



Reports from UKDC 2022

It's great to be with one another again, to share, listen and learn, said Graham Stokes, launching the 16th UK Dementia Congress (UKDC) in Birmingham, the first to be held in-person for three years.

That was how Professor Stokes, dementia care services director at event main sponsor HC-One, summed up the purpose of UKDC, adding one important rider: "This is an opportunity to ask questions. As Voltaire said, judge a person by their questions, not by their answers. Then we can go back from whence we came and do better."

Hundreds of practitioners, academics, people living with dementia and carers, who had gathered at Aston University's conference centre for a plethora of debates, workshops, performances and presentations, clearly planned to do just that. Helping to launch UKDC, Chris Gage, director of event partner Vibrant Communities, captured its spirit as he described the Open Space discussion forums taking place there: "There are pretty much no rules but there is one law: if you're not contributing and learning, go to the next place where you might contribute and learn."

Community-based interventions

As academic sponsor the University of Worcester's Association for Dementia Studies (ADS) showcased its ground-breaking research as PhD students Rosemary Davies and Nathan Stephens described their projects.

Davies wants to challenge the status quo by improving counselling for people when they have had a diagnosis of dementia. "Evidence suggests that older people with dementia are denied counselling and that doesn't sit well with me as someone whose parents are living with dementia," she said. "Counselling helps with resilience and managing change, and shares values of empathy and transparency with person-centred care. People can tell their story without pressure to be smart or logical."

Stephens is looking at scaling up community-based interventions like the Meeting Centres pioneered by the ADS in the UK. What are the principles and theory of scaling up early intervention schemes so that more people can receive timely help and improve their wellbeing?

"Scaling up can build a better society but it will require investment in the adult social care workforce, both paid and unpaid," Stephens said. "About half of those who need it don't draw on community-based support and it's important to fill these gaps in a failed system."

Three important numbers

Colin Capper listed three important numbers, the first of which is that 480,000 people living with dementia have not had an annual care assessment of their needs that they felt was helpful. Capper, associate director of evidence and participation for event partner Alzheimer's Society, added that 75% had had such an assessment in 2018 compared with

just 40% in 2022. That meant that only 120,000 people had had an assessment they regarded as helpful.

The second important number was 1,000, the number of people with dementia discharged from hospital every day. “A third of them will have been in hospital for a day or two with falls, urinary tract infections, etc, all things we could avoid if we were providing really good quality support,” Capper said.

All of which brought him to his third important number: “We’re putting an awful lot of pain and pressure on families. If these admissions were avoided, we would have saved the NHS £326 million a year.”

DEEP and tide

DEEP – the Dementia Engagement and Empowerment Project – is a lifeline, said Dory, who told the audience how DEEP groups across the UK had already had 17 in-person celebrations of the organisation’s tenth anniversary this year: “We’re all unique and wonderful but together we’re a masterpiece. For me DEEP was a lifeline not long after diagnosis. In lockdown, through the power of Zoom, DEEPers from all corners of the country shared so much support through a very dark time: “DEEP represents friendship, unity, kindness and respect. We’re all in the same boat and we can support each other.”

Also helping launch UKDC were carers’ group tide – Together in Dementia Everyday, a valuable resource of support for carers and ex-carers. Ruth Eley (chair of tide) introduced Mary Mitchell and Hazel Barrow, who related harrowing experiences through lockdown, excluded from a care home and unsupported at home.

A global perspective: Call to action

Paola Barbarino, CEO of Alzheimer’s Disease International, concluded her talk (via video) with a challenge that resonated strongly with those present:

- We call on the UK government to commit to the long-awaited reviewing of social care and ultimately improve access to post-diagnostic support for those living with dementia and their families
- We also urge the UK government to resume its international leadership role in dementia as it has fallen by the wayside in the latest years and this has been felt sharply in the international community especially at WHO, G7 and G20 level.

“We have seen a sharp decline in the UK government engagement at all levels”, she said, and the fact that the UK is not engaging at international level anymore “is also having a very detrimental effect on other countries and the international movement.”

Meeting Centres

Meeting Centres, a European concept promoted in the UK by the University of Worcester ADS, are local resources operating out of ordinary community buildings and offering friendly, expert advice to people with mild to moderate dementia and their families. As Shirley Evans, ADS’s interim director who heads up the project, told delegates, numbers of Meeting Centres have surged from two to 55 across the UK in six years.

Funding from the Shaw Foundation has helped the initiative spread rapidly and there have been “huge pockets of interest”, not least during Covid, Dr Evans said. In Wales, for example, there are now five Meeting Centres operating, while in Scotland there are 11 with six more in the pipeline, partly thanks to the release of a £1 million funding pot by the Life Changes Trust in 2021.

“From Stornoway to Prestwick we have live Meeting Centres, an explosion has happened in the last couple of years,” said Graham Galloway, chief executive of the Kirrie Connections

dementia support charity, who found out about the initiative reading an article in *JDC* five years ago. “When I read about the concept, it completely resonated with me as a local community-based approach based on the social model and not the medical model.”

Deborah Gerrard, chief officer of Dementia Matters in Powys, said Meeting Centres were an invaluable resource for the many small towns and isolated villages of Wales: “We had to close our doors during Covid, but we were determined to prioritise support online, providing information, stimulating activities including armchair exercise, support groups, telephone support and more.” Scotland now has some statutory funding for its Meeting Centres. Naturally, Gerrard would like it too for Wales.

Ron Coleman, who lives with dementia on the Isle of Lewis not far from the Stornoway Meeting Centre, vouches for the model. In a recorded message, he told delegates: “They are really important for the future in terms of dementia services, particularly as people living with dementia make up one third of the governing body for each centre. People with dementia are at the centre of a what each Meeting Centre should be. This ensures my agency and autonomy is maintained for a longer period.”

As ADS senior lecturer Mary Bruce was keen to point out, Meeting Centres occupy a significant but specific niche in dementia care and staff have to be trained accordingly. An online training course set up by ADS during Covid has continued and capitalised on its initial success. Before Covid 31 people had gone through the face-to-face training to acquire the knowledge and skills needed for Meeting Centres; now, 131 more people have taken five-week online training programmes. “Online learning gives us a massive opportunity,” Bruce says, “as we can connect and learn together and location no longer inhibits us. Students can study at their own pace and have come from as far afield as Singapore and South America.” It is important to realise that the kind of early intervention service provided by Meeting Centres contrasts with that of a day centre or dementia café, she adds. “Meeting Centres are a different part of the journey with dementia and every member of staff must be able to articulate those differences, which are about an ethos of adjusting to change.”

Trends to ‘keep an eye on’

Dementia diagnosis rates are “creeping up very slowly” following a slump during the pandemic, the government’s national clinical lead for dementia Professor Alistair Burns told UKDC. Running at 67% during the pandemic, diagnosis rates fell to 62% when memory clinics closed down. “There are probably about 40,000 people awaiting a diagnosis, but new referrals to memory assessment services are rising now towards pre-pandemic levels,” Professor Burns said. Government funding of £17 million had been made available to help memory clinics restart after the pandemic.

Burns said he had been concerned that the landmark achievement of a massive cut in antipsychotic prescribing for people with dementia would be compromised by the pandemic. Prescribing rates fell from around one-third of people with dementia in 2009 to as low as 9.2% in the following few years, only to track back up to more than 10% when Covid struck. “I was worried at the start of the pandemic that there would be an increase and it did go up a bit, but now we have seen a reduction again to around 9.5%. That is pleasing but something to keep an eye on.”

He added that trials of dementia drugs designed to slow cognitive decline were still promising, drawing attention to the monoclonal antibody treatments aducanumab and lecanemab in particular. “It’s a slow burn but I feel that we’ll get there in the end,” he said. On the subject of NHS winter planning, Burns hoped that more answers would be found to solve some sobering facts about hospital care: 25% of beds are occupied by people with dementia, 90% of people with dementia find hospital admissions to be frightening and confusing, and 43% of people with dementia in hospital are there due to urinary tract

infections, chest infections and conditions that should have been treatable in the community.

Equality, diversity and inclusion in dementia care

Culturally appropriate services were top of the agenda in the Tom Kitwood Memorial Address, which unusually had several speakers this year in a bid to give an all-round perspective on equality, diversity and inclusion in dementia care.

Dr Nadia Wahid, a GP and dementia lead from Birmingham, said that culturally appropriate services, such as speakers of South Asian languages, halal food and help with prayers, were unknown in her Pakistani heritage community. “There is a lack of awareness of dementia as a disease in the community itself and it is more often seen as part of old age,” Dr Wahid said. “It is a barrier to getting the right care and support to people.”

Lee Allen, Dementia Connect local services manager in the Black Country, said that everything depended on providing the right support by the right people at the right time: “When we were developing culturally specific resources for the Punjabi speaking community, we decided to rock up at the local temple rather than some health centre,” he said. “They could go on our ‘dementia bus’ and ask questions, we had resources in Punjabi, and we had a monthly broadcast on a Punjabi radio station. People won’t come to you if they don’t know what you do - there’s lots of work to do raising awareness.”

Barry Moss, a dementia advocate for the LGBT+ community, believes there could be 68,000 people in that community living with dementia. He detailed the widespread fear of prejudice and how older gay men in particular may have “terrible memories of being persecuted in the times before decriminalisation in 1967”. Moss called for services to put up more visual indications that their spaces were safe for LGBT+ people, including things like rainbow lanyards.

David Truswell, director of Dementia in Dub, introduced Ronald Amanze, a music producer living with dementia, who spoke of his ordeal in care services following a stroke. But DEEP helped him restore his sense of self-worth and he read out his poem, which can be found on the Dementia Diaries website.

This Memorial Address was chaired by Karan Jutlla, senior lecturer in health (dementia lead) at the University of Wolverhampton, who reflected on how Tom Kitwood focused on the psychological and human needs that have to be met in all of us and particularly people with dementia.

“It’s even more important when people have experienced some form of discrimination or exclusion,” Dr Jutlla said. “They need comfort, a sense of identity, a sense of attachment – there is a real need for a sense of belonging, which is what inclusion is all about. So we need more funding, a diverse skilled workforce and diverse leaders who can relate to some of these experiences we’ve been sharing today.”

She concluded: “You can’t be person-centred without being culturally inclusive, and you can’t be culturally inclusive without being person-centred. So why is inclusivity seen as a separate agenda?”

ADAPT film: “Kiran”

“Kiran” is the title of a short film shown at UKDC about the experience of dementia in the South Asian community. The film is based on real life, depicting the traumatic consequences for a British Asian woman of caring for her mother and the apparent inability of service providers to give culturally appropriate support. Produced by the ADAPT South Asian Dementia Pathway, the film can be seen at www.raceequalityfoundation.org.uk/adapt

Advanced dementia in care homes

Effective communication, rewarding activities and image recognition all formed part of a late afternoon discussion on advanced dementia in care homes. The session focused on findings from new research on how people with advanced dementia can be better supported.

Zoom sessions: Nancy Brown, a PhD student at Edinburgh University, has 18 years' experience in dementia care at a memory day centre in Jerusalem and her study focuses on the use of video technology by 25-day centre attendees with advanced dementia. "When the day centre was locked down, there were no family visits, social isolation and stress," Brown says. "We immediately mobilised the clients in Zoom sessions, and I was just taken aback at how well they adjusted to this kind of tech."

"I trained caregivers in using the tech for things like music, movement and sharing items from home, and the results were extraordinary. Older people can Zoom even in the later stages of dementia; they demonstrated pride sharing items from home and they recognised people on the screen. One lady, who is 100 years old, turned to her daughter and said, 'These are my friends!' It doesn't get better than that."

Magic tables: Rachel Fox, who is researching her PhD at Leeds Beckett University, was looking at the use of "magic tables", like Tovertafel, in care homes as an activity primarily for residents with advanced dementia. She has found many plusses but some barriers to the use of magic tables. "They're a good, stimulating activity for people in the later stages, providing fun and laughter and facilitating social interaction," Fox says. But barriers included set-up time, staff availability, portability and the expense of paying for additional games.

Talking Mats: Talking Mats are a well-established tool for helping people with communication difficulties produced by a social enterprise in Stirling. April Dobson and Isabelle Latham described how they have become integral to practice at Hallmark Care Homes. Dobson became an accredited Talking Mats trainer and has trained 52 staff, including the senior leadership team over the past 18 months. The tool is used to communicate with residents for things like care plans, pre-assessment to support transition into the care home, the annual survey, and to support people in expressing an unmet need. Dr Latham, who has evaluated the impact, said that across Hallmark care homes Talking Mats were useful for between 25% and 50% of the population living with dementia. "They tended to be used where there were difficulties communicating verbally or people were expressing needs through behaviour, although they had to have sufficient cognitive ability and be visually able," she said. Latham found that there were fewer reports of distressed behaviour, greater staff awareness of residents' interests around activities, and better relationships between residents and staff. But 46% of staff who had received the training had not been able to use the Talking Mats in all the ways they had hoped, partly due to lack of time.

Diagnosis and memory clinics

It can take up to two years from referral to a memory clinic to receive a dementia diagnosis if you include the additional four-month delay caused by the pandemic. In a session arranged by Alzheimer's Society, Gloucestershire GP Dr Claire Kingswood explained her local initiative to keep the diagnostic process within primary care where possible and reduce delays to a fraction of what they are now.

"We want to drive diagnosis in primary care; GPs give life changing diagnoses all the time, so why not dementia?" Dr Kingswood said. "The idea started before Covid, but Covid gave it a nudge to get going."

The approach depends on a multidisciplinary team – GP, consultant, community dementia nurse, memory assessment service (MAS) nurses, frailty nurses – who take joint responsibility for the diagnosis. It depends on the notion that some diagnoses are much simpler than others, requiring no CT scan or time-consuming referral to a memory clinic. “It’s a lot quicker – people can be diagnosed in a month rather than waiting 12 months in some cases,” Kingswood says. “We always ask the key question, would the family be surprised if they had a dementia diagnosis, and the answer is usually no. “We’re not trying to replace memory clinics because we need those for the trickier cases, but we are trying to free them up so that not every person who needs a diagnosis ends up on their waiting lists.”

By reducing the number of memory clinic referrals, such initiatives may help return diagnosis rates to 67% after they fell to 62% during the pandemic. But Professor Farooq Khan, NHS clinical lead for dementia in the West Midlands, told the session audience that new drug discoveries would only increase pressure for diagnoses.

“Monoclonal antibody drugs for dementia will definitely come and that will drive demand for early diagnosis so that they are effective,” said Professor Khan. “Drugs will be targeted on the early stages – mild cognitive impairment level – and in readiness for that we will need to have an early diagnosis push. But we might be doing a blood test rather than a head scan, so the time will come when we work in a different way.”

Much-needed focus on children’s needs

“Children are invisible in the dementia agenda,” said Professor Al Aynsley-Green, “but bereaved children need to be listened to, encouraged to talk about how they feel, and have access to support to cope with their fears and anxieties.” Professor Aynsley-Green, an eminent paediatrician and England’s first children’s commissioner, lost his wife to dementia earlier this year and rediscovered the pain of bereavement. The first time was when he was aged 10 and his father died unexpectedly.

“Childhood bereavement is not given the attention it deserves,” he says. “It can lead to loneliness, bullying and poor achievements in school... Please think about the importance of grief, even in a very young person. We need to listen.” (See article in this issue of *JDC*.)

Resolving stress and distress

Can dementia care settings become therapeutic communities that mitigate if not resolve stress and distress? Two of the speakers tasked with answering this thorny question - Graham Stokes and Tracey Carter from HC-One - sounded optimistic but they were also clear that change would only come at a price.

Microskills in communication

Consultant clinical psychologist Professor Ian James – based at the CNTW NHS Trust and well known for his work on behaviours that challenge – described CAIT-online, a new stage in the development of the Communication and Interaction Training programme for care staff. CAIT articulates the communication and interaction skills displayed by all those staff who regularly help to de-escalate behaviours that challenge. The key is to understand what these staff do and conceptualise it as a set of “microskills”, incorporating them into CAIT as an evidence-based training programme. The online programme comprises 300 slides, video clips, animations, articles and much else, plus a two-day introduction by Professor James and ongoing supervision.

Music on prescription

Social prescribing has been growing in significance and “music on prescription” is one form of it tested out by Hallmark Care Homes among its residents. Dr Isabelle Latham, Hallmark’s researcher in residence, explained how music on prescription arose from a partnership with Musica, a social enterprise that helps to integrate music into the daily care of people living with dementia. Residents who might be social isolated or displaying behaviours of concern were given the music “prescriptions” (based on highly individual preferences) in 5 – 9 sessions of 30 – 60 minutes with a community musician over a period of 12 weeks. Results included improved posture and movement, improved mood, more smiles, laughter and eye contact, better engagement with others, and reduced distressed behaviours. “We’re seeking to broaden it out to dance and other arts-based interventions,” Dr Latham said.

Life on the frontline

In summer and autumn 2020, 20 care home workers told their stories about the impact of Covid-19 to Bradford University researchers, providing what associate professor Dr Andrea Capstick describes as a “strikingly original” body of first-person testimony about life on the frontline of the pandemic. As a result, Dr Capstick had the idea of turning it into a piece of “verbatim theatre” taking the form of a 25-minute play called “Voices from the Frontline”, which has been performed twice in 2022. Speaking at UKDC via video, she said the workers’ stories conveyed the huge uncertainty and confusion about what to do in the face of Covid, the impact on people living with dementia and their families, and the impact on the wellbeing and mental health of staff themselves. “We’re looking for other venues and events in which to perform the play,” Capstick said. “If we can do this more widely, it could have an impact on the inquiry into the government’s handling of Covid and help make sure nothing like this happens again to care home residents and staff.”

Nutrition in hospital

Imperial College NHS Trust presented their successful Nutritional Support in Hospital (NoSH) Pathway, a nutritional intake plan for hospital patients with dementia where their eating and drinking is giving marked cause for concern. Under the “enhanced support” plan, patients are given regular reviews and goals are set. Their preferred music may be played at mealtimes and aroma stones may be used since evidence suggests that these can increase nutritional intake. A NoSH assessment is conducted giving a full history, a pain assessment and a physical assessment of weight, mouth sores, and constipation, among other things. The scheme has been running for five years with a significant impact on hydration levels, urinary tract infections, pneumonia incidence and distress behaviour, all of which have reduced.

Reports by Mark Ivory