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The Arts for Dementia in North America; Learning from Practice



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¹ Photo of the 'At this Age' group run by Dr Dalia Gottlieb-Tanaka, Chair of the Society for the Arts in Dementia Care

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Introduction

Having spent the last eight years working in ageing policy and research² I am aware of the need for more effective, person-centered approaches to dementia care. While the most basic needs of those living with dementia are often met, policy makers and those involved in service delivery, need to consider how people with dementia can be better supported to live fulfilling and dignified lives.

Dementia is a growing issue. According to the Alzheimer's Society there are currently around 850,000 people living with dementia in the UK. It is predicted that this figure will increase to 1 million by 2025³. Pharmaceutical research is making slow progress, meaning that a cure for dementia is unlikely to happen in the near future⁴, while the frequent use of drugs, particularly antipsychotic drugs, to treat the behavioural and psychological (BPSD) symptoms of dementia (e.g. aggression and agitation), has been recognised as a cause for concern. These medications can cause side effects such as Parkinsonism and drowsiness which can lead to falls and other adverse events⁵. They also possibly hasten cognitive decline. People with severe dementia are found to be particularly sensitive to these effects and their quality of life can be significantly reduced by the commencement of these medications. The testing and promotion of effective non-pharmacological interventions is therefore both necessary and desirable.

Use of the arts as a non-pharmacological intervention for dementia has grown in recent years. Before embarking on my Fellowship to North America, while I was aware of the existence of some arts based dementia programs in the UK, I was unaware of the huge potential that these programs held. My ignorance in this area can be explained in part by my own assumptions. Prior to my Fellowship I subscribed to the commonly held view that people could be divided into non- artists and artists and that I, unfortunately, was not one of the gifted few. Whilst I have always appreciated the arts, I saw no point in developing my own artistic expression. This led me to believe that artistic approaches to dementia care

² I have worked as Research Manager and Policy Officer for Age NI

³ <https://www.alzheimers.org.uk/statistics>

⁴ I'm Still Here; a breakthrough approach to understanding someone living with Alzheimer's. Dr John Ziesel.

⁵ Overshott, R. 'Non-pharmacological Treatment of Severe Dementia: An Overview', in A Burns & B Winblad (eds), *Severe Dementia*, pp. 163-175; New York, NY, US: John Wiley & Sons Ltd; 2006.

would be most relevant to those individuals who had cultivated their artistic expression prior to diagnosis. Since applying to the Winston Churchill Memorial Trust, I have been forced to revisit my opinions. My previously held belief, that (with the exception of the gifted minority), artistic expression had no real benefit beyond being a pleasant pastime or hobby, has been challenged. I am now convinced of the unique healing power of the arts, particularly for those living with dementia.

During my Fellowship I witnessed the huge potential of the creative arts to engage the emotional, social, and spiritual needs of those living with dementia; needs that can often go unaddressed in dementia care. The arts ‘tap into’ many different areas of the brain, (unlike language for instance), which means that the ability to appreciate and even participate in the arts is often less compromised after diagnosis than other activities. Music, art, drama, dance, and poetry can create a new space for communication, expression and human connection. As Dr John Ziesel, an expert in dementia care describes, *‘the arts can provide meaning in what many experience as an increasingly meaningless life.’*⁶

From the outset of my Fellowship I wanted to understand not only the value of arts based programmes, but also the components of various arts based interventions, or the features of these programmes that make them successful. The ultimate aim of the Fellowship was not only to communicate the potential of these programmes, but also to promote ‘best practice’ for those wishing to undertake similar programs.

In seeking to answer these questions, I set out on a six week journey across North America visiting a wide range of arts based programmes. During this time I observed programmes, spoke to older people taking part, interviewed arts practitioners, and explored the existing research evidence base on this topic. Findings from interviews, observations and research papers are outlined below.

⁶ I’m Still Here; a breakthrough approach to understanding someone living with Alzheimer’s. Dr John Ziesel.

Evidence of the value of the arts for healthy ageing

The arts and ageing field has been evolving slowly but steadily since the late 1990s. Since this time there has been a small, but growing body of evidence to show that active participation in the arts can be particularly beneficial to older people.

Dr Gene Cohen was considered to be a pioneer in this area. An American Psychiatrist, Dr Cohen was an advocate of creative pursuits in later life, championing the idea that all people have untapped stores of creativity. His theories were based on the understanding that the brain can continue to create new cells at any stage, so long as it is engaged in new and challenging activities. Dr Cohen not only believed that professionally conducted, cultural arts programs would lead to increased levels of creativity, but that they would also result in improved health outcomes and a reduction in disease. His 2006 study, published in the *Gerontologist* found evidence to support this view. Older participants engaged in a weekly chorale group reported a higher overall rating of physical health, fewer doctor visits, less medication use, fewer instances of falls, and fewer health problems than a comparison group⁷.

In their 2013 review of the scientific literature on arts based interventions, Noice and Noice found evidence that older people who actively participated in dance, expressive writing, music (singing and instrumental), theatre arts, and visual arts showed improvements in memory, creativity, problem solving, everyday competence, reaction time, balance/gait, and quality of life⁸. In their own study of the impact of the theatre arts for cognitive health, Noice and Noice found that those individuals randomly assigned to acting classes significantly outperformed both those undertaking singing instruction and those assigned to a control group on almost all cognitive measures⁹. What is interesting about this study is that participants were randomly assigned to each of the groups (control, singing, and theatre), so that, in principle, effects should not be explained by any bias in those taking part in the theatre group. It also raises the possibility that some arts interventions may be more effective than others.

⁷ Cohen, G. D., Perlstein, S., Chapline, J., Kelly, J., Firth, K. M., & Simmens, S., (2006). *The Impact of Professionally Conducted Cultural Programs on the Physical Health, Mental Health, and Social Functioning of Older Adults*. *The Gerontologist*, 46 (6): 726-734.

⁸ Noice, T., Noice, H., & Kramer, A. F., (2014). *Participatory arts for older adults: A review of the benefits and challenges*. *The Gerontologist*, 54(5): 741-753.

⁹ Noice, T., Noice, H., & Kramer, A. F., (2015). *Theatre arts for improving cognitive and affective health*. *Activities, Adaptation & Aging*, 39(1): 19-31

Learning from Practice

Arts based programs seem to play a valuable role in healthy ageing. The improvements in cognitive capacity demonstrated in the studies above suggest that arts participation may even be effective in preventing or delaying the onset of dementia. However this Fellowship was focused specifically on those currently living with dementia. I wanted to understand how and why the arts are effective for dementia. I wanted to gain a deeper insight into the features of the various art programmes that make them particularly suitable for this population. In order to do this I gathered the views of arts practitioners, administrators and academics, and carried out a series of observations in order to determine what 'good practice' looks like. I also consulted the research literature and include references to academic studies where these were available.

Rather than provide a chronological list of each individual I interviewed and each programme I visited, I have organised this section according to the type of arts based program. A chronological list of my visits can be found in appendix 1.

Museum based programmes

New York is one of the world's greatest hubs of culture and arts, and this is reflected in the amount of activities available for those living with dementia. The Connect2culture program, run by the Alzheimer's Association, is a cultural arts program that supports museums and other cultural venues around New York in developing ongoing programs for people with dementia and their caregivers. With the support of the Connect2culture program, a considerable number of museums in New York now offer these programs.

One of the first museums to develop such a program was the Museum of Modern Art, or MoMA. Developed in 2006, MoMA's offerings for individuals with dementia and their care partners include by-request programs for groups coming from care organizations, such as assisted-living facilities, nursing homes, and adult-care centers. These programs incorporate lively discussions of artworks as well as art-making components, and take place at the Museum or off-site. The Museum also offers Meet Me at MoMA, a monthly interactive art tour and gallery-discussion program for individuals with dementia and their family or professional care partners. MoMA has developed a comprehensive range of materials that are free to the public. They have been developed to support museums that wish to develop their own programs and include guides outlining the processes for creating educational

experiences within museums, care-facilities, and even in the home:

<https://www.moma.org/meetme/resources/index>

During my time in New York I visited with the Connect2culture program, the Brooklyn Museum, the Sights and Scents Program at the Cloisters Museum and Gardens, and the Jewish Museum. Museum programmes typically follow a similar format. Educators who have been specially trained in dementia spend around one hour facilitating conversations with people living with dementia and their care partners. Discussions tend to focus on a small number of art works that speak to the same theme, and each artwork is viewed in turn. For example, during my visit to the Brooklyn Museum, the theme for the tour was summer holidays, and all the paintings related to this theme in some way. Five paintings were viewed in total, with around ten minutes spent at each painting. Depending on numbers registered, two small groups are typically guided separately through a tour as smaller groups are preferred. Tours usually run once a month and often include an art making session either at the end of the tour or at the next session. For example at the Jewish Museum, participants alternate sessions between art appreciation and art making. During art making sessions they will base their creations on what they viewed at the previous session. Participants are given a brief tour of the artwork they had viewed to act as a reminder at the beginning of the session.

Case Study of a museum based program

People with dementia and their care partners gathered in the museum lobby waiting for the art tour to begin at the Brooklyn Museum. Most people in the group were engaged in conversation, but one particular gentleman appeared to be distracted and anxious. He repeatedly asked members of the group where he was, why he was there, and who else was coming. He continued to ask these questions until the tour began. Once the tour started, the change in the gentleman was remarkable. His anxiety immediately appeared to subside. He became calm, energised and focused, and verbally expressed his enjoyment of the different artworks throughout the tour. While his observations were very basic (he mostly pointed out the shapes and colours that he could identify, rather than discussing the theme), the art seemed to offer a source of joy and comfort. It seemed like the art triggered these emotions.

During my time in Washington DC, I spent some time at IONA Senior Services, a non-profit organisation that provides a range of services to older people, many with dementia. It was here I learned about a program offered at the Philips Collection, a modern art museum that

has partnered with IONA. The Phillips and Iona program encourages individuals with memory impairment to connect with each other through conversations in the Phillips galleries. Using the museum's artwork as visual stimuli, individuals engage in dialogue with museum educators. The program continues back at Iona day center where individuals engage in art making that reflects the themes covered at the Phillips. Themes have covered risk-taking, music, journeys, and home, providing people with dementia an opportunity to express their emotions through the art. Artwork is displayed around IONA for family, staff and visitors to view.

In my conversations with museum educators and administrators I asked what factors needed to be considered in order to develop a successful museum based program for dementia. The responses were broadly similar and are outlined below;-

- Tours should always be conducted when museums are closed to the public to ensure minimal distraction.
- Early afternoon sessions are preferable to morning sessions. Program educators stated that early afternoon sessions are better suited to the rhythms of the person with dementia ie less confusion and anxiety.
- Educators should always introduce themselves and wear a nametag. They should state clearly where they are and the purpose of the day.
- Educators should give all participants a name tag and spend time to introduce themselves personally.
- Museum educators must be trained in dementia in order to facilitate effectively.
- With bigger numbers, there should be more than one educator so that small groups can be run simultaneously. Groups should ideally be kept small (around 6 participants).
- Each session should focus on a theme and 4-6 pieces of artwork should be selected that reflect that theme.
- Discussions should typically focus around asking participants to communicate what they see in the painting, what they think is happening, identifying any emotion in the painting, and how the painting links to their own lives. The process should encourage participants to reflect on and express their thoughts. There is less of a focus on education, and testing questions such as 'who painted this?' should be avoided.

- All participants should receive positive feedback for **any** contribution they make.
- Special training is required to ensure that paintings selected are appropriate for those living with dementia.
- Ideally, paintings and sculptures should be specially selected for tours **by those actually living with dementia**. As part of the planning process for a new program, Dr John Ziesel recommends presenting reproductions of paintings for people with dementia in order that they can select the artworks that will be included in the program. He found that educators are often unable to predict the paintings that will most appeal to those taking part in tours¹⁰. A recent study has shown that art appreciation is associated with the viewer's visual working memory capacity¹¹. As visual memory is known to be affected in dementia, seeing the artworks from the perspectives of those actually living with dementia is important.
- If art making is part of the process, have an end of program event with family and friends to celebrate the art work that has been created.

Evidence to demonstrate the effectiveness of museum based programs for dementia has been limited. One study sought to understand the experience of an eight-week art-gallery-based intervention offered at two different galleries for people with mild to moderate dementia and their carers. Interviews with 24 participants (12 with dementia) post intervention, found greater feelings of social inclusion, enhanced cognitive capacities and improved quality of life.¹²

A second Australian study found that for those with moderate to severe dementia, art-gallery programmes can also be worth-while, again citing the importance of social, cognitive and emotional benefits even if they occur 'only in the moment'.¹³

¹⁰ I'm Still Here; a breakthrough approach to understanding someone living with Alzheimer's. Dr John Ziesel.

¹¹ Sherman, A., Grabowecky, M., & Suzuki, S. (2015). *In the working memory of the beholder: Art appreciation is enhanced when visual complexity is compatible with working memory*. Sherman, Aleksandra. Journal of Experimental Psychology: Human Perception and Performance, 41(4), 898-903

¹² Camic, P. M., Tischler, V., & Pearman, C. H., (2014). *Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers*. Ageing & Mental Health, 18, (2), 161–168

¹³ MacPherson, S., Bird, M., Anderson, K., Davis, Y., & Blair, A. (2009). *An art gallery access programme for people with dementia: 'You do it for the moment'*. Ageing & Mental Health, 13 (5), 744–752.

Verbal expression – storytelling and poetry

The Alzheimer's Poetry Project

During my time in New York, I was fortunate to have spent time with the poet Gary Glazner and his Alzheimer's Poetry Project. Gary founded the Alzheimer's Poetry Project (APP) in 2004 in Santa Fe, New Mexico. Since this time the APP has held sessions at over 100 facilities across America and Europe. The APP has given staff training for over 1,500 health care workers and family members in using poetry with dementia.

Before visiting the Alzheimer's Poetry Project, I was unable to find any research literature that could explain the rationale behind using poetry to engage people living with dementia. My observations of the program and my subsequent conversations with Gary however, revealed that poetry can in fact be a very effective way of engaging people with dementia.

The success of the Alzheimer's Poetry Project is in no doubt due to the methods that Gary has developed. His skills as a poet coupled with a flair for dramatic expression means that Gary brings the poems to life in a highly expressive way. The ability to recognise emotions is usually spared in dementia so that, through dramatic expression, participants can connect with the poem and the poet, without necessarily following all of the language. Gary expressed that the rhythmic nature of poetry, much like music, does in fact make it easier to follow, and easier to repeat. I believe that this rhythmic quality, coupled with its dramatic delivery, overrides the communication barriers that are often experienced in dementia when trying to follow 'normal' language.

In terms of his methods, Gary starts by creating a poetry circle and walking around the circle to shake hands and become acquainted with each participant. A warm up exercise typically ensues. One such warm up was 'pass the smile', where each person seated in the circle smiles at their neighbour and they 'pass' the smile along. Gary then recites a poem to set the theme for the session. The theme at one of the sessions I attended was flying, so Gary chose to start by reciting Edgar Allan Poe's 'The Raven'. After reading the poem, it was recited again, except now participants repeated each line as it was read by Gary. Following this exercise, it was time for the group to create a poem together. As the theme was flying, Gary asked the simple question of where we would fly to if we were birds and why. Each person's response was then skilfully pulled together by Gary to create a group poem which was read at the end of the session.

The approach works so well for a number of reasons. Gary takes time to connect with each person at the beginning of the session and throughout the process. He creates a space where participants can freely express themselves, where their inputs are valued and where all individuals are praised for their contribution. He honours and acknowledges each participant in turn by reading back their segment of the group poem and everyone is impressed by what they have helped create. On reflection, poetry is much like the other arts in that it breaks down the barriers to communication that are typically experienced in dementia. The emotions expressed through the rhythm and the acting out of the poem, can be understood and felt in such a way that they create a connection between the poet and the participants, while the dramatic repetition of poems and the creation of the group poem serve to meet the human needs of social belonging, self expression and mastery.

Finally, there is a lot to be said about Gary's talent as a poet. His ability to think on his feet in the creation of the group poem, while staying true to the voice of each participant, was an impressive skill, highlighting the importance of professional artists and skilled facilitation in this process.

TimeSlips

The concept of TimeSlips started in 1996. At the time Professor Anne Basting (University of Minnesota), who holds a PhD in Theatre Arts, was interested in seeing if improvisation techniques could be helpful for people with dementia. Anne recognised the powerful effects of creative drama for healthy older adults, and was curious to see if these benefits applied to people with dementia.

Anne's initial focus on reminiscence based techniques was proving unsuccessful and she attributed this to issues of memory recall. As dementia progresses to the later stages, access to long term memory wanes and recall becomes problematic. Yet creativity remains. Anne understood that she needed to replace the pressure to remember with the freedom to imagine, which is how the TimeSlips method developed.

TimeSlips is one of the many methods used by a New York based non-profit organisation, Elders Share the Arts (ESTA). I attended a dementia care facility with a TimeSlips certified trainer, Marcia Gilden, from ESTA to observe a session. The methods used in TimeSlips are fairly simple and involve presenting the group with a photo and then facilitating that group to work together in order to create a story based on the image in front of them. One person's input to the story will spark a thought in another, and in this way a story is created. It is, in

essence, a method story telling through improvisation. Crucially, the picture is quirky or unusual in some respect, so that it encourages participants to imagine and be creative. An experienced facilitator is required to guide the session with open questions such as *'what do we think is happening here?'*, *'what will we call them?'*, *'where will we say they are from?'* There are no right or wrong answers. Everyone's input is valued and incorporated into the story. The story is read at a number of points throughout the hour long session in order to remind participants of the story so far, and to acknowledge the effort that has been made by the group.

You can listen to Anne discuss the history of TimeSlips in her TED Talk; *'When Art is the only Medicine'* here: <http://tedxtalks.ted.com/video/When-Art-is-the-Only-Medicine->

Case Study of the storytelling method Timeslips

The dementia care facility I visited in the Bronx catered for people in the mid to late stages of dementia. About ten residents and two members of staff gathered round in a circle to create a story based on the Timeslips method. A black and white photo was produced by the facilitator. The photo was of an older gentleman, pouring a glass of champagne into one of two glasses held by an older lady. His arm was wrapped around her and they were smiling, wearing party hats and looking into each other's eyes.

Looking around the group that were about to create the story, I was a little sceptical that the process would work for everyone present. While most participants seemed able to contribute, some of the group seemed distant and uninterested while two members of the group appeared to be in the later stages dementia.

When the facilitator asked what was happening in the photo, someone started the process by stating the couple were celebrating a wedding anniversary. This sparked another person's imagination who thought that perhaps they had won the lottery. Someone else noted that they looked very old and thought they could be celebrating making it to 100 years old. And so an entire story developed about how and where the couple met (maybe in Ireland, or maybe at school where she fell over and he helped her to her feet), where they had their wedding (back in Ireland); and what they did with all their lottery winnings. All responses were included in the final story. With the freedom to imagine, to be creative and spontaneous, the story that developed was both original and entertaining. More importantly the group enjoyed the process, spirits were high and laughter filled the room. Members of the group that had been quieter to begin with joined in enthusiastically.

What really struck me about the session was that the TimeSlips method seemed to foster a sense of community. Everyone got involved, including staff. The two members of the group who had more advanced symptoms were encouraged and supported by other members of the group. When one of these individuals became distressed, one member of the group noted this and suggested that we should sing for her.

A study published in the American Journal of Alzheimer's Disease and Other Dementias, found that the TimeSlips method of improvisation and storytelling held a number of benefits for residents including increased creativity, improved quality of life and positively altered behaviour¹⁴. As was my experience, the same study also found that it creates a meaningful activity for staff and older participants to experience together, and can nurture relationships in the group. Anne Basting refers to 'group solitary confinement', where nursing home residents are in a room with their peers, yet do not interact with each other, and only interact with staff in regards to their care needs. By working towards a common goal, the TimeSlips method seeks to breakdown these barriers to communication.

The Society for the Arts in Dementia Care

I was very fortunate to sit in on a storytelling session with the 'At this Age' group, run by Dr Dalia Gottlieb- Tanaka from the Society of the Arts in Dementia Care. The group meets regularly to engage in various projects related to the arts. In the session I attended, group members were working on their current project, 'My Mother's Story'. Members had been asked to tell the life story of their mother, from their mother's perspective. I was privileged to hear each participant read aloud the (often emotional) stories they had written over the course of the previous weeks. It is important to note that no one in the group had dementia, yet evidence has suggested that engaging in these types of activities can delay the onset of memory problems. As a group, we also created collages from magazine cuttings about our mothers. The session was fun, and it was clear to see that members of this group have a strong social bond, attending various social activities together outside of the group. Continued social engagement is also known to be an important factor in the prevention of dementia, and this is something Dr Gottlieb- Tanaka is keen to promote, through the arts.

¹⁴ George, D., R., & Houser, W., S., (2014) *I'm a Storyteller! Exploring the Benefits of Timeslips Creative Expression Program at a Nursing Home*. The American Journal of Alzheimer's Disease and other Dementias.

Music and movement

Of all the arts, music has the largest evidence base to demonstrate its efficacy for dementia, with studies generally reporting significant reductions in the Behavioural and Psychological symptoms of dementia that include reductions in agitation, apathy, and wandering behaviours, and increases in attention span¹⁵. More than this however, music appears to tap into the emotions and feelings of the individual, and to restore humanity. In his book, *Musicophilia*, the late Oliver Sacks, a highly regarded professor of neurology and psychiatry, shares his account of the power of music;

*'I have seen deeply demented patients weep or shiver as they listen to music they have never heard before, and I think that they can experience the entire range of feelings the rest of us can, and that dementia is no bar to emotional depth. Music is part of being human. Its' very ubiquity may cause it to be trivialised in daily life. But to those with dementia, the situation is different. Music is no luxury to them, but a necessity, and can have a power beyond anything else to restore them to themselves'*¹⁶.

Oliver Sacks provides numerous case studies showing how music can transcend the cognitive challenges posed by dementia. The effects of music that he witnessed were often longer term and resulted in *'improvements of mood, behaviour, and even cognitive function- which can persist for hours or days.'*

The following case study is taken from *Musicophilia*;

Case study taken from the book *Musicophilia*

The simple intervention (was made) of turning on the classical music channel in front of the couch where her mother-in-law had mostly sat watching TV show for the preceding three years. The mother-in-law, diagnosed with dementia, had kept the house awake at night when the caregivers turned off the TV. Daytimes, she would not get off the couch except for toileting or family meals.

¹⁵ Beard, R., L., (2012) *Art therapies and dementia care: A systematic review*. The International Journal of Social Research and Practice, 11(5), 633-656.

¹⁶ Sacks, Oliver. 2007. *Musicophilia: tales of music and the brain*.

After the channel change she had a profound behavioural change: she had asked to come to breakfast the following morning; and did not want to watch her usual TV fare the next day, and asked for her long neglected embroidery the next afternoon. Over the next six weeks, in addition to communicating with her family and taking more interest in her surroundings, she mostly listened to music. After six weeks, she died peacefully.

People with dementia can greatly benefit from having music integrated into their daily lives. As Oliver Sacks regards music as a necessity for people with dementia, Dan Cohen, founder of Memory and Music, has witnessed the powerful effects of implementing iPod personalised music programs in hundreds of care facilities throughout the U.S and Canada. Something as simple as an iPod appears to dramatically improve quality of life. A clip from the film *Alive Inside* provides a moving example of music's ability to restore personhood and can be seen here;- <https://www.youtube.com/watch?v=5FWn4JB2YLU>

I was able to witness the power of music first hand during my Fellowship. Firstly in Washington DC, when I attended a nursing home with violinist Anthony Hyatt, from Arts for the Aging (a non profit organisation that offers a range of arts programs for older people across the Washington DC area). Anthony preformed a range of well known songs for residents, most of whom appeared to be in the later stages of dementia. Many were slumped over in wheelchairs, and seemed disengaged with their surroundings. Yet, when Anthony played, the body language of many of the residents changed. They appeared more alert and engaged. The effects were even more pronounced in certain individuals when Anthony played a particular genre. For one lady sitting next to me, this was Scottish Highland music. I had tried, unsuccessfully, to engage this lady before the session started. Yet, when her music played, it seemed to spark something in her. She called for my attention from her wheelchair, grabbed my hand, and led me in time to the music.

Anthony also introduced simple dance sequences for a number of the songs. The movements, along with the music, added to the sense of a shared experience. Again, my hand was grabbed and moved in a sort of dance. Anthony explained that touch is a human need, but that people with dementia are often touched out of requirement, not out the desire for human connection. Anthony believes that the music he plays creates the conditions for that connection to take place. It taps into deeper emotions, joy and memories that are experienced universally, allowing for an experience that transcends the dementia. Anthony frequently combines dance with music for this reason, creating opportunities for touch through dance in his classes.

The second time I witnessed the potential of music was not at a music program, but at a TimeSlips storytelling session. One member of the group, in the later stages of dementia, was visibly distressed. Yet her intense anxiety disappeared immediately with a verse of 'You are my Sunshine'. She became alert, engaged and calm.

I also visited with Concerts in Motion, a New York based non-profit organisation that brings music to the housebound and performs concerts in hospitals, nursing homes and senior centers. Concerts in Motion prides itself on the quality of musical performances that they offer, using professional musicians who play on Broadway or in the orchestras of the Lincoln Center. I visited an intergenerational program where a number of Concerts in Motion's youth performers took to the stage. Though the audience for this program were considered to be 'healthy elders' (the concert took place in a community center), there is some evidence to suggest that intergenerational programs can have a positive impact on people with dementia^{17, 18} though this is an area which needs further research.

Music creates a connection. *'We bond when we sing together; but bonding is deeper, more primal, if we dance together'*¹⁹. In Washington DC, I attended a Dance for PD (Parkinson's Disease), session at IONA Senior Services. The Dance for PD program is built on one fundamental premise: professionally-trained dancers are movement experts whose knowledge is useful to persons with Parkinson's. While the Dance for PD program is specifically focused on dance techniques that address concerns related to Parkinson's (such as balance, flexibility and coordination), research has shown that 24-31% of those with Parkinson's disease also have dementia²⁰. The session that I attended was led by three dance professionals who integrated movements from ballet, tai chi, folk dance and modern dance, all to live music. All abilities were catered for and variations on each move were provided for those who were chair bound. What struck me most about this program was the huge level of professionalism that I witnessed. Each individual was supported and encouraged to perform to their highest ability. The dance was the focus, not the Parkinson's.

¹⁷ Jarrott, S., E., & Bruno, K., (2003). *Intergenerational activities involving persons with dementia: An observational assessment*. American Journal of Alzheimer's Disease and Other Dementias, 18(1)

¹⁸ Lee., M, (2007). *Effects of intergenerational Montessori-based activities programming on engagement of nursing home residents with dementia*. Clinical Interventions in Aging, 2(3): 477-483.

¹⁹ Sacks, Oliver. 2007. *Musicophilia: tales of music and the brain*.

²⁰ Aarsland, D., Zaccai, J., & Brayne, C. (2005) *A systematic review of prevalence studies of dementia in Parkinson's disease*. PubMed, 20(10):1255-63.

Everyone showed great enthusiasm in mastering the dance move they had been given. Much of the dancing also required that participants danced with a partner. The fun of dance, the physical benefits of exercise, the mastery of a dance move, and the feelings of connectedness through touch and eye contact with a partner, would certainly be beneficial for those with dementia.

In New York I visited the innovative New York Memory Center, which provides a vast range of programs for those with memory loss including; cognitive training; yoga; meditation; exercise; therapeutic recreation classes; trips to concerts and sporting events. Many of the activities in the New York Memory Center focus on the arts where professional artists run a range of programs. A twice weekly program run at the center has a dance and music focus and is run by Rhythm Break Cares. Music, movement and touch are the founding principles behind Rhythm Break Cares' (RBC) *Dance for Dementia* programs which focus on improving the quality of life for early and middle stage Alzheimer's communities and those affected by dementia. In addition to being professionally trained dancers, all staff are trained to interact with those living with dementia and Alzheimer's. The session that I attended at the New York Memory Center encouraged participants to dance in whatever way they felt moved to do so by the music. A range of classics were played and the atmosphere was party like. In this particular session, there was much less focus on the 'art' of dance and technique, rather the aim of the session was to create a fun and energised environment – and it seemed to work. The hour flew past, with most people on their feet dancing, or tapping their feet to the music. While this session didn't focus on teaching dance, the program coordinator and professionally trained volunteer did demonstrate some salsa and jazz moves for participants to observe or follow if they wished.

With more of a focus on movement, Tai chi, a form of martial art, is also being used as a movement based relaxation technique for people with dementia. Chinese martial arts combine simple physical movements and meditation, with the aim of improving balance and health by concentrating on a series of integrated exercises. I took part in a Tai Chi session at the Veterans Association in Washington DC. All participants were wheelchair bound, so the session focused on the upper body. The program facilitator took us all through a series of slow and controlled movements, which were quite challenging. Participants were encouraged to take breaks when needed. While the dance moves of Rhythm Break Cares were fun and energising, the tai chi session created a peaceful and relaxing environment-evident when a number of participants 'nodded off' at different points. At the end of the session, all participants were vocal in terms of how much they enjoyed the experience.

In a review of the academic research, Renee Beard (2011) found that Dance Movement Therapy studies do report small reductions in the Behavioural and Psychological symptoms of dementia, such as decreased agitation, increased self-care practices, and improved cognitive performance or procedural learning²¹. Beard found that the primary benefits however related to an increase in communication and a focus on empowering people with dementia. Non-verbal communication means that any 'lost skills of ordinary conversation' can be rediscovered. Dance emphasizes quality of life, encouraging a sense of community, and the ability of people with dementia to meaningfully interact.

Art making

One of the highlights of my trip was a trip to a residential care facility in Canada with Jeanne Sommerfield, Secretary for the Society for the Arts in Dementia Care, where we visited a program run by a trained art therapist.

What struck me about this particular program was the level of professionalism and attention to detail. The day-long, twice weekly arts session is open to all residents and they can come and go as they please throughout the day. The room had been specially designed for the purpose of making art and was cut off from other distractions in the facility. Quality arts materials were provided (aprons, easels, brushes, paint palettes etc). Each participant had their own station, materials and plenty of space). Classical music was playing in the background. When I arrived, participants were all painting with an intense focus, thoroughly engaged in the process of making art. The art seemed to have an almost hypnotic effect. There were none of the typical signs one would expect with dementia. Everyone was calm and engrossed in their work, and the atmosphere was incredibly relaxing.

I spoke with the art therapist during a break. She was pleased I had witnessed the effects of the program, and the potential of the art making process to provide relaxation, focus and purpose. Many of the participants who took part in the program were new to art making, having had no previous experience before entering the home. Yet, they enjoyed attending the art class every week. The art therapist believed that the setting was just as important as the art itself. She believed that by running the program in a professional way, with quality materials, in an appropriate setting, meant that participants knew they were respected and

²¹ Beard, R., L., (2012) *Art therapies and dementia care: A systematic review*. The International Journal of Social Research and Practice, 11(5), 633-656.

taken seriously, and so they were also committed to the process. She pointed out that we all want to be respected and not patronised.

In addition to creating a professional ambience, the art therapist stated that choice should also be offered at every opportunity, from where participants would prefer to sit, to what brushes they would prefer to work with. People with dementia are rarely given choice in their day to day lives. As such, it is important to offer choice whenever possible.

The research literature would support these findings²². One study found that when twelve individuals engaged in art making they demonstrated significantly more interest, sustained attention, pleasure and self-esteem, than when the same individuals participated in more traditional adult day center activities, such as current events and crafts.

²² Kinney, J., M. (2005). *Observed well-being among individuals with dementia: Memories in the Making©, an art program, versus other structured activity*. American Journal of Alzheimer's Disease and Other Dementias, 20(4), 220-227.

Common themes

From the programs I observed and the artists, administrators and participants I spoke to, the same sentiments were often expressed in terms of what constitutes a good arts program and why the arts are so effective. Matters relating to funding, evaluation and research were also raised frequently throughout my trip and so I have also included some brief commentary on these issues.

1. Human needs

The arts are seen as a unique and effective way to meet human needs for those living with dementia. A person with dementia has the same needs as everyone else. The need to communicate and be productive doesn't end just because someone receives a diagnosis of dementia²³. Like all people, those living with dementia have a deep need to experience social belonging and to feel connected to others. They have a need to express themselves and to communicate their feelings, to be productive, to accomplish goals, and to contribute to something bigger than themselves.

With a diagnosis of dementia, meeting these needs becomes more of a challenge. This is of course, in part, due to the cognitive effects of dementia. With the loss of memory, an individual's identity and sense of purpose can start to erode. The activities that gave the person a sense of satisfaction and accomplishment may be more challenging or no longer possible. With the loss of language their ability to communicate their feelings is compromised. The impact of these limitations, are often compounded by well meaning caregivers who can overlook the individual's need for agency, accomplishment and belonging. They can (lovingly) direct the person with dementia, making decisions on their behalf. They can also underestimate the capabilities of the person with dementia and focus on what they can't do, rather than what they can achieve. Introducing arts based activities can be a creative way to reintroduce agency, a sense of achievement and a feeling of belonging into the lives of a person with dementia. This is possible because the creative capacity remains long after a diagnosis is received. The '*universal, pre-existing, and hardwired abilities*' often remain intact and the arts therefore '*serve as the basis for successful expression and appreciation throughout the progression of the disease*'²⁴.

²³ Jennifer Brush & Kerry Mills. *I Care: A Handbook for Care Partners of People with Dementia*.

²⁴ Dr John Ziesel. *I'm Still Here; a breakthrough approach to understanding someone living with Alzheimer's*.

Caring for someone with dementia can be particularly challenging due to the communication impairments that often accompany the disorder. This can lead to increased stress for caregivers who struggle to engage effectively with the person they are caring for. It can lead to a situation where care is done 'to' the person, with the individual's preferences and opinions no longer taken into account. The person can be viewed as no longer really 'there'. Yet, the person is still there. Caregivers need to find new and creative ways to engage and to tap into the emotions and capabilities of the person they are caring for. The arts represent an effective way to do this. They focus on the individual's strengths, not their limitations. According to Anne Basting, the arts give caregivers and people with dementia a new way to be 'in relationship' with each other. They create a new space in which a caregiver (formal or informal), and the person with dementia can engage. All the programs I witnessed used the arts to create an environment where participants could connect to one another.

The best programs I witnessed however also showed 'intentionality', as in they had a specific goal, for example, to produce a poem or a story. Participants were aware of how they contributed to this larger goal. One particular example that sticks in my mind was at a residential care facility in Vernon, British Columbia. The President for the Society for the Arts in Dementia Care, Dalia Gottlieb-Tanaka, took me to the Gateby Care facility in Vernon BC, which specialised in dementia care. The activity therapist at the facility ensured not only that a wide variety of arts based activities were made available for residents, but that these activities were all part of a bigger purpose. The art and poems that residents created were displayed throughout the facility, the cookies they baked were eaten at birthday parties, the crafts they made decorated the garden. Another facility auctioned art that the residents produced to raise funds for more art materials. These activities acknowledge and value the contributions that people with dementia can make, while giving them a sense of purpose.

2. Choice

On a number of occasions during my trip I was reminded of the importance of choice. As stated, people with dementia often have choice removed from their daily lives. Care partners and care staff often direct the person with dementia, and make decisions on their behalf. They may even discuss the person's care as though they are not in the room.

The best arts programs I witnessed were mindful of this and took steps to empower people by giving them a choice at every opportunity. In an art therapy session I visited, participants were encouraged to select the colours and brushes they preferred. In a live musical performance, nursing home residents were encouraged to request songs. In the TimeSlips storytelling session, participants were asked to pick an image to base their story on from 3 photos. In a tai chi workshop, nursing home residents were told they could pick and chose which segments of the routine they would like to participate in. Most importantly perhaps, these artists did not assume that everyone present would want to take part in their programs. They asked, and they respected the wishes of those who preferred not to engage.

One of the most encouraging programs I witnessed was the Healing Arts Programme at the Veteran's Association in Washington DC. The facility offers a wide range of arts based activities on a daily basis and demonstrates how effectively the arts can compliment health and social care. The energy and enthusiasm of staff and residents in the facility was like nothing I have witnessed in a residential setting. This, I believe was at least partly attributable to the management's focus on the mental, spiritual and emotional needs of residents through the Healing Arts Program. I also witnessed a huge respect between staff and residents. Staff took time to know the residents, their life stories, and what activities they enjoyed. They recognised that residents had different preferences and so catered for a range of tastes. Activities included tai chi, storytelling (using the TimeSlips method), Jazz, art making classes, museum visits etc. With such a wide range of classes offered on a daily basis, all residents attended at least one session a week, though most took part in many more. Many, who had not taken much of an interest in the arts before, were learning new skills, well into their seventies and eighties.

Arts activities can give back choice and control to the person with dementia. In her handbook for care partners of people with dementia, *I Care*, Kerry Mills argues that some degree of choice can always be given to a person with dementia, even in the very late stages. She gives the following case study example;

Case study taken from the book 'I Care'

'My nine year old son supported my mother while working on an art project. He helped her create a notecard out of felt card shapes. He showed her two different shapes and asked if she liked the blue one or the purple, and sometimes she would say 'blue'. If she couldn't he would try to notice if her eyes settled on one shape rather than another. Then he took the shapes she had chosen and placed one on the card and asked, 'Do you like this here?' and she could reply yes or no. He moved the pieces around until she liked them and glued them

down for her. In this way he gave a person who could barely move or talk, agency in her own life. In the end he showed her the finished card. She opened her eyes, smiled and said 'It's pretty honey'

3. Professionalism

During my time in Washington DC, I attended a 3 day conference run by the National Center for Creative Ageing. At numerous points during the conference, the importance of using professional teaching artists was discussed. I tend to agree. One of the features of these programs that makes them so successful is their focus on teaching 'the art' of painting, dance, drama etc. As stated, running these programs in a professional way, with trained artists, quality materials, and in an appropriate setting, means that participants feel respected and valued. Another realisation I had during my observations was the level of skill involved in facilitation. It would be easy to underestimate the artistic skill required for teaching people with dementia. Quite the opposite is true. By way of example, when involving people with dementia in the creation of a group poem, the poet Gary Glazner had to use his skills as a poet to weave the different contributions together into a poem. As a poet, Gary did this with ease. Likewise, in the Dance for PD session I attended, the trained dancers could correct technique in a way that non- professionals could not. They also know where to 'set the bar' so that people feel challenged, but not overwhelmed.

Trained arts professionals delivering programs are much preferred for the reasons outlined. Yet, I believe the arts are something that can be integrated into everyday life for people with dementia. To achieve this, carers should receive training on the value of the arts, and how they can implement the arts in their own care-giving practice. Training is available for carers from TimeSlips and from the Alzheimer's Poetry Project (see appendix). Arts and crafts can be created together. Music on iPods can also be an effective way of improving quality of life for people with dementia. The arts should be integrated into daily care practices, yet, to gain the benefits outlined in this paper, a focus on activities that are taught by professionally trained artists are also necessary and should be included as often as possible.

4. Funding, Research and Evaluation

Much of the NCCA conference in Washington DC focused on issues of funding, evaluation and research. The funding environment for the arts and dementia can be challenging and

this was considered to be largely a result of the lack of research to prove its effectiveness. Despite the existence of a small body of robust research, and the experience of those individuals directly involved in these programs; the value of the arts for dementia is poorly understood. Funders want evidence that programs deliver results, yet there is only a small body of academic research that explores the potential of arts based programs. Furthermore, much of the existing research is limited in the conclusions that can be drawn (this is discussed below). With a more solid evidence base, funders will be more likely to support programs.

Delegates at the conference spoke of the need for greater collaboration between universities, artists and administrators to conduct relevant research. Much of the research to date has been criticised by both artists and academics. Two major shortcomings relate firstly, to the absence of a 'person centered' focus, and secondly, to a lack of appropriate outcome measures on which the effectiveness of these programs can be judged. One artist likened the research and evaluation process to *'attempting to measure the temperature of bath water with a ruler'*. Clinical scales, that are often inappropriate, continue to be used to judge the success of these programs, while the views of participants are often not considered. As such, the true value of these programs is poorly understood. In order to address this issue, the value of arts based programs need to be reconsidered from the nuanced perspective of the participant. This should not only give a better insight into how the arts impact on the person with dementia, but should also inform the development of more appropriate evaluation measures which can then be used to demonstrate success to funders. The lack of robust research evidence in this field has prompted the Alzheimer's Society to fund a Doctoral Training Center for the Arts and Dementia. The training center is a joint initiative from the University of Nottingham and Worcester University. Over the next three years, I, along with three other PhD students, will be exploring the value of arts interventions for people living with dementia. You can find out more about the training center here; <http://www.worcester.ac.uk/discover/tandem-phd-studentship.html>

The use for the arts for dementia is a promising and growing field. It is recognised that practice needs to develop in an evidence based way, not only to satisfy funders, but also to inform best practice as the field continues to grow. The focus of my forthcoming PhD will involve working alongside artists to understand how different individuals experience arts based programs. The current research literature reveals very little about how programs are experienced differently based on the type of dementia (Alzheimer's as opposed to Lewy Body Dementia), the stage of dementia (early vs late stage), and other individual differences (in cognition, abilities, preferences, experience etc). It is a fair assumption that some

approaches may be more suitable than others based on these factors and that this knowledge would help to promote 'person-centered' practice.

Conclusions and recommendations

Arts based programs are an effective means of engaging people with dementia. Despite a very limited number of studies in this area, observations of existing programs clearly demonstrate the effectiveness of professionally conducted arts based programs for dementia. The United Nations Principles for Older Person's encourage governments to incorporate the principles of independence, participation, care, self-fulfilment, and dignity into their programs wherever possible²⁵. Providing a model of dementia care that addresses these principles and that goes beyond the most basic of care needs however can be challenging. Yet the arts hold a huge amount of potential in this regard. In the dementia care facilities I visited, the healing potential of the arts was understood and integrated into the daily lives of service users. They used the arts to compliment more traditional forms of care and in doing so they found a way to encourage self-fulfilment and participation by focusing on the strengths that remained. They acknowledged independence by taking account of each person's interests and preferences. They saw the person, not just the illness and a collection of symptoms to be managed and in this way treated the person with dignity. The power of such arts based programs to improve quality of life was very apparent as was their potential to address the behavioural and psychological (BPSD) symptoms of dementia. Individuals, who had initially appeared anxious and easily distracted, became focused and calm during arts based activities. In summary, the arts offer a unique way to engage with people who experience the cognitive limitations associated with dementia, and can restore humanity to the individual. Those involved in service delivery and policy development need to consider the potential of the arts in the delivery of person-centered care for dementia.

Despite the existence of some well established and seemingly effective arts programs across the globe, and the rapid growth in this field, the use of the arts for dementia is still a relatively new concept. Part of the challenge ahead will be to develop an evidence base that will not only promote the case for the arts to funders and policy makers, but that will also help us to refine arts based approaches based on the opinions and experiences of those actually living with dementia. Moving forward, collaboration between academics,

²⁵ The *United Nations Principles for Older Persons* were adopted by the UN General Assembly (Resolution 46/91) on 16 December 1991.

administrators and artists will be essential if this field is to grow. Despite the existence of a small body of academic research, more research will be required in order to demonstrate value to funders and to refine practice. Older people living with dementia must be consulted as part of this process.

Appendix 1

Itinerary of trip

Location	Program	More info
Washington DC, Weeks 1&2	The Healing Arts Program at the Veterans Association.	http://www.creativeaging.org/programs-people/healing-creativity-washington-dc-va-medical-center
	Iona Senior Services	https://www.iona.org/
	The Creative Age Conference: The National Center for Creative Ageing	http://conference.creativeaging.org/
	Anthony Hyatt with Arts for the Ageing	http://www.aftaarts.org/
	Dance for PD	http://danceforparkinsons.org/
New York, Weeks 3-5	The Alzheimer's Poetry Project	http://www.alzpoetry.com/
	TimeSlips observation with Elders Share the Arts	http://www.estanyc.org/ http://www.timeslips.org/
	The Connect2Culture program at the Alzheimer's Association	http://www.alz.org/nyc/in_my_community_17047.asp

	J M Journeys at the Jewish Museum	http://thejewishmuseum.org/programs/visitors-with-disabilities#dementia
	Sights and Scents program at the Cloisters Museum and Gardens	http://www.alz.org/nyc/in_my_community_17047.asp#jm
	Brooklyn Afternoons at the Brooklyn Museum	http://www.alz.org/nyc/in_my_community_17047.asp#bk
	RB Cares	http://www.rbcares.org/
	The New York Memory Center	http://nymemorycenter.org/
	Concerts in Motion	http://www.concertsinmotion.org/
British Columbia, Canada, Week 6	The Society for the Arts in Dementia Care	http://www.cecd-society.org/aboutus.html