



## Association for Dementia Studies

### Newsletter

July  
2023

*Welcome* to the July 2023 ADS newsletter!

It may be the summer break for the University of Worcester but research never stops – and at ADS things are as busy as ever. It's been a packed few months!

In this newsletter we talk about new research focussing on the experiences of family carers (see **Crossing the Line**, below), as well as a big event to mark the completion of another research project into **Meeting Centres** (see right and page 2).

We also talk about a **new book**, a **new App** and **new courses** (page 3), and what we were doing at a zoo in **Antwerp** and with a film crew in **Amsterdam** (page 4)!

Thanks for reading – **the ADS team**.



**Left:** Dr Shirley Evans welcoming everyone to the **Get Real with Meeting Centres** end-of-project celebration event – a chance for people involved and interested in Meeting Centres across the UK to come together to hear about and discuss the latest research.

**For our full report, see page 2!**

**NIHR** | National Institute for Health Research



## Crossing the line

Support for family carers providing personal care for people with dementia

### Survey on the experiences of family carers

Our new 'Crossing The Line' research project is now under way, with a survey regarding the experiences of people who care for family members with dementia with providing personal care. Please take a look below to see if you, or anyone you know, could help.



Above: Members of the Crossing The Line team meeting with people who are experts by experience to advise on the project in June.

**Are you a current or previous family carer of a person with dementia? Do you have direct experience of providing personal care to a person with dementia in the past 10 years? If yes, we would value your help!**

ADS is undertaking a research study called Crossing the line, funded by NIHR. The study looks at the experiences of family carers who currently provide or have past experience of providing personal care for someone who is living with dementia. Personal care can include different activities such as helping with going to the toilet, washing, mouth care, haircare and foot and nail care. The study will be used to develop advice and guidance resources for family carers.

[Please contribute to our study by participating in our survey by clicking here.](#)

To request a paper version of the survey, or for more information about the study, please contact Pauline Finlay: [p.finlay@worc.ac.uk](mailto:p.finlay@worc.ac.uk)

Contact Us

Twitter: [@DementiaStudies](#) Website: [www.worcester.ac.uk/dementia](http://www.worcester.ac.uk/dementia)

Blog: [adsdementiablog.wordpress.com](http://adsdementiablog.wordpress.com) Email us: [dementia@worc.ac.uk](mailto:dementia@worc.ac.uk)



## The Get Real with Meeting Centres end-of-project celebration!

On July 12th we hosted a big conference-style celebration to mark the end of one of our research projects – **Get Real with Meeting Centres**. More than 100 people involved or interested in Meeting Centres from across the UK came to the University of Worcester Arena to hear about the project, but also to discuss the current situation with Meeting Centres in the UK. It was especially good to bring everyone together who has an interest in this area, to meet and talk in person.

It can be challenging for community-led dementia support initiatives like Meeting Centres to keep going long term and this project, funded by the **NIHR (National Institute for Health and Care Research)**, was to take a deep dive into exploring all the factors and issues to do with this. Over two years we talked to dozens of people attending, running and supporting case-study Meeting Centres in England and Wales to help us find out how things work and what the challenges are. We also conducted a UK-wide survey to help understand what elements of Meeting Centres people most value.

The event got underway with background to the project provided by **Emeritus Professor Dawn Brooker MBE**. **Thomas Morton** then talked about what we did, before discussing the importance of the involvement of people with direct experience of dementia with **Nigel Hullah**, who chairs the 3 Nations Dementia Working Group. **Dr Ruby Swift** talked about potential barriers to accessing Meeting Centres and **Dr Michela Tinelli** (from London School of Economics and Political Science) presented about our 'Discrete Choice Experiment' survey to find out what people value about Meeting Centres. We then unveiled our series of **videos and booklets** which present the learning from the project (see below for an online link).

In the afternoon, **Dr Shirley Evans** provided a UK update on Meeting Centres, and the situation in England; **Deborah Gerrard** from Dementia Matters in Powys talked about Meeting Centres in Wales; and **Graham Galloway** from Kirrie Connections provided an update on Meeting Centres in Scotland, along with **Willy Gilder** from Edinburgh, who is living with dementia.



We were also privileged to have BAFTA-award winning film-makers capturing some of the event (see the Antwerp report on page 4!) – and the event was a chance to show our Meeting Centre blanket, which brought together squares designed and created by members at various Meeting Centres (see left).

To see our full range of videos, or download our booklets, please follow this link to our "blog" webpage: <https://scidemreview.wordpress.com/>

### ADS Travels!

In June we were invited to **Swansea University's Awen Institute**, along with various people working in dementia support in the area, to speak about getting Meeting Centres up and running in **South Wales**.

We also went along to the **13<sup>th</sup> National Dementia Care Awards**, held again in the grounds of Winchester Cathedral. There was a sing along to start, a thought-provoking talk with guest of honour, rugby legend Steve Thompson MBE, and once again handmade trophies by John Jacques.



**Shirley Evans & Thomas Morton, with Deborah Gerrard (Dementia Matters in Powys) & Gary Christopher (Awen Institute)**



**Trophies and a sing-along at the National Dementia Care Awards**

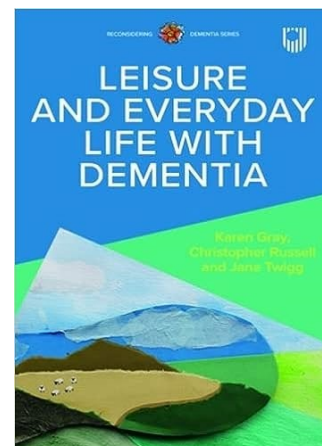


## Leisure and Everyday Life with Dementia book now available for pre-order

Edited by ADS's Dr Chris Russell, researcher Dr Karen Gray (former ADS), and physiotherapist Jane Twigg (who has experience living with dementia and caring for someone who has), this book examines leisure in the lives of people with dementia, emphasising the active role people with dementia can play as citizens in contributing to the world in which they live, given opportunities to make choices about their participation in it.

Contributors from multiple disciplines discuss involvement in leisure interests and activities from sports and physical activity, and the arts, to hobbies, games and crafts. The book is designed to align with the needs of those studying and working in nursing and dementia care, occupational therapy, social work, arts therapies, arts, health and wellbeing, sports and exercise, and gerontology.

Leisure and Everyday Life with Dementia is part of the Open University Press **Reconsidering Dementia** book series, jointly commissioned and edited by ADS Professor Emeritus Dawn Brooker and Dr Keith Oliver. **To pre-order your copy, visit:** <https://www.amazon.co.uk/Considering-Leisure-Christopher-Russell/dp/0335251307>



## Dementia-Friendly Environments App to be launched

Thanks to funding from Betsi Cadwaladr University Health Board, we have been able to work with Crystal Presentations to develop an App version of our suite of environmental assessment tools. The App covers the whole suite of tools – which you will still be able to download as pdfs from our website (see: <https://www.worcester.ac.uk/about/academic-schools/school-of-allied-health-and-community/allied-health-research/association-for-dementia-studies/ads-consultancy/the-kings-fund-environmental-assessment-tools/>) – and will be available in both English and Welsh. There will be a formal launch with the Health Board in early September, but we are hoping that the App will be available to download and use for free from early August. Keep an eye on our social media and website for updates.

## Courses: Study with ADS

### Post Graduate Certificate in Dementia Studies

In September we will welcome new students to our Post Graduate Certificate in Dementia Studies. Why not join? There is still time to find out more and sign up!

The course is provided on a distance learning basis and offered online. Building on the wealth of research evidence held by the Association for Dementia Studies, our priorities are to support students do their very best in their studies and enable them to use their learning to make a real difference to people's lives.

Interested in finding out more? Please watch this short film <https://youtu.be/ofYrLaW0xN4> and visit the webpages for the course, from where applications (either to study the full course or select an individual module) can also be made <https://www.worcester.ac.uk/courses/person-centred-dementia-studies-pg-cert>

Enquiries to the course leader, Dr Chris Russell [c.russell@worc.ac.uk](mailto:c.russell@worc.ac.uk) are most welcome. We look forward to hearing from you!



**Championing**  
physical activity  
for people affected  
by dementia



*"I've learnt so much about how physical activity can impact the lives of our customers with dementia and how I can begin to introduce it in an approachable, appealing way" (Student)*

Interested in providing opportunities for physical activity to people affected by dementia? Then why not find out more about our fully online course, 'Championing physical activity for people affected by dementia'? **Places are limited so please be in touch to avoid disappointment.**

The course is for colleagues supporting people affected by dementia, who are employed or volunteer in care, health, housing, sport, leisure, or community-based settings. It develops the knowledge and confidence of students to facilitate physical activity for people affected by dementia. There are live and interactive sessions with tutors, as well as a multitude of resources to support learning and practice.

**To find out more please follow this link:**

<https://www.worcester.ac.uk/documents/CPA-flyer-v2.pdf>

**or contact Course Leader Dr Chris Russell:** [c.russell@worc.ac.uk](mailto:c.russell@worc.ac.uk)

Please forward this newsletter on to others who you think would be interested.

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## Talking Meeting Centres in Antwerp and Amsterdam

In May, ADS Director Dr Shirley Evans went to the [23rd International Conference on Integrated Care in Antwerp](#) – and took part in the filming of a documentary about Meeting Centres in Amsterdam.

The conference was held at the Queen Elisabeth Hall (at Antwerp Zoo!) and was on the theme of *Care in action: how to work together, a participatory approach* - bringing together leaders, researchers, clinicians, managers, citizens and beneficiaries from around the world, engaged in integrated health and social care.

Dr Evans said: "It was very interesting and very insightful to attend such an event that was not dementia-focused but that has great relevance. I was delighted to be presenting with Graham Galloway, CEO of Kirrie Connections and leading on Meeting Centres in Scotland; Ron Coleman, a person with lived experience of dementia and founder of Deepness Radio; and his wife and co-founder of Deepness, Karen Taylor. Our theme was *Dementia Meeting Centres: People Affected by Dementia Take the Lead*. Our main messages were around the different contexts and the flexibility of the Meeting Centre model in meeting the needs of people affected by dementia in different communities; the grassroots community development approach; and the involvement and impact of people affected by dementia in the meaningful ongoing co-production of Meeting Centres."

After the conference the group from the UK was joined by a film crew (Kelman Grieg-Kicks and Ian Bustard) who are making a pilot film to pitch for a documentary about Ron and the Scottish Meeting Centre initiative. They travelled to **Meeting Centre Menno Simons in Amsterdam** where we were welcomed by Professor Rose-Marie Droes, the founder of Meeting Centres.

Dr Evans said: "We met Meeting Centre members and Maria (their wonderful co-ordinator), drank delicious lemonade and had a great chat sharing experiences of Meeting Centres in the UK and The Netherlands. The Meeting Centre is situated alongside other community provision and has a green and vibrant outside space for gardening and socialising. There were opportunities galore for some great filming, not least Rose-Marie and Joke Bos (manager of one of the first Meeting Centres) talking about the roots of Meeting Centres, going back to the early 1990s and how they developed."



**Top: Dr Evans at Antwerp Zoo, the venue for the International conference for Dementia care; Middle: Ron, Graham and Karen speaking at the conference; Bottom: Karen and Ron meeting people at Meeting Centre Meno Simons in Amsterdam**

## Say hello to...

## Faith Frost, Research Associate



Faith Frost joined us in 2017 as a research associate on the Namaste Care Intervention UK project. She has just returned from maternity leave after having her second baby and is now working on the NIHR funded research study, Crossing the Line.

Faith started her working life in a care home as part of the domestic team when she was 14. She built fond relationships with residents and staff there and knew she wanted to work with people living with dementia from then on. Before she started work as a researcher, she graduated from the Royal College of Art in London, where she focussed her studies on using sensory and creative stimulation to engage and communicate with people with dementia during their stay in hospital.

Faith is passionate about building strong working relationships with people who are engaging in research, and translating research findings in to considered, accessible design. Faith is now delighted to be back working alongside her colleagues at ADS.

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