEIR PARTNER DOES NOT INTERFERE AND INFLUENCE THEIR ANSWERS.]

'I WOULD LIKE TO ASK YOU SOME BRIEF QUESTIONS ABOUT YOUR MOOD, PLEASE ANSWER YES OR NO.'

1. Are you basically satisfied with your life?
YES NO
2. Have you dropped many of your activities and interests?
YES NO
3. Do you prefer to stay at home rather than going out and doing things?
YES NO

'I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent. *[Point to each word (poor, fair, good, and excellent) on the show card as you say it].* We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.'

4. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?
5. How about your memory? Would you say it is poor, fair, good, or excellent?
6. How about your ability to do things for fun that you enjoy? Would you

say it's poor, fair, good, or excellent?

- 7. CARER/PARTNER ONLY:** Does your husband/wife/partner do regular routine tasks alone such as washing, dressing, making a cup of tea, etc., or do you do this for him/her?
[EXPLORE PERCEPTIONS OF CAPABILITIES]

- 8. CARER/PARTNER ONLY:** Do you do other activities to encourage your husband/wife/partner to be independent? [RECORD VERBATIM]

- 9. CARER/PARTNER ONLY:** How would you describe your husband/wife/partner's day to day memory? What impact does it have?

ASK BOTH PARTNERS AND RECORD ANSWERS SEPARATELY:

- 10.** Do you do any other leisure/social activities (separately and together)?

11. Have your leisure/social activities changed since experiencing memory problems? [EXPLORE REASONS WHY]
12. Do you both have past experience of visiting museums/galleries or taking part in creative activities? [PLEASE SUMMARISE AN EXAMPLE]
13. What are your Expectations of the programme? What do you want to get out of it?

'THANK YOU VERY MUCH FOR TALKING TO ME TODAY. I HOPE YOU ENJOY THE PROJECT AND WE CAN MEET UP AGAIN AT THE END TO TALK AGAIN.'

Appendix 2: Lost in Art Interviews (Follow up)

As part of the lost in art evaluation I would like to ask you some questions. There are no right or wrong answers; we simply want your views on the project now that it is complete.

This should take approximately 30-45 minutes.

What was your previous Employment?

To what level were you educated (School leaving age - University)?

(If appropriate) How long have you been married?

I WOULD LIKE TO ASK YOU SOME BRIEF QUESTIONS ABOUT YOUR MOOD, PLEASE ANSWER YES OR NO

- | | | |
|---|-----|----|
| 1. Are you basically satisfied with your life? | YES | NO |
| 2. Have you dropped many of your activities and interests? | YES | NO |
| 3. Do you prefer to stay home rather than going out and doing things? | YES | NO |

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent. *Point to each word (poor, fair, good, and excellent) on the show card as you say it. . We want to find out how you feel about your current situation in each area. If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.*

4. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?
5. How about your memory? Would you say it is poor, fair, good, or excellent?
6. How about your ability to do things for fun that you enjoy? Would you say it's poor, fair, good, or excellent?

7. Only ask Daughter/ Son of participant if attended sessions

Do you spend much time with your Mother/Father outside of the sessions? Can you describe some examples of these? (Record all scenarios described)

8. Have you noticed any differences in mood/ confidence since the start of the sessions? Can you describe some examples of this? (Record all scenarios described)

9. Thinking about when you come home after the sessions, have you noticed any changes in capabilities such as more independent action? Can you describe some examples of this? (Record all scenarios described)

10. Are there other benefits you have experienced from going to the sessions? Can you describe some examples? (Record all scenarios described)

11. For those who attended together Do you feel that attending the sessions together has had any impact on your relationship with each other? [Probe: see each other differently, increased/decreased any existing difficulties, etc.]

12. For those who have attended previous sessions Do you notice any differences in your partners' mood during the weeks when the Art sessions are on? Can you describe some examples of this? (Record all scenarios described)

How does this compare to when the art sessions are not running? Please can you describe?

13. Partner Have you been surprised in any way by the response of your husband/wife to taking part in Lost in Art? (explore: where they surprised by the degree of engagement/communication during the sessions, any increases in alertness, interest in the topic due to the influence of the artist, sharing the experience with others, etc.)

14. Partner Has your partner demonstrated memory of the sessions? [EXPLORE] have they, brought things up from the sessions at home, spontaneously discussed the sessions, or been able to discuss them with prompting? Can you describe some examples of these? [record all scenarios described].

How did you find these discussions?

15. BOTH [Record separately] What was the best thing about the sessions? Was it everything you expected (If participated before get them to think back on the initial art sessions, as well as feelings about the project explored here)

16. BOTH [Record separately] Anything you particularly didn't like about the sessions?

17. BOTH [Record separately] Any suggestions for the future?

18. BOTH [Record separately] Would you attend this kind of thing in the future? Why/Why not?

19. BOTH [Record separately] What kind of activities would you like to do in future?

20. BOTH [Record separately] Do you have any general comments on Dementia care in the area? The help and information? How you are perceived in the community? Are people patient, friendly, understanding?

21. BOTH [Record separately] Any Questions ...Thank you for your time

Appendix 3: *Focus group with children (and teachers)* exploring perceptions of people with dementia will be undertaken soon after their visit.

- What did you expect to find when you came along? (Explore answers)
- Before you took part, what did you think/know about dementia?
- Has this changed? How?
- What did you do during the art session?
- Did you learn anything new? (about the process and the people)
- What did you enjoy about the session?
- What would you say to other people coming to do what you did today?

Appendix 4: Individual participant questionnaires for each session – Artists' assessment

Date:

Name of participant:

A. Did he/she show interest and pay attention to the process of the workshop?

1. Yes, continuously during the entire session
2. Yes, but at intervals
3. No
4. Not sure, could not really say

B. Did he/she finish the work?

1. Yes
2. Partly
3. No

C. Did he/she enjoy the workshop?

1. Yes, clearly [participant said so, or it was clearly observed by artists]
2. Yes, possibly [based on artists' observation]
3. Cannot really tell
4. Did not enjoy it [based on observed displeasure or dissention]

D. Was their carer/partner present during the workshop?

1. Yes all the time
2. Yes some of the time
3. Not present

IF YES: Did you observe any situations where in your opinion the participant was potentially capable of doing the task/communicating, etc., but the carer/partner stepped in/took over and did it for them? PLEASE PROVIDE AN EXAMPLE.

Do you have any further observations about the participant in this session?