

Dance and Dementia Project: findings from the pilot study



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Cover image

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Introduction	3
1. BACKGROUND	3
1.1 Background to the subject	3
1.2 Background to the project	4
2. PURPOSE OF THE STUDY	5
2.1 Project Aims	5
2.2 Working with a partner agency	5
3. METHODOLOGY	6
3.1 What we did/techniques	6
3.2 Participants and how selected	6
3.3 Ethics, consent process and risk assessment	7
3.4 The kinds of data we collected	9
3.5 Analysis and dissemination	10
4. FINDINGS	11
4.1 What we found out – participants	11
4.2 What we found out - process	16
4.3 The importance of how we worked	18
4.4 CHALLENGES	21
4.4.1 Process	21
4.4.2 Personal	23
4.5 THE VIEW FROM OTHERS	24
4.5.1 Participants	24
4.5.2 Carers	26
4.5.3 Staff	28
5. CONCLUSIONS	30
Appendix 1 : References	33
Appendix 2 : Project Documentation	35

Introduction

The project was a small pilot study seeking to explore the role of dance in maintaining and developing relationships between people with dementia and, between people with dementia and those who care for and support them. Sitting within the context of a growing body of work on the use of creative therapies and interactions with people with dementia it sought to develop thinking on the use of dance as a communication mechanism particularly focusing on the potential to increase social interaction and on the importance of the relational network in care for people with dementia. A joint project between academics, creative practitioners and local authority staff it gathered data on the impact of a series of dance movement sessions at a residential and day care unit in Brighton & Hove. The data was gathered through engagement and observation by the dance, research and care staff involved in delivering the sessions, through interviews with participants and their carers and from reflections recorded by staff working with the participants. The project ran between January and March 2011.

1. Background

1.1 Background to the subject

'Dementia is a progressive and irreversible brain disease which erodes the capacity to reason, to think, to learn and to remember. Some skills survive longer than others, however. The capacity to respond to music lasts almost to the end' (Jerome 2002)

Dorothy Jerome in writing about her use of therapeutic circle dance with older people with dementia discusses how powerful dance in general can be in both enabling people to inhabit their physical bodies and regain a sense of movement and balance and in connecting them to others through a sense of 'collective identity and belonging'. (Jerome 2002)

Since the mid 1990s there has been developing interest in the use of creative dance interventions with people with dementia and it is increasingly being shown that whilst the cognitive capacity of people with dementia is gradually diminished the emotional and physical memory lasts and people can continue to respond to creative interventions like art, dance and music. There is increasing current interest in working in this way (Evans & Garner 2004, Meekums 2002, Stockley 1992) and a developing body of practical guidance on working with creative therapies with people with Dementia. Examples include publications and videos produced by the Dementia Services Development Centre at the University of Stirling(www.dementia.stir.ac.uk).

Dance as a means of expression is both intensely personal but also connects us with others. It is a way in which we can often access memories of ourselves as individuals and within the context of our lives and cultural environment as we age. Heather Hill in her article A Space to be Myself describes a research study with an individual with dementia in which the dance sessions 'offered Elsie a space and time to be herself – in dancing she could re-discover her 'old' self and re-experience it in the present' (Hill 2003)

The late Tom Kitwood speaks powerfully of the importance of maintaining a sense of identity and personhood for the person with dementia and suggests that we need to continue to recognise the person and their history in order to develop understanding of how we might enrich their lives. (Kitwood 1997)

Work using reminiscence techniques and music and dance are all ways that enable people to inhabit again the people they once were and may even still have memory of. Working with dance in particular because it is an embodied activity can encourage memory and response in people with dementia. (Coaten 2001). Hill also speaks of how the experience 'demonstrates just how much our stories, our selves are embodied' (Hill 2003). Dance also provides a means of non verbal communication which as dementia advances becomes more important. Dance is an 'essentially human activity of expression and communication' (Hill 1999)

1.2 Background to the project

The idea for this project grew out of connections made between the University of Brighton, Chichester University and Brighton & Hove City Council during the planning and running of a Making Research Count event on Dementia at the University of Brighton in December 2009.

Sussex has a significantly high elderly population and a high percentage of people living with dementia. Figures from the Brighton & Hove Older People Mental Health Planning Framework indicate that there are at least 3,260 people in B&H living with dementia (BHPCT and B&HCC 2009). This represents around 8% of the over 65 population. The Dementia UK report (LSE, PSSRU 2007) estimates that there are around 670,000 people over the age of 65 with dementia in the UK, around 63% living in private households and 36% living in care homes (Alzheimer's Society 2007). Research developing knowledge and awareness on issues to do with dementia care and practice continues to be of importance to this geographic area.

The research team is a group of academics, dance artists and practitioners with a shared interest both in working with dance as a creative mechanism of communication with people with dementia and in looking at how we might research the impact of dance on people with dementia and those who care for and support them. The team was particularly interested in understanding people's engagement with dance and how they might use it to continue to express themselves and to be seen and understood by those caring for them or working with them.

As a research team we are also interested in the impact of working with dance on staff working with people with dementia. The major finding of the work done by Jill Hayes and Anne Colvin in the Creative Arts Component of the Skills for Care Dementia Project East and West Sussex 2008-2009 was that staff felt that the Creative Arts training had enhanced their ability to empathise and attend to the feelings of people with dementia. The book which followed the project 'The Creative Arts in Dementia Care : Person-Centred Ideas and Approaches' (Hayes and Povey 2010) records the outcomes of the project and develops the ideas explored in it.

The team is aware that there is an increasing amount written on the use of creative interventions and activities with people with dementia. We recognise that dance movement practice and therapy sits within a broader group of creative therapies and seek to learn from the research done using other creative mechanisms. (Waller 2002; Rusted et al 2006). Our aim is to add to the broader knowledge and understanding and to make a contribution to writing and thinking particularly on the importance of using dance to promote the relational network in care for people with dementia.

In starting out with a small pilot study we hoped that the knowledge and experience of working in this way would enable us to do further work on the subject and put forward strong proposals to develop a larger project. A small grant of £500 from the Community University Partnership Project (CUPP) at the University of Brighton gave us the resources to pay for the dance artist time and both the university research time and the practitioner time was given in kind to support the pilot. The project ran over a period of three months from January – March 2011.

2. Purpose of the study

2.1 Project Aims

- To explore and understand more about dance as a mechanism for working with people with dementia.
- To consider what impact a series of dance sessions have on the quality of life for a group of people with dementia, their social interactions and their communication with each other and those who care for them.
- To consider whether there is any learning that can be taken forward into changes to practice in providing care and support for people with dementia and their carers.

2.2 Working with a partner agency

Through the connections made with Brighton & Hove City Council staff at the Making Research Count Dementia event the researcher was enabled to visit and talk with the management staff at Ireland Lodge about the possibilities of running a pilot project there. The council was from the outset supportive of the project and keen for the work to be done at Ireland Lodge. Staff were able to suggest a suitable quiet room for the sessions to take place in and advise on timing and the best way to communicate and engage with the day centre users. Time for staff members to be involved in the sessions was also agreed in advance. This partnership created early on in the pilot was significant in the project's delivery and the willingness of the staff to invite creative practitioners and researchers into the centre and support the process was key to developing the work and understanding and dealing with any problems that arose.

3. Methodology

3.1 What we did/techniques

Initially we had planned one introductory session but it became clear that people needed to see what the sessions would involve before they were sure they wanted to take part. We eventually ran three introductory sessions. The first to introduce the project and invite participation and the second two talking to and working with the group to familiarise them with what we were asking them to be involved in and finding out more about them and their stories. All sessions took place in the late morning period before lunch on consecutive Mondays covering in total a period of nine weeks. During the period of the introductory weeks the consent process was undertaken so that all consents could be obtained by the start of the main sessions.

The intervention

Creative dance sessions were offered by a qualified dance artist and focused on developing the wellbeing of the participants through movement activity and reminiscence. Each session followed the same format with a warm up session followed by a more complex movement development session. The group then paused for a short reminiscence session followed by another short movement session based on the reminiscence. The final part of the session involved some calming and relaxation movement and leave taking. The sessions were predominantly seated. The physical warm up sequences were taught and then developed or adapted in different sessions. The sessions also included physical exploration based on familiar movement, or inspired by visual stimuli and discussion. Each session lasted for about an hour.

The sessions used a thematic stimulus and were supported with visual and audio prompts including pictures, clothing, props and a variety of music to facilitate conversation and share memories, thoughts and feelings. The overall theme explored over the six sessions was 'What does dance mean to you?'

The creative dance practice underpinning the techniques used sits within the person centred approaches inspired by the teachings and writings of Rudolf Laban, (Laban 1971, 1984) and the practices developed by dance movement therapists for work with different client groups. (Payne 1992; Violets-Gibson 2004)

3.2 Participants and how selected

Ireland Lodge is one of two residential units run by Brighton & Hove City Council for people with dementia. Initially the pilot looked to work with both residents of Ireland Lodge and users of the day centre based there.

For the purposes of such a short pilot it was essential as far as possible to invite a group of participants who were available to take part for the whole six week period. We were keen to work with both residents and day centre users, however the

predominant use of beds at Ireland Lodge for respite meant we were only able to include one of the longer term residents.

At the time of the pilot day centre care was available at Ireland Lodge on a regular basis seven days a week. As the pilot had no budget for transport or care we chose a day for the sessions which suited the day centre in terms of other activities, staff availability and transport provision. Having selected a suitable day in consultation with the staff this then gave us a sample of the day centre users who attended on that particular day.

It was agreed that the researchers would join the day centre group on the day and time chosen to introduce the project to them and see if they were interested. Staff were given information about the sessions and followed up with the group to see who would be interested in joining in. Information on the project was also sent to the family carers of the day centre users and they were invited to respond on both whether they thought the person they cared for would be interested and also on whether they would be prepared to give feedback as well.

We hoped to work with a group of no more than 10 and agreed that if those interested numbered more than 10 that we would select participants randomly from the group balancing the gender split proportionally to the whole sample. We agreed that we would explain to those who were not selected why we could only deal with a small group and that we might be able to run more groups in the future that they could be part of.

In the event a group of 12 users were interested in the sessions and five of their carers agreed to take part in interviews. Most of the group were in their 80s and some were over 90. They were all mobile with assistance. There were three men and 9 women.

3.3 Ethics, consent process and risk assessment

Ethics

The pilot obtained ethics approval from the University of Brighton and from the local authority.

Consent

Considering the issues of obtaining informed consent from people with dementia we were mindful of the research on process consent by Jan Dewing and used elements of the framework she advocates in our process. This included working with those who know and understand how participants consent in other situations and ongoing consent monitoring as part of the warm up and ending part of each dance session. (Dewing 2007)

The project was introduced to the potential participants as a group and they were given written material explaining the project and why they were being asked to participate. Materials were also sent to carers. Whilst we were using a written

consent process the research team also worked with staff at Ireland Lodge to explain to participants the nature of the research project and their involvement in it. The staff were able to assist the research team in talking to the day centre users and establishing whether they would like to take part.

The research team made contact with carers of all those interested in taking part to seek their consent and to ask them to act as a 'personal consultee' for the person they cared for. If family carers were not available then staff not directly involved with the sessions were asked to act as a 'nominated consultee' for individuals. (DOH 2008)

The pilot study involved a series of group dance sessions and some individual semi – structured interviews. The dance sessions were carried out by the dance artist with assistance from the researcher and the member of Ireland Lodge staff. The dance artist and the member of staff from Ireland Lodge were experienced in working with people with dementia and the researcher was experienced in working with older people using group and individual qualitative research techniques. It was agreed that all those involved in the direct work with the day centre users would hold enhanced CRB checks including the dance artist and the university research staff. CRB checks were facilitated by Brighton & Hove City Council.

A written consent process was used with the family carers and the Ireland Lodge staff involved with the project.

Risk assessment

The consent interviews with some of the day centre users took place in their own homes with their carers and carers' consents were done at the same time. Where this was not convenient consents were done at Ireland Lodge. All the sessions and interviews with people with dementia took place at Ireland Lodge. Interviews with family carers took place in their own homes at a time when the person they cared for was at the day centre.

We acknowledged that our intervention might involve us in re engaging people with memory and reminiscence events that they may have ceased to be involved in. There was a need to manage and support this process and to ensure both that the experience of taking part was a positive one for participants and that their experience was valued equally with the useful material that would come from the study.

Evidence from the literature indicates that the effect of dance is likely to be mostly positive, but provision was made with staff that they would engage with users after the sessions if the research team was aware that memories were stimulated that were upsetting. Having a consistent member of staff in the sessions who all the day centre users knew helped this to happen. The timing of the sessions in the late morning slot with lunch to follow was also important as all participants were in the centre for the remainder of the day with support available should any issues arise.

To minimise risk of harm or injury it was agreed the sessions would initially be seated only, progressing to non seated gently and if it was clear participants were able. The Dance Artist running the sessions was experienced in running similar

sessions with older people and with people with dementia and the presence of a member of staff with knowledge of participants assisted us in the understanding of each individual's capacity for movement. The Dance Artist checked at the beginning and end of each session how people were feeling and adapted sessions accordingly.

After each session there was a short debrief for the participating research team including the member of Ireland Lodge staff. Within the broader research team there were two very experienced research supervisors (one also an experienced dance supervisor) who were available to offer support should the need arise. The members of staff who took part were fully supported by the day centre manager.

3.4 The kinds of data we collected

Data was collected from a number of different sources and in a number of different forms.

The one source of data not originally planned was the observation diary used by the researcher which provided a record of the content of each session including the debrief as well as observational notes. This diary, originally used by the researcher to record and understand her own experience and challenges (See Etherington 2004) became to some extent the central core record of the pilot. The dance artist used process notes and also reflected on the researcher's observation diaries which were shared with her.

Care staff were asked to complete a short prompt sheet after each session to record any perceived impact on participants e.g. ongoing interest in the sessions, mood, engagement with others, memories generated. This proved the most difficult record to keep as staff were busy and the most appropriate person to do this (the member of staff involved with the sessions) did not have time.

It was originally intended that one third of the participants (there was not time within the pilot to work with more) would be asked to do a short interview with a member of the research team to talk about how they felt about the sessions and that these would be recorded by one of the research team. Participants were to be selected randomly from all those participating and interviews were to take place after the third session with a follow up after the final session. It was hoped by talking to the participants twice during the period of the pilot that different levels of engagement and interest might be detected at different stages. In initial discussions the research team had felt that these interviews should be done by someone other than the researcher as she had been part of the sessions. However we quickly learnt that the issue of familiarity was important and the participants felt comfortable talking to the researcher and were also more able to recall having been with her in the sessions if not the detail of what happened. It was also clear that it was not possible just to talk to some of the participants as some were in friendship groupings or just keen or able to give feedback. The researcher therefore captured views from as many of the group as possible in a more relaxed way by just chatting later on the same day of the third and the final sessions. None of these chats were audio recorded but notes were made and written up with quotes where possible.

Key staff involved with the research (Ireland Lodge Manager, Day Centre Manager and member of staff participating in the dance sessions) were asked to record a journal over the period of the six sessions to offer their reflections on any impact they had seen for participants, for themselves, for other staff and for the atmosphere and operation of the organisation as a whole. Again due to the pressure of work this was impossible for the member of staff participating in the sessions to do but the Day Centre Manager was able to.

It was originally intended that one third of the carers/ family members would be asked if they would do a short interview covering any impact/ changes they were aware of in the person with dementia following the sessions particularly how they related to them as carers or to others. Interviews were to be with the carers of those individual participants who were also being interviewed. Carers of nearly half of the participants agreed to be interviewed and these interviews were done after the final session by the researcher.

We were mindful of the different possibilities there are for data gathering using film/video and will explore this in a larger project but were not able to in this pilot due to the costs/skills involved.

3.5 Analysis and dissemination

Our first aim in collecting data from completed prompt sheets, reflective diaries, notes from interviews, feedback interviews and written records from the dance sessions was to be able to capture the impact on participants both as individuals and as a group. We also wanted to observe whether any interactions or changes in relationships with each other or the group that happened within the sessions lasted outside the sessions. Our second aim in analysis was to understand how suitable our methodology was, how appropriate it was to the context and the group and how well it had worked.

The data was therefore analysed thematically to consider the impact of the sessions and in detail to consider the effectiveness and success of the methodologies used. The initial data was analysed by Diane Waller and Naomi Smith, both experienced qualitative researchers with input from the rest of the research team. This report of the project will be available to the broader research community and a findings summary will be made available more widely to all those who took part in the project or who are interested in the work we are doing.

Within this pilot study we wished to learn about the best way to work with dance in this kind of setting and how best to work with those with dementia and those who care for them either as family or professionals. We would hope in any follow on project to be able to add to the knowledge base and methodologies in researching the impact of creative work with people with dementia.

4. Findings

4.1 What we found out – participants

Attendance

We started with a group of 11 participants. Included in that group was one of the permanent residents of Ireland Lodge and 10 of the day centre users. The permanent resident was unable to continue after the first session. Her level of dementia was significantly more than the other participants and, without the one to one staff support that was not always available, the research team was unable to facilitate her being successfully in the group. We discovered after the first week that another of the participants did not have dementia and even though she continued with the group for a few weeks we did not include her in our findings. One further participant joined the group in week four. Overall 12 participants attended some or all of the sessions. We had been advised that some of the participants might want to stop coming to the sessions but this did not in fact happen. Unless people were physically not at the day centre no one chose not to attend.

Familiarity, safety and belonging

Over the period of the six sessions familiarity with the process and the group increased. We noted that the participants were quicker getting into the group as the weeks progressed. The regularity of the sessions and the consistent timing were both important in this familiarity developing as was the engagement of staff in reminding people that it was dance session day. After the first session it was agreed that the group would come directly through to the dance room when they arrived at the centre and this helped them to settle with us more quickly. Their association with us was started in the introductory sessions and became stronger as the weeks progressed. They would spontaneously greet us with songs or use movements that showed that they associated us with the dance sessions. One participant asked for each of the first three sessions whether observers were allowed but then just joined the group each week clearly feeling part of it. We had one participant who displayed what was for him normal wandering behaviour and left the room during the first two sessions. He did not wander in any subsequent session which staff said was unusual and although he was the least engaged of the participants he sat happily watching through all the remaining sessions and would occasionally join in or burst into song.

Within the group itself a sense of belonging developed. As the weeks progressed we noticed that the members of the group would greet each other more as they came into the dance room and occasionally would make definite choices as they entered the room who they would sit with. Two women regularly sat together and on one occasion one of the men greeted another man who had been absent for two weeks with a handshake as if they were old friends. As the weeks progressed and particularly in the reminiscence part of each session many of the participants shared personal memories about themselves and their lives with the research team and increasingly with the group as a whole. In feedback the member of care staff said that she could not have imagined some participants sharing those memories in the broader day centre and that they seemed to feel safe to do so within the group.

The participants were unfailingly good tempered and polite with each other and the research team. The member of staff in the sessions was well known to all of them and the impact of her presence and how she engaged with and supported them without ever directing, helped with their sense of safety and familiarity. There was only one occasion in all the sessions where one participant got frustrated with another and told her off for making a noise. There was an underlying issue that day for this participant and whilst she exhibited some anxiety behaviour she was able to stay in the session. Two or three of the participants did sometimes have spontaneous, occasionally noisy, reactions to something they enjoyed or knew like a song or a movement and, whilst this could have been disturbing, the rest of the group generally smiled at them and seemed to accept.

As the weeks progressed and the participants felt more relaxed we were aware of more humour and relaxed banter in the interactions with the research team.

Increased engagement with the movement

We noticed increasing comfort and freedom with the movement as the sessions progressed. Some of the group were physically quite stiff and initially had to make the movements quite small. As the weeks progressed their level of movement increased and the capacity to move arms and feet together increased for some. Some showed an increased flexibility in their joints and an embodied awareness of movement qualities and energies. Movements also became more defined. The level of engagement with the movement also increased. Initially it was largely copied from the dance artist, but again as the weeks went on, some of the routine movements became familiar when the music played. On occasions the group also began to take their lead from other members in the group who were anticipating the next movement in the dance sequence, not just from the dance artist.

One participant had said at the beginning that she just wanted to listen to the music and not do any dance. This participant actually moved quite strongly although she used a mobility aid. During both the first two sessions she sat and listened and on a number of occasions seemed to be dozing. As the sessions progressed this participant became more engaged, particularly with the reminiscence sessions, and by the fifth session she was much more alert and engaged with the movement, singing and the reminiscence. We also noted that she was walking quicker in the transfer from the session to the day centre.

One participant within the group was noticeably more physically frail than the others. She used a mobility aid and was often very worried by the transfer to sitting in a chair at the start of the session. We assisted her posture with cushions and foot rests but she was limited in her ability to sit up tall in her chair. As the sessions progressed this participant did become more comfortable and confident with the movement and particularly enjoyed some of the arm movements. The fifth session of the group was one in which there had been a lot of engagement between the members of the group around their ability to whistle which had encouraged quite a few of them to have a go. This participant was an extremely good whistler and the activity seemed to make her very engaged and happy. We noted that during the final relaxation movement session she became very engaged with the free movement to music that the dance

artist was encouraging. She became completely engrossed by the expressive hand movements she was doing and appeared lost in them.

Interactions in the group

Initially the interactions between members of the group were limited. We did note a small 'friendship' group of women who sat together and who we noticed did sit together in the day centre as well. This little group seemed to operate around one individual who was very friendly and cheerful and still very able to engage in this way with others. During the reminiscence part of the sessions participants were encouraged to talk to each other about the objects or props they had. Some of the participants were noticeably not very interested in the reminiscence sessions but even these participants did engage on some occasions implying that it was the particular prompt that they had that engaged their memory.

We noted that initially the group responded well to the research team and the member of care staff but did not seem to be so familiar with each other. As the sessions progressed we noted that this changed and the group began to recognise each other more when they were in the group. On one or two occasions we noted people acknowledging others in the group with smiles and even greeting each other. In talking to some of the participants the researcher asked if they had got to know anyone different as a result of the group. This did not seem to be the case and the issue as one participant was able to voice was that they thought they recognised people but could not remember their names. We also asked the staff carers for feedback about this but again with the exception of the small friendship group they were not aware of any other relationships forming.

At the start of the final session two of the group were talking and as they saw the researcher one said that they had been out dancing at the weekend 'down the Regent' making a connection between themselves and the dancing session. At the start of the fifth session as the group were coming in the researcher noticed one of the men had the oldest member on his arm coming from the car and he brought her through to the session in that way. Whether this was politeness or familiarity is hard to say, but when he stopped at the desk to pay something she waited for him and they came through together. According to the care staff they had been speaking about the dance session in the car on the way in.

The care worker involved with the group gave feedback that she saw the members of the group relating to each other differently when they were in the group. She felt that they were more focused and interactive together and they did seem genuinely pleased to see each other at each of the sessions. The care worker was also interested in the 'friendship' group which did seem to be sustained throughout the sessions and within the day centre. The participant who had joined in session 4 was part of this group and the participant who seemed central to this little group had asked if she could be included which we agreed. Interestingly, the family carer for the central member of this 'friendship' group had no idea that her relative had friends at the day centre as they had never been mentioned.

Without a doubt by about the fifth session the group was very clear about the association they had between themselves and with the research team during the sessions and recollected us and why we were there very quickly.

Insights into the people they are

We found that there were triggers both from the movement and from the reminiscence that enabled participants to engage with and express something of themselves. Very early on in the movement part of the sessions one of the participants had a swimming movement and she talked a lot about a long distance swim she had done. This movement became incorporated into the session and we found that others joined in with it and with a diving movement. Over the course of the sessions we learnt that a number of the group had been very fit swimmers and sports players and these movements brought out their memories of that. One of the men became so involved in doing the swimming movement correctly that he would often do the swimming breathing as well.

Many of the group were good singers and knew much of the music. There was one participant in particular who could sing every song that was put on and knew all the words. She could not have told us which songs she knew but any association like mentioning a film or hearing the start of a song and she would immediately be able to recall and sing all the words. The conversation mentioned above between two of the participants about going out dancing at the Regent involved this participant and the conversation they started about going out dancing continued when he asked her if we had ever come up with a tune she didn't know and she answered no with a laugh.

Most of the group had been dancers at some stage when they were younger and could remember all the old dance halls in Brighton and which were considered smart and those not so smart. In talking to some of the family carers it was clear that one or two had been very good dancers and one a very good jiver. This latter participant was one of the few who felt confident to get to his feet to dance with the dance artist, even though her movement was waltz and his was jive.

The reminiscence props triggered different things for different participants and nothing for some of them. The men were less engaged than the women with the props which were designed to encourage memories of dancing and celebration. Overall the props led us to have glimpses of what people did in their work lives, where they had lived, how active they had been, what parties and celebrations they had been at and the part that the dance halls played in their courtship during the war. In the final session some of the props were about games and there was an end of term feel. This was mainly led by the discovery of some yoyos which a lot of the group were very proficient at and found great fun. A number of people got to their feet to play with them and the men engaged with these props more than some of the dance ones.

Following each reminiscence part of the session, the dance artist worked with the group to encourage them to develop a movement which reflected their memory and which the group then used. Most of the group found this quite difficult as it can be an abstract process to respond to a prop which triggers a memory, and then to translate

what that symbolises into a movement. However, with encouragement they could find a movement that expressed their feeling which then become part of a little routine. These movements were shared around the group and a verbal insight into the reminiscence that inspired the movement was also given. There was some acknowledgement of the connection to the memory and the movement through nods, verbally, and in copying the movement that had just been performed.

As the group became more familiar with each other, with us and with what we were asking them to do, we noticed that personalities became more distinct and in particular that humour and playfulness appeared. Particularly in the yoyo playing and in the whistling episode there were insights into the fun that the group could experience and the happiness they felt at being engaged with memories. We were fortunate not to have triggered any very sad or difficult memories for the group, although this is clearly something we may encounter in a longer project and will need to make provision for. Certainly for some their level of pleasure and relaxation at being engaged with and included was very evident. For the one or two who sang well and confidently this was clearly a huge pleasure for them and something which made them feel happy and safe.

Soon forgotten?

We considered this point closely and it was clear that whilst the detail of what had happened in the sessions was forgotten by many of the group, if they saw or talked to the researcher or the dance artist they could make an association with having been part of the group and what the group was about. This was shown by people remembering some of the music we used or one of the movements. The detail of the sessions was not recalled by any of the group, but a few did recognise that the session had different parts and in the feedback chats were able to express an opinion on which bits they liked best. For a few of the group the memory of the session was gone almost immediately, but when talking to the researcher they would be able to recall that they knew her and had been involved in an activity with her, but not when. Once back in the group they would be able to engage again, but would not necessarily remember that there had been previous sessions. This suggested that whilst there was a lack of conscious memory there was embodied and emotional memory.

Interactions outside the group

The group was aware that they knew each other when they were in the group and some were able to continue to recognise each other out of the group, although names could rarely be recalled. As far as we could ascertain no new relationships developed as a result of the dance sessions and certainly one of the men told his family carer that he had been the only man in the group. The small 'friendship' group of the three women continued and the care worker reflected that she felt the bond between two of the women was stronger.

4.2 What we found out - process

The importance of the space

We were fortunate in having what turned out to be an ideal space for this group. The quiet, self-contained meeting room was situated along a short corridor in the residential part of the building. It was light and warm with windows on three sides looking out on a quiet street and lawn. We were able to arrange a simple circle of chairs and, apart from the tea trolley and the audio equipment, the room was otherwise empty. The room was big enough to accommodate our twelve participants and their various mobility aids, but was not so big that they did not feel safely contained. The space helped to frame the sessions giving boundaries and excluding distraction. The room was ideal for a largely seated group, but there was sufficient space for a few to stand if they wished. The room was close to facilities in the residential part of the centre and there were plenty of staff around if we should have needed support urgently.

The room was a short walk down a corridor from the day centre and after the first session it became clear that if participants came directly into the dance room when they arrived at the centre and had their tea with us this helped the group to focus and engage more quickly. The walk did take a few of the group a little while, but it also provided a sense of going somewhere else which they seemed to like.

Organisationally we learnt very quickly that we needed one of us at each end of the corridor and one with the group as they were apt to go off in other directions and in addition occasionally our group would be joined by one of the permanent residents. Physically and mentally adequate time had to be allowed for all the group to make the transfer to and from the day centre and our room, and early on we had to deal with one participant feeling she had been rushed and not settling at all well. From then on we made the getting to and coming from the session very much part of the engagement and we would sometimes sing on the way up the corridor or talk about what was for lunch.

We were able to use the space for all but the final session of the group. We did not know until we arrived for the final session that we would not be able to use our usual room and the quick and thoughtful action of the day centre staff and the security and familiarity of the group by that stage meant that we were able to deal successfully with what could have been a very challenging change.

The importance of fully involving care and management staff in the project

Significant preparation went into meeting with and engaging with the care and management staff at Ireland Lodge, the day centre, the residential and the overall management staff. The day centre staff were actively involved in supporting the project and were largely positive about it. Even those who were more sceptical became more engaged as they could see that the participants were enjoying it. They saw that the room was prepared and ready and helped to encourage and direct the group to join us as soon as they arrived. They gave us feedback after the sessions as to whether anyone had felt it was too much or were unhappy and overall helped develop our better understanding of the people we were working with.

On the final session the room was not available and the extent of the good working relationship was evidenced by the day centre staff creating an enclosed area in the day centre for us to work in and engaging calmly with our group and the other users not involved so that no one felt disturbed or excluded.

The benefits of the breadth of experience and skill in the research team

We had a fortunate combination of skills and perspectives within the broader research team and a high level of commitment. There were two more senior academics within the team, both of whom had worked and researched with people with dementia using creative techniques. The majority of the work was carried out by the dance artist and the university researcher, but other members of the broader team were able to lend support and guidance in the development of both the dance and the academic content. In the broader group all but the researcher had worked already with people with dementia and the member of council staff had many years service management and user involvement experience. This meant in particular that there were three people who could deal with the consent process and some of the carer interviews.

The breadth of experience and skill provided plenty of scope for checking things out as the pilot progressed. Overall the methodological structure of the project proved to be sound, but there were plenty of points at which particular issues had to be rethought. It was extremely useful to have a broad and varied understanding of the challenges of consent processes, confidentiality and boundaries in working with people with dementia within the team. The positive and collaborative approach within the team to working across practice, academic and creative fields was significant in supporting the pilot and how positively it was received.

The time you need

It is certainly true to say that research always takes longer to set up and carry out than you think and research with people with dementia clearly takes even longer if it is to be done well and to good ethical standards. We had underestimated the time required for a number of aspects of the pilot.

Firstly we underestimated the number of lead in sessions needed to introduce and demonstrate the project to those we wished to take part. We eventually had three lead in sessions during which we got to know more about the participants and they about us, and started building the relationships for the sessions.

We also underestimated the time that the consent process would take and if we had not had the extra lead in time we would not have got through this before the sessions started. We did in fact start with two participants not fully consented, but in both cases family carers had expressly said they would like their relative to be part of the project. The remaining consents were all completed in the week of the first session.

Finally, we had underestimated the time that would be needed around the actual sessions for the process of transferring people to and from the dance room and dealing with helping them settle and feel safe. In one of the early sessions a rush to bring people in who had arrived late was detrimental to some of the participants and

coloured the tone of the group for that day. The experience of the dance artist in understanding the need to accept that 'their' sense of time was not 'ours', and that we needed to work in 'theirs', was important in getting the right approach to the timing of the sessions. We came to an acceptance that if some sessions ran for a shorter time that did not matter as the process of coming together as a group in a settled safe way was more important to everyone's experience on the day than insisting on a rigid time frame for each session.

4.3 The importance of how we worked

Group work with movement and routine

As the sessions progressed we became more and more aware that a lot of the group had been very physically active in their lives as dancers, playing sport at quite a high level, being swimmers, recreational walkers and generally fit people. Although initially some were stiff and wary of expansive movements, it was clear that some really relished the movement and as they became more confident would really enjoy it. There is perhaps a cultural assumption at some level in dementia care that because people are less mentally strong that their physical strength is also less. Whilst there are certainly challenges in providing physical activity for people with dementia we noted in our group that participants' movement became more confident and expansive as the group sessions progressed.

In feedback a couple of people had complained that they had ached a bit and on one occasion the staff had noticed some of them were tired after the session, but this did not seem to have stopped them coming back and the physical movement did not seem to have caused long term negative reactions in anyone. The eldest member of the group delighted in movement and would at times lift both her legs off the floor at the same time as flinging her arms wide. Despite this level of movement she never had difficulty keeping her balance in her chair.

After the third session two of the participants who were most able to recognise that we were doing a research project and were interested in what we were asking them, gave some good feedback. Both at that stage said that they enjoyed the movement part of session best and neither were as interested in the reminiscence. After the final session one of these two was even more sure about the benefit of the movement and said 'exercise is what we need the day to day is not enough'. When we started the sessions this particular participant had a broken wrist but still continued to try and make all the arm movements despite the extra weight of the wrist support. By the fourth session the wrist was out of the support and she clearly enjoyed moving it more freely. She told the researcher she had been given exercises and it was possible to observe her incorporating some of the wrist exercises in some of her movements.

Reminiscence and embodied movement

As part of the sessions we worked with reminiscence props and then followed with a movement session where participants were encouraged to develop a movement to express their feelings or memories from the reminiscence. This was difficult for many

of the group initially as it required them to objectify feeling into movement. However even in the first session, one participant was able to respond to a picture of a dance shoe by moving her own foot and looking at it as if she was trying on a shoe. As we worked with this technique over the sessions some of the movements came easily to participants and some came with encouragement. These movements were then put together in a little routine to music.

It seemed that moving the body to express the memory would unlock other things. Mentioned already is the participant who used a swimming movement. This movement, which became part of a number of routines, would lead the participant to talk about her experience of swimming, but also clearly filled her with happiness when she did it and she would often shout out with joy.

The second session had a particular feel to it. This appeared to reflect both the before and after time on that particular day, (discussed later) and also the fact that it was Valentine's Day and the discussion and reminiscence was about that. One of the men had initially been reticent about taking part in the group and in the first few sessions had found it difficult to engage in the initial part of this activity i.e. making a connection between a prop that didn't belong to him and a memory which did. In this session he was looking at a picture of a red rose and on this occasion was able to engage with the whole process with some encouragement. He recalled his life with his wife during the war when they would go to a dance before he left to go back after his leave. The movement he generated was a hand on heart movement and he very clearly articulated the movement and it's symbolism when sharing with the group. Their responses were very positive and encouraging: they acknowledged an understanding of the movement connection to the visual prompt and offered their opinions of how 'lovely' his movement was. This movement unlocked for him a special recollection of his feelings for his wife which was profound and moving to witness. Many of the prompts on that day were romantic including pictures of dancers, celebratory cakes and Judy Garland's red shoes. In generating movements from their reminiscences the group came up with a swaying movement generated by one participants' memory of having been a professional cake maker and the movement of the industrial mixer, some floating ballroom arm movements and a skipping movement from the Wizard of Oz. The quality of the hand movement was different in this session with a tenderness that may have reflected the memories that the group had shared.

Relaxation and breathing

At the end of each session was a short time to relax and breathe during which we closed the session and did leave taking. The group began to respond well to this and on occasions would enjoy some free movement in time to the music encouraged by the dance artist. In the later sessions this level of independent rather than copied movement was more evident with one or two participants becoming very engaged with making their own movements to the music. The participant who loved exercise enjoyed this part of the session and would take the relaxation breathing very seriously.

Before and after

We realised early on that it was important to treat the whole session as the interaction, including the arriving and leaving. Seeing it this way and working to 'their' time not 'our' time made an important difference to the quality of the sessions. The process of greeting people as they arrived at the Day Centre and bringing them through to have tea in the dance room was an opportunity to see how people were and to help them recall what they were going to do with us that day. It also created a sense of belonging to a group. They could greet each other as they arrived and with the music playing and some chat were able to settle into the group and the time together. Equally the closing of the session and the journey back to the day centre and lunch was also an important way of checking how everyone was and getting any feedback from them.

The Day Centre users arrived in different forms of transport and therefore not always at the same time. The second and fifth sessions both had a longer and more staggered lead in time because of this, but interestingly were the two sessions when the participants seemed most engaged and calm both individually and as a group. On both these occasions as they had come in the Dance Artist had made tea and started chatting with the group about the day. The first of these sessions was the Valentine's Day session and the other was the 'whistling' session, both already mentioned elsewhere. What we noticed on both these sessions was that, as participants came into the room and had their tea with the music playing, the extra time gave them an opportunity to become settled and used to being in the group again. On both these occasions when the session began the group already seemed very focused and not distracted and as a result the experience of the session seemed deeper. On both of these occasions there had also been a particular memory prompt: Valentine's Day and whistling, that had led them to engage with each other quickly.

Person centred

Throughout all the sessions we worked in a person centred way. Participants were always invited to join us each week and were free to participate or not as they wished. There were a few participants who had initially not shown much interest in joining in the movement although they liked the music. None of these participants chose to leave the sessions or not to come and would sit quietly just watching and listening or occasionally dozing. As the sessions progressed, even those who had not initially wanted to join in, or who had specifically said they were coming to observe or just to see what it was like, had become fully engaged and were actively taking part.

The one exception was the man who initially wandered in the first two sessions. Whilst he did settle into the group and did not wander again his engagement was limited and it was usually to join in the singing not the movement. On several occasions both he and other participants did exhibit anxiety behaviours in the group and the care staff were able to help us understand what might have been going on that was increasing their anxiety. For some this was about medical treatment, whilst for others it was about changes to home or living situations. The anxiety was often exhibited in a lack of engagement, withdrawal, distraction or in repetitive movement.

We were always conscious of their choice to take part and having the understanding and the knowledge of the participants was enormously useful. Overall it helped us create an atmosphere in which they could feel safe and at ease in the group without feeling excluded or required to join in all the time.

4.4 Challenges

There were significant challenges in the pilot. Described below are the challenges of the process which affected most of the team, and the personal challenges which to a great extent represent the reflections of the researcher for whom working with people with dementia was new.

4.4.1 Process

Explaining what we were doing

As mentioned earlier we had underestimated the lead in time needed for the sessions. Part of this was a misjudgement of the need for people to be able to see and experience what we were going to do before they could decide whether they wanted to take part. In any research project the lead in time is crucial to how the project works out and fortunately we were able to put extra time in to meeting the potential group and demonstrating what a session would be like. If time had allowed, it would also have been helpful to do a session showing the carers what their relatives would be doing.

It was also important to spend time talking to people and finding out what their experience had been. A number of people, for example, said they couldn't dance or weren't interested in dance, but when we talked with them and found out more about them it was clear that they had enjoyed dance and movement and music. One participant was particularly clear that she couldn't dance but she turned out to have great ability to keep time with music and hear rhythm.

The consent process

We had a clearly laid out and approved consent process which we were largely successful in using. We did have to involve some of the care staff in consent interviews where users had no family carer available and some of our assumptions about using an ongoing consent process were challenged. Having thought about having a checking process each session we found in reality that this would have interrupted the flow of the session. We developed a more fluid way of reminding the group of why we were there and checking that they were still comfortable with that.

Who participates

Selecting the group to take part was difficult and the issue of exclusion came up. Fortunately selecting a specific day gave us a limited initial group to approach. There were some in this group who were excluded in consultation with the care staff due to the level of their dementia and/or physical mobility. The day centre users not

involved in the dance sessions received individual attention from the other staff whilst the sessions were running. We did exclude two users who clearly showed an interest in joining the group after the sessions had started because we had been advised that they were imminently being moved into residential care. This was delayed and as a result we included one of them in the sessions part way through. Again this provided us with reflections that we would use in a future project as to how to deal with selection. We were fortunate overall in that we were able to include everyone who had expressed a definite interest. This would have been harder to deal with if we had been working in a day centre with many more attendees.

Being responsible and consistent

On the third week there were staff shortages at the day centre and the research team got involved in the initial meeting and greeting of all day centre attendees to help out. This led to us taking our dance group through after tea in the main day centre which was different to how we usually did things. Whilst the group did not appear to mind, a couple were late and were a bit rushed coming into the dance room. Overall the session was fine, but the group was quieter than normal and seemed to lose concentration quicker.

We reflected after the session on the change of roles and routine and the fact that to help out we had acted into the roles of the day centre staff. This clearly impacted on our group who whilst generally still happy and engaged were definitely quieter and some exhibited anxiety behaviour. Our reflection on this led us to an understanding of the need to be consistent in our relationships with people with dementia and that if we inadvertently show our anxiety to them, or change their routine we can make them feel unsafe. They may not voice it but, they will show it in their withdrawal or their apparent lack of engagement or interest.

Finding the right balance of research tools between observation and feedback

It was clear that the role of observation and visual methodologies was far more important than we had the resources for in this pilot. It was also clear that individual feedback interviews with the participants were not always possible and may have generated a feeling of anxiety in some. The observation and reflection diaries kept by the researcher supported by the dance artist's input became the central evidence gathered of the session themselves. With more time and preparation we would have liked to have designed a different methodology for the staff to use for feedback after the sessions and for use in the feedback sessions with the participants. Both Dementia Care Mapping techniques and visual feedback mechanisms like Talking Mats will be explored for any future project. We would also have liked to have been able to use filming and visual mechanisms to record not just the impact, but the experience of the sessions to be able to capture something of the moments we saw and to share them with the participants, their carers and the staff.

4.4.2 Personal

Unfamiliar landscapes and going walkabout

One of the most striking personal challenges in working with people with dementia is that of feeling in an unfamiliar landscape and having to understand that previously learnt ways of working or researching are not going to make sense. The ordering of things is different and the work is with emotional and physical memory rather than linear or chronological memory. In a person with dementia it can seem that the psyche 'goes walkabout' (Montani 1994, 'quand la psyche s'égaré', literally 'when the psyche strays'). It is almost like the person is periodically coming back into focus or as if they are passing a window and you catch a glimpse of them. In order to work effectively with them you need to be able to make what sometimes seem like disjointed shifts to follow where they are rather than expecting them to focus to where you are.

Being present, open and aware

We were also challenged to see the importance of time and how it is defined for them and for us as researchers and practitioners. When you forget about the forgetting you start to work differently and 'do you remember?' becomes a useless thing to say. We have to be there and present in the moment because to some great extent that is all they have and we have to work within 'their' time not 'ours'. The meeting and the communication in that moment does make an impact and is stored somewhere as the person will recall us again and have some understanding that they shared something with us even if they cannot recall who we are or what we did together.

Boundaries and caring

For a researcher boundaries are always seen as very important to ensure the robustness of the research and good ethical practice. Working with people with dementia challenges some of those boundaries as so much of the communication is based on emotion and direct engagement and physical contact is also important. Whilst being very clear about issues of consent and risk it is also important to recognise that we may well be touched both physically and emotionally in our interactions with people with dementia. This can be surprising and challenging.

When your hand is taken as you are walking, or if supporting someone walking or standing by holding an arm calms them, you realise that this contact is part of how you are communicating and it is understood. When you witness expressions of emotion and personality from memories triggered it can move you to tears and it can be difficult to maintain the separateness needed to observe. It is hard not to be moved to great sadness by the destructive nature of the disease and what it takes away from people. Even in a short space of time we got to know a lot about this group of people and it was hard to leave them knowing that whilst we would remember what we had shared that they might not if we were to meet again.

Risk and responsibility

We were reminded at different stages of the pilot of the tendency to feel very responsible for this group of participants and were conscious that inadvertent changes to routine or allowing ourselves to show stress or concern could result in an impact on them. They might not voice it, but they would show it through their withdrawal or their apparent lack of engagement or interest.

4.5 The view from others

4.5.1 Participants

As explained in the data collection section trying to do individual interviews with the participants was not really possible due to lack of memory or anxiety about being asked about the sessions they could not remember. In response to this and the fact that the group were generally together, the researcher adopted a more relaxed and inclusive way of seeking feedback from the group loosely working with interview topics but having a conversation rather than an interview. The researcher did try and gather data about how people had felt during and after the sessions, what they thought of props and what they remembered about dance in their lives. Also what they felt about the different parts of the session and whether they felt they had got to know anyone better as a result of being in the group with them.

The participants were talked to twice; once after the third session and once after the final session. In total seven of the group were talked to each time of whom six were talked to at both sessions. After the third session only four of those whose carers were also being interviewed were talked to as one was away, but after the final session all those whose carers were also being interviewed were talked to. The others were included either because they were interested and wanted to tell the researcher what they thought, or because they were sitting with the others and joined in. Overall talking to more of the group was good as it gave a variety of feedback.

Feedback after the third session

All the participants talked to were positive about the sessions describing them as 'enjoyable'. When asked how the sessions made them feel a couple of the participants said the session made them 'feel good'.

A couple of the group were more able to remember the session and to understand that the researcher was looking for feedback. Both were less sure about the reminiscence part of the session and despite being 'nosy' about the prompts neither felt really sure what we were looking for from them. Both these participants and one of the others clearly enjoyed the movement part of the sessions best and told the researcher about the kind and variety of movement they had done. One of them had been an ice skater and talked about balance and finding movement quite easy. One had been a strong swimmer and her movement often reflected this. The other said she would be happy to have more movement as she 'loves exercise'.

Of the others, none could remember the content of the sessions well, but knew they had enjoyed them and liked meeting the people there. Three of them were particularly responsive to music and indicated this with arm movements and singing when the researcher asked about the sessions.

Feedback after the final session

After the final session the feedback was a bit more substantial in part probably due to the familiarity individual participants now had with the researcher. Again the researcher asked how people had felt during and after the sessions, what they thought of props and what they remembered about dance in their lives. She also asked what they felt about the different parts of the session and whether they felt they had got to know anyone better as a result of being in the group with them.

Again all participants expressed enjoyment at the sessions saying they had been 'fun' and 'energetic' and that they had made them 'feel better' and 'not tired'.

Also they all talked about enjoying the movement and the music. One participant who had actually got to his feet and done some dancing in one of the sessions said he would have liked to have been up on his feet more. Another participant talked about the increased movement and said 'it gives you a buzz'. The participant who had talked about loving exercise returned again to the subject and said 'exercise is what we need, ordinary day to day is not enough'. This participant had started the session with a broken wrist and not using one arm, but had found some of the movements useful to help her with her recovery. This participant had also been keen on the breathing and relaxation at the end of the session.

Again two of those talked to had recollection of the content of the sessions, however two of the others also recollected that they had been in the session with the researcher but not exactly when it had been although one thought it had been on a Monday (which it was).

What was interesting in this final feedback was that the two participants who had most recollection were both able to comment on the impact the sessions had had on them. One of the two, a man, had originally been very reserved and not at all sure he wanted to join in. He said at this final feedback stage that he had felt able to be more open 'rather than closed' and 'able to express myself differently'. He also said that he was 'pleased I had been sensible enough to apply to join the group' which indicated that he had awareness of what the sessions had given him. The other, who was the woman mentioned above who loved exercise, had started the first few sessions by asking if observers were allowed in. After a few sessions she no longer asked this and in this final feedback she said that she liked to do new things but didn't have much opportunity and that she was 'lucky to be here' when we did the project. She also very usefully said that it was important to show people first or they 'might think it's new or might make a fool' which to some extent clarified why she had put herself in the position of observer until she was sure she felt ok to join in. Both of these participants were very self aware and neither had wanted to be involved in something that might make them look foolish. Both of these participants also clearly found it interesting to have met both the researcher and the dance artist and asked about the work we did and whether we were doing more of it.

Finally, there was a strong response to music, particularly from the participants who had less recall. Despite limited recall most of them could recall a couple of the regular songs we had used in the group and sang bits of them whilst we were talking.

These final interviews were taking place at the end of the final week of the sessions and there were other day centre users around. As the researcher was finishing the interviews one of the participants had been singing and spontaneously some of the others not from the dance group started singing as well. There were a few very good singers including two from the dance group and it seemed a very fitting way to conclude the interviews.

4.5.2 Carers

Interviews were planned with the carers of five of the participants. The relationships to the participants were two spouses, two daughters and one niece. In all but one case the participant lived with the carer. In these interviews we looked at whether they had noticed any change in mood, whether the participant talked about the session or shared any memories triggered by the session. We also asked whether they talked about anyone else who was at the sessions, and whether they responded any differently to their carers or shared any of the session with them.

Sadly one of the participants was quite ill at the time of the interviews and the carer was unable to do more than speak briefly on the phone. This carer had not seen any impact of the sessions and felt this was due to the memory problems that the participant had. She did however share what the participant had been like and was sure that they would have enjoyed the sessions. Both the enjoyment the participant had in the sessions and the difficulties the memory problems caused were borne out by the researcher observations.

Of the other four interviews in two cases the carers could offer little in response to the questions, although in both cases they were sure that the participant enjoyed the sessions and they could see no adverse effects. In both cases the carers fed back how much both participants enjoyed interacting with people and both had been interested in dance and music. One of the carers commented 'she doesn't remember but I know she would enjoy it because she loves music and being included in a group'. The memory of events happening even a short while before was very limited for both participants. Again, both the limits of the memory and the interest of both of these participants in engaging with people in a group were borne out by the researcher observations.

In the final two interviews there was, however, some feedback that the carers could give about impact. In the first case the participant did not live with their carer but saw them every day. The carer talked to the participant after each session and asked how it went. The participant on all occasions could remember having been in the session that day and had enjoyed it 'it has been fun and it passes the time a bit'. After the first session the participant had complained that they were a bit stiff from the exercise, but did not complain of this again as the sessions progressed. Along with one of the other participants this participant had reported that there were only a

few of them to start with but as the weeks went on more joined in. This was not in fact true as all the group were there from the beginning. It could have been that as the weeks went on the participants became more familiar to each other and therefore more memorable, or for this particular participant it could have been the fact that her friend joined the group half way through. There was no negative feeling about the sessions.

The carer explained that the participant (who was one of the oldest in the group) had always been fit and active and was still physically very active for her age. She shared that there had been one Monday about half way through the sessions when the participant had gone home and done a lot of cleaning and she wondered if the extra energy might have come from doing something more active at the day centre. One thing we noticed in the sessions was the increasing comfort and energy with the movement and in participants' feedback they were generally very positive about doing movement and it making them feel good. This was an interesting point to cross reference and to consider whether the dance movement had increased the confidence the participants had in movement and their energy levels.

In the final interview the carer had been very active in talking to the participant each week after the session and had also told the participant the night before about the interview with the researcher and asked what they had felt about the sessions. The carer explained that the participant always remembered he had been in the session and would show her a couple of the dance movements. She said 'in fact we have quite a laugh about it, he seems so much happier'. She explained that the participant had been a very fit and active man involved in sport at quite a high level. She felt that the dance sessions had really engaged him and he liked the activity. This participant had originally presented as very reserved and not sure whether to join in. The carer said that he had always been very involved and engaged with people, but that the dementia had led to this withdrawal. The participant had commented that he was the only man in the group (which was not the case) but that he didn't feel embarrassed about the sessions and clearly engaged with the dance artist and thought she was very good. As mentioned earlier this participant along with one other had a self awareness about the sessions that they did not want to look foolish.

In terms of response the carer felt that the participant was always happier on a Monday 'oh he does come home so different, sits over there....yes I think he's happier definitely I do notice a difference'. When asked if there had been any difference in the participant's response to memories, the carer mentioned a particular Monday when they had talked about a time when they had used to go dancing before he went back from leave during the war. When asked which week this was the carer remembered it as the second week and this cross referenced for this participant with a particularly strong memory of his wife in the dance session that week which had been carried back into his conversation with her that evening. When asked if the participant was more tired on Mondays after the dance session the carer replied 'Oh no, not really, more alive more like my old George' (name changed). The sense of this participant becoming more engaged and progressively sharing more of himself was also borne out by researcher and dance artist observations from the sessions.

In the interviews with carers there was a lot of learning for the project. In at least two cases the carers had asked the interviewer what the participant was like in the sessions and they were clearly seeking an insight into how the person was in other environments and when they were enjoying themselves. This posed some ethical problems for the researcher because of the confidentiality of the sessions. As already mentioned in the section on data gathering, it became apparent that it was more appropriate in this pilot for the researcher to interview the participants because of familiarity and the relationship built up in the sessions. This was not necessarily the case for the carers and it might have been more robust for the carer interviews to have been done by another member of the team. What the researcher was able to do was to make the connections between the sessions and the interviews with both participants and carers to develop a more vivid picture of the participant to confirm some of the glimpses seen in the sessions.

Talking through these issues within the team it was clear that this was something we needed to think through differently for the next stage of the research. We recognised that it might be better to do some joint sessions with participants and their carers and then to involve the carers more specifically in following up outside the sessions. This might show us something about the communication that would be more useful than just asking whether they had noticed any impact when the questions we had designed were largely answered negatively. As already mentioned in the section on process we were also very aware that given the time and resources that there were additional tools that we could use, like care mapping and film/video, that would give additional feedback. In particular film/video would enable a sharing of the experiences in the group with participants and their carers together.

4.5.3 Staff

Formal feedback from staff was sought in two ways: through the use of a prompt sheet that staff carers could complete with any observations they had of impact of the sessions on individuals, and the staff journal sheets to be completed by key staff each week to record reflections on the impact on individuals, staff and the organisation. The prompt sheet proved somewhat unsuccessful largely because the most appropriate member of staff to complete them who had been in the sessions was too busy. In the event, only two forms were completed, one for each of the first two weeks. In both cases they recorded that the participants had been happy and calm after the session and had both said they would look forward to coming again.

As far as the staff journal sheets only one member of staff was able to find time to complete them. Other sources of feedback included conversations between the researcher and the dance artist with both the day and residential centre staff and management and feedback from staff involved in the sessions during the debrief time.

Overall the staff feedback fell into four areas:

Impact on participants

Staff had noted when participants had said they were looking forward to the sessions or asking when they were happening again. They also noted that participants

became progressively more familiar with the sessions, joining them more quickly and associating Monday mornings with the sessions. On a couple of occasions staff had noted that participants were tired after the sessions, but when asked had been very positive about going next time. They felt that the consistency and reliability of the sessions happening on the same day and the same time throughout the period of the project had been important and appreciated by those who took part as it helped them to focus when the day came round. Overall staff had felt the sessions had been very beneficial to those day centre users who had participated in them and were not aware of anyone not wanting to continue to come. Managers and staff felt that the sessions were beneficial to the participants and also felt encouraged and motivated to consider organising more similar activities for users. Staff noted that two of the small friendship group were spending more time together by the end of the sessions.

Impact on staff involved in the sessions

There was one key member of staff who attended the sessions regularly, although two others attended one session each. This member of staff was involved in the debrief after each session and was able to bring information about users that helped the researcher and the dance artist to confirm and understand their observations and things that had happened during the session. For the staff member the opportunity to be observing rather than being in charge of running the sessions had been very positive. Whilst she didn't feel she saw the participants differently she owned that she felt she saw more of how they interacted, their humour and personality and the different bits of them and what they could do. The opportunity to sit and watch without being responsible was not something staff often had.

Managers felt that the impact on staff was beneficial and that the staff directly involved seemed very motivated by the project. Managers would have liked more staff to have had a chance to join the sessions as a training opportunity, but recognised that the consistency of one regular member of staff support had been important to the research aspect of the project.

Impact on staff not directly involved in the sessions

Not all the staff were as positive about the impact of the sessions on individuals or on the working environment and initially found the organisation and focus around the Monday sessions a bit disruptive. Despite some negativity staff were personally very supportive of the research team. One positive impact that these staff and the managers did see was for the users who were not part of the dance group and in some cases needed more attention than they could usually be given: 'service users not involved have benefitted from an increased amount of individual quality time with staff and more individual activities'. The managers felt that by the end of the project there was a 'gradual increased understanding of the relevance and benefit of the sessions'. Managers also commented that it was 'benefitting all staff to see an activity being done well and being enjoyed by service users'.

Impact on the overall atmosphere and operation of the organisation as a whole

With such a short pilot it was difficult to see a lot of impact on the overall atmosphere and operation of the day centre. One staff comment, however, did highlight that as

the sessions progressed the participants would come back into the day centre and talk more about the session they had just completed and seemed more motivated.

The research team was aware of some organisational challenges during the period that the project ran as the staff team was small and very busy and the service was undergoing a consultation on the level of future provision. The research team had much more success getting feedback through informal conversations and involvement with staff than through formal written methods. There will be a variety of reasons for this to do with staff resources, levels of user need and the difficulty of supporting different and intensive ways of working with users with dementia. It was certainly the case that, despite some initial resistance from a few staff to seeing the project as useful or valuable, as a group they supported the opportunity for the users to take part and encouraged them. The staff team also made it practically possible for the project to take place and helped with organisation where they could.

The research team has reflected on the feedback methods used and would consider in a longer project using different mechanisms to seek feedback or seek to access more staff time specifically for the purpose so that it did not conflict with their responsibilities in the day to day work with users.

5. Conclusions

This was a small pilot study which aimed to add to the body of knowledge on dance movement work with people with dementia and to research techniques and methodologies. We considered the impact of dance movement work on people with dementia and explored the role of this kind of work in maintaining and developing relationships between people with dementia and between them and those who care for and support them. The pilot was an opportunity to consider the techniques we might use, reflect on their effectiveness and consider other options for a larger project.

Despite being a small pilot study we felt there was significant learning within three areas; the methodologies and process used, the impact on the participants and the collaborations necessary to work successfully with people with dementia. The pilot also developed the knowledge and understanding of the research team and refined their thinking on how to structure future projects.

Methodology and process

The design of the methodology was essentially good. It was limited in two of the feedback mechanisms used; for the participants and the day centre care staff.

The feedback mechanism for the participants could have been helped by using a visual tool like Talking Mats (www.talkingmats.com), for example, to help them to express their views on the sessions. To enable the care staff to feedback on impact the use of an observation methodology like Dementia Care Mapping (www.brad.ac.uk/health/dementia/DementiaCareMapping/), could have been useful providing that staff time could have been made available. Given the resources in a

larger study the use of film/video would also have made a difference and offered a way of capturing both impact and insights for the benefit of participants, staff and carers. In a future project we would also like to explore the potential for the use of embodied feedback methodologies.

In terms of the process, the findings of the pilot did indicate that the content of the sessions and the way they were run was successful and well received. Attention to how the group came into and left the session was key in developing the participants' familiarity and pleasure with the process. Within the six weeks we were able to see the relationships build when participants were in the group, but with such a short pilot there were but small glimpses of whether any of these relationships continued outside the group. Any future project would offer at least twice as many sessions including more introductory sessions and we would work more closely with family carers to introduce them to our techniques and involve them more in assessing impact both on themselves and the participants.

Impact on participants

The pilot gave some clear indications of positive impacts for the participants as they increasingly became familiar with the group and more comfortable with the movement and expression. We recognised how important a feeling of safety and belonging was to the participants and when those feelings were present how much they were able to relax and over the course of the sessions, feel comfortable with, and increase their capacity for the movement. Over the course of the sessions the participants became more engaged with the researchers and more aware of the others in the group. Working with reminiscence and embodied movement seemed to unlock memories for some participants and gave insights into the people they are and have been. Feedback that could be gathered from the participants indicated that their experience had been both fun and exciting and, for some, calming. Feedback from staff and carers also indicated that as the sessions progressed participants appeared to look forward to taking part more. Staff also fed back that if the project ran again there would be great value in it being over more weeks.

Collaborations necessary to work successfully with people with dementia.

The findings of the pilot clearly bore out the importance of the collaboration with the day centre staff without which the pilot would not have been possible or shown such good results. This collaboration started before, but developed during the course of the pilot and enabled the research team to work in an appropriate space and have undisturbed time with the group. The presence of a member of care staff in all sessions supported both the researchers and the participants and increased the feeling of safety and familiarity of the participants whilst also providing the staff with an insight into the work being done. Recognising the boundaries for both the research staff and the practice staff the collaboration enabled issues of consent and confidentiality to be handled well and feedback to be given on both sides.

A secondary outcome for this pilot was to begin to develop an understanding of the challenges and obstacles for care workers in using creative ways of working and being with people with dementia in their everyday practice. The feedback from staff indicated their interest in how creative work could benefit their users although the

researchers were only too aware that there were limitations on the time that staff could offer to support such interventions.

Central to our reasons for doing this pilot was our interest in developing a way of working with dance movement with people with dementia and having an opportunity to consider the impact. This we were able to do and the findings even from a small pilot have given us much to think about and have helped us to refine and develop our techniques and methodologies and to feel confident in seeking funding to develop our work further.

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Appendix 2 : Project Documentation



University of Brighton



Participant information sheet

Dance and Dementia Project

“What does dance mean to you”.

We are a group of academics, dance artists and practitioners who are interested in doing research about dance and dementia and would like to **invite you** to be part of our research project. We hope our project will help us to understand better how people with dementia respond to dance and whether it helps them develop and maintain relationships with those who care for or support them.

The project will involve six weekly dance movement sessions at Ireland Lodge Day Centre on a day that you are normally there. Each session will be about an hour and there will be a mixture of seated and standing movement depending on what you can manage. The sessions will be run by Anne Colvin, an experienced dance artist and will be supported by staff at Ireland Lodge. Naomi Smith, a researcher from the University of Brighton will also be involved. The sessions do not require you to have any previous experience of dancing and you can take part as little or as much as you like.

We may also ask some of you if you will talk to us in an individual interview after the sessions to tell us what your experience has been. We will also ask the person who looks after you at home talk to us as well.

We will be writing about our project and what we find out and will produce a report. You will not be mentioned by name in the report but we may ask your permission to quote something you have said.

The people involved will be **Anne Colvin, Naomi Smith, Diane Waller and Marnie Naylor** and you will meet them during the project.

For more information about the project you can talk to Naomi Smith on 01273 644530 or the staff at Ireland Lodge.



University of Brighton



Dance and Dementia Project

Participant consent form

- ◆ I agree to take part in this research about dance and dementia.
- ◆ The researcher has explained to my satisfaction the purpose of the study and my role within it.
- ◆ I have read the information sheet and I understand what taking part will involve.
- ◆ I understand that my contributions to the sessions will be recorded and used as research.
- ◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.
- ◆ I understand that I am free to withdraw from the sessions at any time.

Name (please print).....

Signed.....

Date.....

Name of Researcher

.....

Date.....

SSPARC, Mayfield House, University of Brighton, Falmer, Brighton BN1 9PH



University of Brighton



Dance and Dementia Project

Participant interview topics

- How they felt during and immediately after the session
- Whether they enjoyed some parts more than others
- How they responded to the props etc
- What they remembered about their life and dance
- Whether they talked to anyone in the group about the sessions afterwards
- Whether they remembered any of the movements
- How they felt afterwards calm/agitated/happy/sad
- Whether they would take part again



University of Brighton



Carer information sheet

Dear Carer

Dance and Dementia Project

The University of Brighton, the University of Chichester and Brighton & Hove City Council are working together on a small pilot research project on dance and dementia. The aim of the project is to get a better understanding of how people with dementia respond to dance and whether it helps them develop and maintain relationships with those who care for or support them.

We are contacting you because the person you care for may be approached to take part in our project which will take the form a series of six dance movement sessions based around the theme "*What does dance means to you*". The sessions will take place at Ireland Lodge on a day that they are normally there and will run weekly for six weeks. They will last for about an hour and there will be a mixture of seated and standing movement depending on what they can manage. The sessions will be run by an experienced dance artist who has worked with other groups in this way and will be supported by a member of Ireland Lodge staff and a researcher from the University of Brighton. The sessions do not require any previous experience of dancing and we would stress that they can withdraw or sit aside at any point if they feel uncomfortable.

We would like to ask you if you would agree to two things.

- Firstly to be part of our discussion with the person you care for to ensure that they are fully able to consent to being involved in the project.
- Secondly to be involved in a short interview with one of the research team who will ask you some questions about what impact you think the dance sessions have had on the person you care for.

Some of the things we will be interested in finding out will be if you have noticed changes of mood, whether the person you care for has talked about the sessions and the others who were in them and whether they have responded any differently to you or others as a result of the sessions. We will also be talking to some of the participants individually and to the staff at Ireland Lodge and the Day Centre who work with them.

We can visit you at home to interview you or arrange to talk to you at another location if you prefer. We can cover limited travel costs but would hope to be able to talk to you perhaps at a time when the person you care for is at the Day Centre.

After we have collected people's experiences and feedback we will produce a report that we can use to gain a better understanding about using dance to work with people with dementia. There will not be anything in the report that would identify you personally, although with your permission we may ask to reproduce something you have said as an example. The information we collect will be stored securely according to the University's data protection guidelines and the research project has received approval from the University Ethics Committee.

The main researcher on this project is Naomi Smith. If you would like to talk to Naomi you can call her on 01273 644530. If you would like to speak to someone who is independent of the study you can contact Phil Haynes who is the Head of the School of Applied Social Science at the University of Brighton on 01273 643465.

These details have been sent to you by Ireland Lodge. If you would be happy to take part in the research please complete the following and return it to Naomi Smith, SSPARC, Room 229, Mayfield House, University of Brighton, Falmer BN1 9PH in the stamped addressed envelope provided.

Name

.....

Address

.....
.....
.....
.....

Phone

Name of the person you care for who attends the day centre or who lives at Ireland Lodge

.....
.....



University of Brighton



Dance and Dementia Project

Carer consent form

- ◆ I agree to take part in this research about dance and dementia.
- ◆ The researcher has explained to my satisfaction the purpose of the study and my role within it.
- ◆ I have read the information sheet and I understand what the interview will involve.
- ◆ I am aware that I will be asked to talk about my own experiences and the person I care for. This may mean talking about things of a personal nature.
- ◆ I understand that I am free to stop the interview at any time.
- ◆ I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else. But if this information raises serious concerns about the safety and well-being of anyone the researcher may need to contact somebody who can help.
- ◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.
- ◆ I agree to the interview being recorded.

Name (please print).....

Signed.....

Date.....

Name of Researcher

.....

Date.....

SSPARC, Mayfield House, University of Brighton, Falmer, Brighton BN1 9PH



University of Brighton



Dance and Dementia Project

Carer interview topics

- Did you notice any change of mood happy, sad, calm, agitated?
- Did they talk about the dance session?
- Did the session trigger other memories and did they share that reminiscence with you?
- Did they talk about anyone else who was there?
- Did they respond any differently to you i.e. closer or want to show you some of the dance moves or do them with you?
- Did they want to come to the sessions next time?
- Did you notice any other impacts?



University of Brighton



Staff information sheet

Dear staff member

Dance and Dementia Project

The University of Brighton, the University of Chichester and Brighton & Hove City Council are working together on a small pilot research study on dance and dementia. The aim of the study is to get a better understanding of how people with dementia respond to dance and whether it helps them develop and maintain relationships with those who care for or support them.

We are contacting you because you work either at Ireland Lodge or with the day centre clients who attend there. For our research we will be working with a group of the day centre users and some of the permanent residents, a group of 8-10 people in all. The study will involve a series of six dance movement sessions based around the theme "*What does dance means to you*". The sessions will take place at Ireland Lodge on a day that day centre users are normally there and will be timed to fit in with the usual routine. They will run weekly on the same day and at the same time for six weeks. The sessions will last for about an hour and there will be a mixture of seated and standing movement depending on what participants can manage. They will be run by an experienced dance artist who has worked with other groups in this way and will be supported by a member of Ireland Lodge staff and a researcher from the University of Brighton. The sessions do not require any previous experience of dancing and we would stress that participants can withdraw or sit aside at any point if they feel uncomfortable.

We would like to ask you if you would agree to help us by filling in a prompt sheet for each of the participants you are working with after each session. This prompt sheet will be short and will help us to gather information about impact on mood and ongoing engagement with the sessions or with other participants. We will also be talking to some of the participants individually and to some of their family carers.

After we have all the experiences and feedback we will produce a report that we can use to gain a better understanding about using dance to work with people with dementia. There will not be anything in the report that would identify you personally, although with your permission we may ask to reproduce something you have said as an example. The information we collect will be stored securely according to the University's data protection guidelines and the research project has received approval from the University Ethics Committee.

The main researcher on this project is Naomi Smith. If you would like to talk to Naomi you can call her on 01273 644530. If you would like to speak to someone who is independent of the study you can contact Phil Haynes who is the Head of the School of Applied Social Science at the University of Brighton on 01273 643465.



University of Brighton



Dance and Dementia Project

Staff consent form

- ◆ I agree to take part in this research about dance and dementia.
- ◆ The researcher has explained to my satisfaction the purpose of the study and my role within it.
- ◆ I have read the information sheet and I understand what my input will involve.
- ◆ I am aware that I will be asked to comment on the impact of the dance sessions on the residents or day centre users that I am involved in caring for.
- ◆ I understand that I am free to withdraw from the research at any time.
- ◆ I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else. But if this information raises serious concerns about the safety and well-being of anyone the researcher may need to contact somebody who can help.
- ◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.

Name (please print).....

Signed.....

Date.....

Name of Researcher

.....

Date.....

SSPARC, Mayfield House, University of Brighton, Falmer, Brighton BN1 9PH



University of Brighton



Dance and Dementia Project

Staff carer prompt sheet

Participants name.....

Staff carer.....

Date of your observation.....

Date of dance session.....

- What was the participant's mood after the session and later?
e.g. calm/agitated/happy/sad/other

- Was there any change in their engagement with others who had been at the session or those who hadn't?

- Was their engagement with you any different? Did they share anything from the session with you?

- Did the session generate any other memories for them either positive or negative and did they share that reminiscence with you?

- Did they have any ongoing interest in the sessions for example expressing looking forward to the next one?

- Did you notice any other impact?



University of Brighton



Dance and Dementia Project

Staff journal sheet

Week

Date completed.....

Name.....

- What impact have you seen for those participating in the sessions?
- What impact has being part of the project had on you?
- Are you aware of any impact on other staff not directly involved in the project?
- Has there been any impact on the overall atmosphere and operation of the organisation as a whole?
- Have you noticed any other impact?

Guidance Notes

With this process we are looking at any overall and developing impact of the project as it progresses both positive and negative. Please record something during the week after each session. If you have nothing to report or haven't had time please record that on the week's sheet. In this pilot we are also trying out different methods of data collection so by doing this you will also be contributing to the development of our methodology.

These reflections will be treated as confidential data and will only be accessed by members of the research team. As part of the overall project we will report back on any perceived impact of the project beyond the participants themselves but will only use your observations anonymously as agreed in the consent process. If any reflections are of concern to the research team we will come back to you to discuss them before we use the data any further.