



The Arts and Dementia: Shaping the Future

Roundtable Report: the implications of TAnDem PhD research for the Worcestershire Region

Event held on 10th December 2019

at The Hive in Worcester, UK



Professors Dawn Brooker and Tracey Williamson with
TAnDem PhD students Becky Dowson, Ruby Swift and Karen
Gray at the Roundtable event

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Speakers: Emma Broome, Becky Dowson, Maureen Gamble, Karen Gray, Alison Reeves, Chris Russell, Ruby Swift, and Yvonne Thomas.

Notetakers: Jennifer Bray and Becky Oatley.

Chairs: Dawn Brooker and Tracey Williamson.

Participants: Christina Agiropoulou, Diane Amans, Katie Babb, Steve Boffy, Melody Carter, Angela Conlan, Jenny Davis, Caroline de Souza, Sharon Webb, Kim Fuller, Pippa Galpin, Natasha Green, Victoria Harrison, Lorna Horton, Susanna Howard, Nicola Jacobson-Wright, Lynn Kay, Linda Martin, Wendy Martin, Maura McCrann-Smith, Sarah-Jane Morgan, Maria Parsons, Sue Pope, Kit Showande, Mary Stevens, Joanne Unitt, and Sharon Wu-Carr.



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Context

In early 2015 the Alzheimer's Society funded eight Doctoral Training Centres in various aspects of dementia to help to increase research knowledge and capacity in this vital area. A partnership between the Association for Dementia Studies, University of Worcester and the Centre for Dementia, University of Nottingham was one of the successful Centres. Its focus was on research into the arts and dementia, and its name was TAnDem.

Since that time, six PhD students have conducted foundational research into this important area. Two have now been awarded their doctorates. The remaining four others will complete in 2020. These PhDs have created a wealth of in-depth knowledge about how the arts can support people living with dementia.

PhDs are complex and it will take some time before all the results are published or appear in the public domain. All the students have relished the experience of conducting research with people directly affected by dementia, staff who support them and artists and therapists who work in this area. They have all developed very good research skills and are now equipped to become researchers and lecturers in the field.

The legacy from TAnDem will grow over the years to come. This report focusses on some of the emerging findings and insights from the TAnDem PhDs and how these can inform the work of local artists, care providers and the University of Worcester going forwards.

In December 2019, Professor Dawn Brooker and her team at the Association for Dementia Studies, University of Worcester hosted an invited roundtable event focussed on how the arts, culture and creativity can support the wellbeing of people living with dementia. The event was attended by 35 people. Among them were artists, arts therapists, arts managers, occupational therapists, care workers, care professionals, university researchers and educators from various disciplines.

At the event, five of the six TAnDem PhD students shared various aspects of their research. The aim was to seek the thoughts of attendees on how this research could lead to:

- better, more effective arts and dementia practice;
- the provision of the education, training and other resources that the arts and health and care sectors need.

Educators at the University of Worcester highlighted existing opportunities for students to get involved in the arts and dementia, such as projects in community organisations as part of the BSc Occupational Therapy course. They also shared information about the courses in which they are involved as a starting point for thinking about how arts and dementia might fit into these curricula. These Worcester University courses included:

- BA Drama and Performance, Touring Theatre MTheatre and BA Drama with Psychology
- BA Fine Art and BA Fine Art with Psychology
- BSc Occupational Therapy and MPhil/PhD Occupational Therapy
- Post Graduate Certificate in Dementia Studies

Presentations followed from five TAnDem PhD students, accompanied by facilitated discussions. Attendees were asked to consider:

- How does this relate to your professional practice in the arts and dementia?
- How can we use the findings to help us do things better?
- What can the University of Worcester do to help equip those working in the arts and dementia care, to get this into practice?

The TAnDem PhDs



Dr Emma Broome,
completed TAnDem
PhD Student

Exploring the role of care staff in creative arts interventions in residential homes - Emma Broome (University of Nottingham)

Emma's study examined how care staff influenced the access and experience of people living with dementia in two care settings taking part in the Imagine Arts programme. Based in Nottingham, the Imagine Arts programme is a collaboration between a national care home provider, the city council, a local arts organisation and arts providers. The programme enriches the lives of older residents through use of the arts and supports engagement in the wider community.

Her findings enabled her to theorise about what kind of conditions need to be in place for care staff to actively engage in creative activity; conditions such as an environment of caregiver understanding, encouragement, and response. The study

demonstrated that when these conditions apply it is likely that there will be positive interactions between care staff and people with dementia.

Arts activities offer opportunity for people with dementia to be included and share fun and enjoyment. Care staff are well placed to contribute towards creative activity in care settings. They have knowledge of the residents' skills, abilities and preferences. Care staff participation in arts activities can be a means to upskill and train activity coordinators who can then provide and sustain creative activity within the setting. The understanding from this research of how creative arts such as drama, textiles, and music can be implemented within care settings adds to existing knowledge in this field and offers a basis for developing programmes of arts in care settings.



**Amy Veale, TAnDem
PhD Student**

Arts engagement in care homes: Lessons for effective and ethical practice - Amy Veale (University of Worcester)

Amy's PhD focused on understanding the experience of arts practitioners working in care homes and how they worked with the range of individuals living with dementia to help them get the most out of arts sessions. Arts practitioners include poets, musicians and visual artists as well as arts therapists who have had specific training in the use of arts as therapy. Amy also explored the ethical decisions that arts practitioners have to make. Insights were gained from in-depth interviews with many arts practitioners and observations of arts sessions conducted within care homes.

Arts practitioners require the ability to create clear and compelling opportunities for engagement. While arts can provide accessible and potentially attractive forms of engagement, it seemed particularly important that practitioners should be skilled in communicating its meaning and value to residents living with dementia.

Arts practitioners also required the ability to remain flexible about what would happen during an arts session. This was important in the context of care homes where it was impossible to control the environment and where residents might have limited capacity sometimes to understand the "rules" of engagement within arts sessions. Some practitioners talked about the need to engage with residents in unanticipated ways, for example, by allowing residents to share their stories and to reminisce in activities rather than trying to follow a set structure.

In terms of ethical practice, arts practitioners felt that all forms of engagement needed to be valued equally. They felt that subtle forms of engagement, like tapping one's foot, watching or listening, should be valued as much as more overt signs of

engagement. It was important to acknowledge quieter group members and their contributions.

Arts practitioners also talked about the importance of keeping an open mind when working with residents, avoiding assumptions about what residents would like or dislike, or what they would be capable of. Having due regard for health and safety, arts practitioners felt that it was important not to place limitations on the person or to disempower them by making decisions on their behalf. For example, it was not uncommon to find that a resident engaged well when others had anticipated that they would not.



**Becky Dowson,
TAnDem PhD
Student**

Skill-sharing in music therapy and dementia - Becky Dowson (University of Nottingham)

Becky's PhD focused on the challenges and opportunities offered by a music therapy skill-sharing based approach to group singing for people with dementia. Skill sharing between music therapists and others who support people with dementia has many potential benefits. It can increase access to music, empower care staff to feel more confident and skilled in their role, and provide them with the confidence to use music within

day-to-day care situations. However, there are several challenges which must be addressed, including the risk of added burden on staff, and finding the right medium and resources to share skills.

The CHORD manual is an example of music therapy skill sharing in action. Written by music therapists, the manual is about 50 pages long and contains advice on setting up your group, possible session structures, how to cope with problems and musical matters. It has an emphasis on working sensitively with people with dementia and is designed as a collection of "hints and tips" rather than a set of instructions. It may be used by anyone who wishes to lead a group and is not solely aimed at musicians. Becky's PhD study evaluated a novice facilitator's use of the manual to set up and run a community singing group attended by 25 people with dementia and memory problems, and their supporters. The facilitator was an amateur musician with counselling training and some experience of dementia. 10 singing sessions were provided. Each session lasted an hour and had the same flexible format based around singing familiar songs and shaped by input from the group members.

Findings from the study showed that the facilitator appreciated the manual's brevity and accessibility but thought that it could benefit from more advice about musical aspects and keeping sessions fresh. The facilitator's relaxed attitude to her lack of experience leading a singing group meant that group members felt they had

something in common with her and felt more comfortable making mistakes. This particular example of the CHORD manual demonstrates some of the potential of skill sharing but raises questions about what skills can be shared with whom, and what formats are most appropriate. The need for responsive and compassionate working with people with dementia may mean that written resources alone are not enough, and could be accompanied by training if they are to be used by facilitators with limited experience.



**Ruby Swift, TAnDem
PhD Student**

Sharing music at home - Ruby Swift (University of Worcester)

Ruby's PhD focussed on how music can be and become part of caring relationships for people with dementia living at home. During her study, she visited people with dementia and their family carers in their own homes, and together they explored music.

Ruby found that dementia had brought changes to the ways in which the individuals in these caring relationships related to one another. Together with each pair, Ruby explored accessible sensory experience, including listening to music and music-making. Participants' musical experience ranged from no real interest in music to experienced musicians. With all pairs, shared music listening promoted interaction that did not depend upon conceptual understanding and communication but could support it. Music making not only promoted interaction, but also became an activity of relating for all pairs that completed the study. Singing together in particular was a means to relate through the equal sharing of voices where conversation had reduced.

Within these caring relationships, music brought new opportunities. This included new shared sensory experiences, new experiences of each other and new forms of self-expression and creativity. All these honoured individuals' human potential to grow, develop and enrich the lives of others through the changes of dementia. It was not musical skill that was needed for music to grow in the caring relationships of the pairs who participated in this study. What was needed were opportunities, ideas and resources to experience and explore music as a means to relate. Taking her fieldwork experience forward, Ruby is now developing indications and resources with the potential to support music sharing in the caring relationships of people with dementia living at home more broadly.



**Karen Gray, TAnDem
PhD Student**

What is it about arts and dementia that makes it so hard to evaluate? - Karen Gray (University of Worcester)

Karen's presentation reflected findings from her PhD that had greatest relevance to a largely practice-based audience. She discussed the challenges of evaluating arts activities for people with dementia and explained that, while the effects of the arts can seem hard to grasp, there are outcomes that we can and do measure, although doing this is challenging. These outcomes may be clinical, or relate to mental, physical or social wellbeing or quality of life. They might be psychological, physiological or artistic.

When evaluators and researchers of arts and dementia activities report limitations to their work, they often talk technically about things like study design, sample size, lack of information about participants, and the fact that projects and their effects are often short term. But other evaluation stakeholders (such as artists or funders and commissioners) talk more about how to understand the arts in this context. They want to accurately report the value of arts activity in a way that is going to make sense and be useful to everyone involved. For artists and funders, it is the lack of money, resources and skills available for evaluation, along with the practical and ethical aspects of working in dementia contexts (such as people's homes, care homes or hospitals) that seem particularly problematic.

Artists and arts organisations need to build knowledge about evaluation and be able to access support to help them resource, plan and fund it so they can communicate more confidently about evaluation.

Arts evaluators need dementia knowledge. They would benefit from greater understanding of how to build relationships with busy health and care staff, and of how complex dementia contexts work. They also need arts knowledge and skills to communicate and work with artists and arts organisations effectively and to understand the cultures and structures within which the arts are commissioned.

Collaboration and partnership across disciplines and sectors, and shared communities of practice and languages for communication are vital. We may also want to explore qualitative forms of evaluation that are rigorous and include use of written and/or verbal accounts and reflective practice. Finally, it is imperative for evaluators to learn from the skills and experience of people with dementia, artists or health and care staff, rather than viewing them as data 'subjects' or routes to collecting data.

Summary of Roundtable Discussion



Discussion at the roundtable event, facilitated by Professor Tracey Williamson

The following points were raised in the roundtable discussion:

- In care homes it can help to see care and arts activities not as separate but as integrated and interconnected. It might be necessary to consider care workers playing an equal but different role to artists. When the arts and creative practice are viewed as an add-on, this can detract from their value. It makes the benefits they can deliver less visible within a care home.
- For care staff, the experience of being involved in arts and creative activity can be a rich one. However, if the home is short-staffed, it will not always be possible for care-staff to engage.
- It can be costly for a care home to engage arts practitioners. The cost is compounded if only low numbers of residents take part. Low engagement will be impacted by residents and staff not understanding what the arts offer, or because staff don't understand who might benefit from the activity, or because there has been a lack of promotion or awareness of the session in the care setting.
- Any training for care staff has to be sensitive to the limited time and resources available. Few staff will want to follow the formal route of a university degree such as a BA/BSc or Masters. For those who do go through the formal education route, the career pathway and what exactly they might gain through the degree may not be clear. For many, learning 'on the job' and through example may provide a better way forward.

- For this to happen, there may need to be a shift in the culture in a care setting, to prioritise this sort of working. The support of management is essential for embedding and enabling any kind of change, along with attention to processes that might allow staff to carry on or implement training over the longer term. This could ensure that enthusiasm, learning or new practices will be sustained in the face of staff turnover.
- Mentoring by arts practitioners for care staff or less experienced artists was discussed as a potentially effective and cost-effective way for enabling sustained and sustainable change within a care setting.
- There was general agreement on the importance and significance of music in dementia care. Many people feel that people with dementia appear able to engage in musical activity even when many other activities are not possible. Different kinds of music offer were thought to be important - including individual as well as group activity.
- It was observed that music can be an enabler for other kinds of activity, such as dance; people might not feel they can dance, but once music is playing, it promotes movement. In care practice, music may be used as a supportive environment, activity or distraction to assist with personal care tasks.
- There was discussion around the way in which different art forms can complement and support each other. Artists learn a lot from those who practice different art forms and there may be a need for more collaborative practice.
- Attendees described and recognised a need for the production of evidence that would encourage continued funding of artists and arts organisations working in dementia contexts. It was noted that evaluations might therefore be steered by the agendas of commissioners and funders.
- It was also suggested that evaluations were sometimes too narrow in focus (e.g. looking at a single factor or outcome, such as anxiety, rather than broader effects) and that this was not always helpful for the sector. It was agreed that arts and creative practitioners would benefit from training in evaluative and critical thinking as part of their own practice.
- There was discussion about the concept of 'honesty' in evaluation. Some attendees suggested that the value or importance of the arts for the person with dementia was not being properly assessed because the focus of evaluation was often on the needs of the care settings, funders or commissioners.

- It was felt to be important to guard against assumptions and to be realistic about what an arts activity can achieve. Artists are particularly well placed to understand and communicate what is happening during a session. Care staff are well placed to understand what has been changed after it. Finding ways to build their knowledge into evaluations in a rigorous way could be revealing.
- Attendees wanted to connect with others working in the field – including those involved in different roles. They felt there was a need to make arts and dementia practice more visible, and to promote the work more widely – embedding it, for example, within social prescribing schemes or other kinds of health and care provision.
- Local networks were felt to be of particular importance to arts practitioners in the region, who can easily feel isolated. Attendees expressed an interest in some form of directory or resource bank where knowledge and opportunities could be shared. It was not clear who might be able or be best placed to take network and resource activity forward, or where the funding for this might come from.

Notes were taken on discussions throughout the day and, with the presentations, these were analysed for themes. The following needs for future arts and dementia practice were identified:

1. **Build understandings around the practicalities and complexities of integrating the arts into care practice and within dementia contexts** – identification and discussion of factors, cultures and structures that can be barriers or facilitators to sustainable provision of arts and creativity activities, and of support for both artists and care-workers
2. **Practical training and educational support to build knowledge of arts and creativity for people with dementia, dementia, and evaluative skills** – provided through short courses, integration within existing training, learning on the job, support for mentoring, reflective practice, and collaboration with researchers – for both artists and caregivers/health professionals
3. **Provision that enables connection, collaboration and sharing of resources** – locally focused and across various media (connection should be face to face as well as digital)

Recommendations for University of Worcester in relation to arts and dementia



Roundtable event attendee connections board

1. *Arts and creative activities are fully integrated into the Association for Dementia Studies Education Programmes and resources in person-centred dementia care.*

Action: By December 2020, Professor Brooker will have worked with Association for Dementia Studies colleagues to identify ways that arts and creative activities can be integrated within education programmes and resources.

Action: The Care Fit for VIPS website is used by thousands of practitioners worldwide each year and the content are managed by the Association for Dementia Studies. It includes a significant section on activities and occupation. By September 2020 Professor Brooker and her team will ensure that this section speaks to the barriers and facilitators for arts and creative practice and will ensure that arts and creative activities and resources are well referenced.

Action: The Care fit for VIPS website includes different versions for care homes, hospitals, community contexts, day and domiciliary care. By September 2020, Professor Brooker and her team will ensure that the website is updated with relevant resources around arts and creativity across all these service settings.

Action: The Association for Dementia Studies delivers Distance Learning and face-to face education Programmes on a variety of dementia care related topics. Professor Brooker and her team will ensure that arts and creativity references appear in all courses where relevant.

Action: The Association for Dementia Studies offers a fully on-line Post-Graduate Certificate in Person Centred Dementia studies. As part of this, students take modules on core topics in dementia care. Professor Brooker and her team will develop a new Distance Learning Module on the Arts, Culture, Creativity and Dementia that will be available from September 2021 (subject to validation).

2. *Arts and dementia mentoring and placements for students are integrated into relevant University of Worcester courses.*

Action: The University of Worcester offers a range of BA/BSc/MA courses related to both arts and health. With support from Professor Brooker and her team, course leaders Alison Reeves, John Cussans and Alison Blank will organise arts and dementia mentoring and placements within local dementia care settings for Worcester students on the following courses by September 2021: BA Drama and Performance, BA Drama with Psychology, BA Fine Art, BA Fine Art with Psychology and BSc Occupational Therapy. This will require identifying and brokering relationships with local care settings and artists currently working in this or allied fields and working with artists to offer mentoring opportunities.

3. *The Association for Dementia Studies will seek opportunities for research and consultancy for care home group leaders and care home managers to support individual care settings to successfully integrate arts and creative practice.*

Action: By September 2021, Professor Brooker and her team will plan and seek funding for a research project pilot to identify barriers and facilitators to effective arts practice in a care home context and ways different care home contexts can work with these barriers and facilitators. The pilot will be completed with a view to seek funding for a larger scale project by September 2022 as a basis for future consultancy.