

## **Introduction**

There is increasing interest in the use of arts and creative activity to enhance dementia care (e.g. Beard, 2012; Cowl & Gaugler, 2014; Young, Camic & Tischler, 2016), and to bring together and support professionals and those who use services, see Creative Practice as Mutual Recovery (2018). Over the past decade a growing body of research has established this interdisciplinary field of study and there are strategic moves to embed the arts in healthcare more widely (All-Party Parliamentary Group for Arts, Health and Wellbeing, 2017). However, existing research and arts practice have often proceeded in parallel with practitioners criticised for not providing evidence of efficacy, and researchers berated for not working collaboratively with artists (Zeilig & West, in press) and not involving people living with dementia in the co-design of research.

## **Programme rationale and goals**

The Dementia, Arts and Wellbeing network (DA&WN) was established to enable researchers, creative practitioners, carers, and people living with dementia to draw out their tacit knowledge and reveal best practices. Its aims were to: foreground the views of people with dementia, to share different creative approaches, to integrate a variety of academic perspectives, to create inspiring outputs, and to disseminate its activities to the public.

## ***DA&WN workshops***

The primary focus of DA&WN was a series of 4 workshops held in a Midlands city (UK) over a period of 12 months. Different members of DA&WN led on each workshop, focussing on a specific artform chosen according to expertise within the network.

The first three were held over two consecutive days, and the final workshop (music) was one day due to pragmatic considerations. Together, the workshops enabled in-depth exploration of each artform and opportunities for the group to socialise and reflect on the

process, for instance, art practitioners would deliver a session to the whole group, which would be followed by discussion, reflection and critical examination with contributions from all participants.

### **Programme evaluation**

The workshops had an action-based learning and research approach and were thus highly experiential, focused on reflecting these experiences in a reciprocal way, drawing out knowledge and practice, and creating inspiring outputs. This circular structure of experiential investigation and critical reflection was explored by recording reactions using still and video photography, through designated participants taking notes, and using snap surveys with the results being presented back to the community of participants.

### ***Dance***

Co-ordinated by dance practitioners Richard Coaten, Fergus Early OBE (Green Candle Dance Company) and social care academic Justine Schneider this workshop aimed to explore the benefits of dance through both directed exercises and free improvisation in combination with brief presentations and reflective sessions.

Based on these activities, the participants discussed principles of person-centredness, dance and well-being as well as professional development of dance practitioners. One participant reflected on the benefits of these engagements and discussions during the workshop: *'Our sense of wellbeing affected by physical activity itself. I realized we can forget how important it is to 'awaken' our bodies – on purely health grounds but also how it releases endorphins and makes us feel better too'*. [Arts practitioner (theatre)]

### ***Visual Art***

Coordinated by academics Victoria Tischler and Christian Morgner (psychology and sociology respectively) *'Visual Art Appreciation and Creation'* aimed to examine and

investigate the role of visual art in dementia care. Participants explored artwork using sensory approaches, including touch and vision. They also experienced the impact of a different environment, when discussing and making art work in an art gallery.

Resulting from these activities, participants commented upon the impact of visual arts on the relationship between identity and dementia and the cognitive dimension of works of art. In the context of these discussions, one participant living with dementia stated: *'I want to come again'* and another highlighted: *'the wonderment of trying to imagine ourselves into each other's shoes.'* [Arts practitioner (theatre)]. A programme for an external project *'The Imagination Café'* (see below) was developed during this workshop.

### ***Theatre***

Coordinated by theatre practitioners' Arti Prashar (Spare Tyre Theatre Company) and Tanya Myers (Meeting Ground Theatre Company), clinical academic Tom Denning, and theatre academic Nicola Shaughnessy, *'Using our Imagination'* featured immersive and prop-based experiential sessions that focused on inclusion. Participants were invited to an interactive theatre production designed for people with dementia (*The Garden*, by Spare Tyre). They composed stories following a Timeslips method, see [www.timeslips.org/](http://www.timeslips.org/) and they improvised theatre based on lines from Shakespeare.

The role of imagination, play and their impact upon inclusion, mutual recognition and interaction were highlighted in the discussions. As one participant living with dementia said: *'Who'd have thought we'd act in a Shakespeare play.'* Another stated: *'We've travelled over a bridge we'd never crossed before.'* A clinician researcher attending the performance of Spare Tyre's multi-sensory, non- verbal performance *'The Garden'* stated: *' [it] abolishes dementia and does what no tablet can.'*

### ***Music***

Coordinated by musicians and academics Claire Garabedian and Orii McDermott, music practitioner John Osborne, and social care academic Justine Schneider, the music workshop included a presentation using live cello, guidance on developing personalised music playlists (JoCo), a singing session by Rosslyn Bender, and group drumming led by Biant Singh.

In this workshop, discussions explored questions of identity and dementia, the impact of dementia on carers and ways to express feelings and thoughts through sound. One participant with dementia said: *'It has stimulated pleasures from music and gives you new pleasures from the improvisation, and that you can create music and sound with everyone.'* A carer explained she felt she could sing for the first time and reported her husband (with dementia) was acknowledging this by *'looking (at her), smiling and humming'*. Asked for views on the music workshop process, a participant living with dementia added: *'You don't have to worry about what you say, you can be yourself and express yourself.'*

## **Outputs**

Developments and innovations followed each workshop. These are recorded on the DA&WN website, discussed below. The first workshop on dance led to an audit of dance providers in the region. In addition, a 2-day training course to work with frail older people and those with dementia was piloted and completed by 20 individuals, all of whom work in care settings. A dance and dementia network established in Northern England by Richard Coaten promotes communication across the sector, see: [www.southwestyorkshire.nhs.uk/quality-innovation/initiatives-projects/movement-dance-and-dementia/](http://www.southwestyorkshire.nhs.uk/quality-innovation/initiatives-projects/movement-dance-and-dementia/)

*The Imagination Café* is a pop-up art installation in public locations that provides food and creative activities, developed as part of dementia research, offered alongside specialist advice, devised by the lead author. Touring across Wales, Scotland and England in

2018, the first *Imagination Café* took place in Nottingham in May 2017, during Dementia Awareness Week. Participants at the DA&WN Visual Art workshop formulated ideas, concepts and activities for the event including décor, music events, and invigilation of the café space by actors.

The theatre workshop included a storytelling exercise around a picture of an overweight cat on a pavement. The participants collaborated in developing a story about the cat, and this was written up into a play, which became an output of that workshop.

A further development encouraged by the workshops was 'Training in Music and Care', in 2017. This is being followed up by further training opportunities leading to a university-recognised accreditation.

### **Involvement of people with dementia**

A group of 21 people with dementia and carers became part of DA&WN. Several of these pairs attended the workshops on visual art, theatre and music, and two people living with early onset dementia attended the dance workshop, indicating strong commitment to the project.

The link person, responsible for liaison with people with dementia and carers, reported that participants spoke of feeling safe in a supportive environment which gave them the freedom to express themselves, their thoughts and feelings, and to be themselves. They valued the opportunity to try new activities and to challenge themselves, sometimes feeling surprised at what they could achieve. They felt listened to, stimulated, cared for when needed but not patronised, and valued for their contributions. It was noted that a participant with dementia recalled the sessions afterwards which was a pleasant surprise for her carer.

Other feedback included the key importance of a link person to *‘engage...advocate...and build trust’* [facilitator of people with dementia and carers] and *‘we learned some important lessons about the amount of support that people with dementia (and carers) need in order to attend and to participate meaningfully’* [Clinician researcher].

### **Integration and learning**

Overall feedback suggested that involvement in the network was highly valued and that a new 'community' was formed as a result. Specifically, a stronger connection between artists, clinicians and academics was forged, united in the wish to develop better care for people living with dementia. One creative practitioner stated:

*‘new ideas, creative partnerships, friendships and creative working practice have developed over this last year. I for one will miss many of the people we forged friendships with. I have grown in courage and confidence in my own arts practice and look forward to applying this into creative projects in the future’.*

Another referred to the importance of engagement with people with dementia as part of the process: *‘Demonstrates how effective a form of non-pharmacological intervention the arts can be – if done with time, care, and understanding of the needs of people with dementia and carers, and [given] sufficient resources.* [Artist facilitator of people with dementia and carers]

It was noted that whilst participation was strong, involvement, especially for those living with dementia, should be a goal in future projects: *‘True involvement to me is about people having the opportunity to plan and contribute in some way. Perhaps in the future participants (now having some experience) may have some opportunity to be ‘involved’ in all*

*aspects of an events from planning, contributing, feeding back and suggestions.*’ [Clinical Trainer]

The considerable organisation required to build and sustain a network such as this, to organise, document and plan was noted by another participant: *‘The work that went on in the background – keeping communication channels going – organising transport and food – documenting and facilitating shared feedback has been incredible’*. [Arts practitioner – (theatre)]

One participant noted that the format of the workshops and the nature of material e.g. visual, theatrical, were an excellent way of building dynamic web content: *‘a great way to get website content. From my experience such a website would benefit from stories (blogs, photos, videos) portraying the different experiences and benefits that people have had’*. [Clinical trainer]

## **Dissemination**

A website has indeed been established, see [www.nottingham.ac.uk/research/groups/dawn/index.aspx](http://www.nottingham.ac.uk/research/groups/dawn/index.aspx). This has had 3511 hits (over 24 months). It showcases visual and video material from the workshops and links to other related national and international activities. In addition the network was held up a model by the International Longevity Centre’s report on Music and Dementia (Bowell & Bamford, 2018).

## **Conclusions and future plans**

The DA&WN project demonstrated a valuable means by which to bring together and build meaningful and productive activity between academics, creative practitioners, people with dementia and carers. The project's model of sharing of leadership i.e. workshop facilitation, an emphasis on participation, and sustained engagement of people with dementia and carers facilitated commitment to the network and a sense of community that was retained by professionals and people with dementia alike is likely to be valuable to other similar initiatives.

The group indicated commitment to further activities such as training and collaborative projects including dance and music workshops and bidding for future research funding. Given the wider interest in arts and dementia practice and research, it is timely for similar projects to build on this learning; to explore collaboration across disciplines and to utilise the arts to reach those with lived experience of dementia in novel, engaging and positive ways. Methods to make such communities self-sustaining should be considered in future projects of this type.

### **Acknowledgements**

Arts and Humanities Research Council (Network funding AH/N00650X/1), University of Nottingham, Institute of Mental Health, Emma Wass and people with lived experience who took part.

### **References**

All-Party Parliamentary Group for Arts, Health & Wellbeing (2017) Creative Health: The Arts for Health and Wellbeing. Retrieved from



www.artshealthandwellbeing.org.uk/appg-

inquiry/Publications/Creative\_Health\_Inquiry\_Report\_2017\_-\_Second\_Edition.pdf

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

Bowell, S. & Bamford, S. M. (2018) 'What would life be – without a sing or dance, what are we?': a report from the Commission on Dementia and Music. Retrieved from [http://allcatsrgrey.org.uk/wp/wpfb-file/what\\_would\\_life\\_be\\_-\\_a\\_report\\_from\\_the\\_commission\\_on\\_dementia\\_and\\_music-pdf/](http://allcatsrgrey.org.uk/wp/wpfb-file/what_would_life_be_-_a_report_from_the_commission_on_dementia_and_music-pdf/)

Cowl, A. L. & Gaugler, J. E. (2014) Efficacy of Creative Arts Therapy in Treatment of Alzheimer's Disease and Dementia: A Systematic Literature Review. *Activities, Adaptation & Aging* 38(4): p. 281-330.

Creative Practice as Mutual Recovery (2018) Retrieved from

<http://cpmr.mentalhealth.org.uk/>

Kontos, P. C. and Naglie, G. (2009), Tacit knowledge of caring and embodied selfhood. *Sociology of Health & Illness*, 31: 688-704. doi:[10.1111/j.1467-9566.2009.01158.x](https://doi.org/10.1111/j.1467-9566.2009.01158.x)

Young, R., Camic, P. M., & Tischler, V. (2016) The impact of community-based arts and health interventions on cognition in people with dementia: a systematic literature review. *Aging & Mental Health* 20(4): p. 337-351.

Zeilig, H. & West, J. (in press) Co-creativity: New paradigms for using the arts with people with a dementia *Quality in Ageing and Older Adults*