

# The Journal of DementiaCare

For all who work with people with dementia

Vol 31 No 6 November/December 2023



**Love  
through  
double  
glazing**

**Also inside  
this issue:**

■ Grief and dementia

■ Generations together

■ Digital technology

■ DiADeM for diagnosis



learning | sharing | inspiring

# Our new name is Dementia Community

**Dementia Community** is a Charitable Community Benefit Society, a membership cooperative that provides learning and networking opportunities for the dementia care community. Community members own a £1 community share in **Dementia Community**.

Dementia Community is the organisation that provides:



## You are warmly invited to join us!

Membership benefits include a discounted subscription price for the *Journal of Dementia Care* (published bi-monthly), reduced delegate fees for the UK Dementia Congress and other events that **Dementia Community** will host. Plus a members' newsletter, a discussion forum and many other opportunities for networking and involvement. **Dementia Community** has co-produced and adopted the following values:

- ▶ **Trust:** steadfastly believing that everyone has potential and a unique personhood to be honoured and upheld. Confident that collectively and individually we can improve the experience of dementia care.
- ▶ **Inclusive community:** embracing, supporting, valuing and sharing contributions from everyone committed to our common purpose.
- ▶ **Inspiration:** igniting creativity, energy and new possibilities.
- ▶ **Quality:** equipping the delivery of excellence in care and support for those affected by dementia.
- ▶ **Learning:** encouraging, equipping, sharing and celebrating personal growth so that people enjoy their full potential and all our dementia care communities flourish.

**Our core purpose is to connect and empower the dementia care community and our vision is of a world where all people in the dementia care community feel connected, informed, empowered and purposeful, and are actively engaged in co-producing changes that improve everyone's experience of dementia, in care and in wider society.**

By reading the *Journal of Dementia Care*, attending the UK Dementia Care Congress or The National Dementia Care Awards you will have already experienced our commitment to combining research with best practice, and valuing those who are passionate about improving the experience of dementia. Whether you are working alone, a care provider, a commissioner, a researcher, a person living with dementia or a family carer our invitation to join our Dementia Community is warmly extended to you.

Join our community and subscribe to the *Journal of Dementia Care* at

[www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)



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# Who we are

## Our Founder



**Dr Richard Hawkins**

Having worked for more than thirty years in the dementia care world, I have learned that simply wanting to provide the best possible dementia care is not enough for those providing care to people living with dementia. You need much more. You need to learn from trusted sources of information and guidance, you need to share your knowledge and enthusiasm, and you need to feel inspired yourself and want to inspire others. Our Dementia Community provides you with the means to make a difference, by learning, sharing and inspiring.

## Our Staff



**Sue Benson**

I've been deeply touched by the terrific work and inspiring ideas described in so many wonderful articles, presentations and awards entries over the years. I hope to nurture that inspiration and support to continue, to grow and widen into an all-embracing dementia community.



**Isabella Barclay**

Bringing people together and working towards positive change are key motivators for me, and 'Dementia Community' achieves both of these things within dementia care.



**Melanie Blake**

I am proud to be part of 'Dementia Community', making a difference to how people living with dementia are regarded, respected and supported.



**Beth Britton**

'Dementia Community' is a fantastic way for everyone living with, working in, or connected in any way with dementia, to come together. I look forward to some great collaborations.



**Beth Lang**

I take pride in being a member of the 'Dementia Community' as I aspire for knowledge and understanding to reach as many individuals as it can.

## Our Board



**Karen Harrison Denning**

The sharing of expertise and knowledge that comes with being part of this particular community has been a great enabler throughout my career. Whatever your own relationship to dementia, whether you have a diagnosis of dementia, are caring for someone with dementia, or working as a professional with families, this 'Dementia Community' will provide you with a sense of being an important part of the larger whole.



**Dr Kellyn Lee**

I've attended many conferences in my career but the UK Dementia Congress was the first I really enjoyed. It was a community of people really driven to change the current landscape of dementia care, importantly including those who are living with the disease. Using evidence based approaches teamed with common sense we are in a great position to really make a difference.



**Suzanne Mumford**

The *Journal of Dementia Care* and the UK Dementia Congress have embraced professionals working in academia and health and social care together with people with lived experience in an inspiring community of practice. The evolution of "Dementia Community" offers a unique opportunity to build on this achievement with the genuine intention of improving care through dialogue, publications and events.



**Maria Parsons**

In a world full of challenges, we can easily lose heart. By being part of this community, we will be stronger. We will be empowered to bring about change with and for people living with dementia, here and now. We can, together, learn and share, build and connect through our website, the *Journal of Dementia Care*, national events, seminars, discussion groups, networks, and other means of relating to each other, both face-to-face and virtually.



**Jude Sweeting**

The *Journal of Dementia Care* and the UK Dementia Congress have motivated and inspired me for 25 years. I am genuinely excited by the next step we have taken in becoming a Dementia Community (Benefit Society) enabling us to expand our learning and networks together. Everyone has a voice in our new 'cooperative' structure which calls for us to form a unique and powerful collective.



**Barbara Stephens**

As Society Secretary and co-founder of Dementia Publishing Community Benefit Society, it is very rewarding to reach this milestone. I am delighted to be serving the team that is launching 'Dementia Community' providing a unique opportunity for us to unite, make our voices heard and become a powerful force for change.



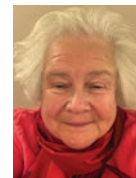
**David Truswell**

Inclusion is an important part of the dementia experience we must all keep pushing for, especially when it seems – increasingly – that the voices in favour of exclusion, across a whole raft of everyday social experiences, become more and more amplified. 'Dementia Community' is an opportunity to press forward collectively and support each other in a spirit of hope and inclusion.



**Jane Ward**

As my mother's full-time carer, I experienced first-hand how difficult it is to support someone without knowledge and understanding of how dementia affects every aspect of life. The *Journal of Dementia Care* is a crucial source of up-to-date information about gold-standard dementia care, vital for all people involved in caring for a person with dementia. I am proud to be part of 'Dementia Community' and to support its work going forward.



**Kate White**

I look forward to being part of the Dementia Community team bringing my experience as a former care partner for John who lived with Alzheimer's. I feel we have a unique opportunity to promote inclusive change: including and listening to people with dementia and their families, bringing together a community of informal and professional carers, trainers and researchers in the field of dementia.

### 17 Love Through Double Glazing Innovative work by Vamos in the pandemic and beyond

Vamos is a full mask theatre company known for its performances and workshops exploring and supporting people living with dementia. Janie Armour highlights the innovative work it has done recently, particularly during the Covid 19 pandemic.

### 19 Grief and Dementia: In conversation with Dr Esther Ramsay Jones

We are familiar with the idea of grief after death, but a carer may also experience "anticipatory grief" while a loved one is still alive. In conversation with Emma Smith, psychotherapist Esther Ramsay Jones explains what it means.

### 21 Evaluating a reminiscence project (RYCT) in a residential care home

As a well known arts-based reminiscence programme, Remembering Yesterday Caring Today has traditionally been delivered in community settings. Sandie Woods set out to discover how it would work in a care home, and shares her findings.

### 23 Turning a crisis into an opportunity: taking dementia training online

Lockdowns during Covid gave the charity Understanding Dementia a chance to rethink its approach to training. Interactive online courses now provide a cost effective means of training family carers and professionals, turning a crisis into an opportunity, says Shirley Pearce.

### 25 Re-inventing a space for intergenerational use

A former day care centre next to Suffolk care home "the Dell" has been reinvented as an intergenerational space where care home residents socialise with tenants of Dell View, independent living for people with learning disabilities. Joy Henshaw shows how the programme is proving beneficial for older and younger generations.

### 27 Making a diagnosis of dementia using DiADeM

DiADeM is a tool for diagnosing advanced dementia when it is neither necessary nor appropriate to involve local memory services. Mark Kitchingham and Kevin Tan describe a project to extend its use from care homes to people's own homes.

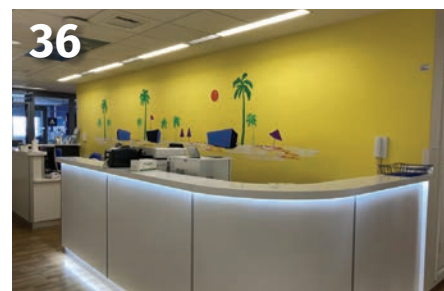
### 29 Digital technology as a tool for predicting deterioration in frail older people: A case study

Digital technology can provide a comprehensive picture of a care home resident's health and wellbeing and identify any signs of deterioration. Anita Astle explains how this was done in her care home.

### 31 Introduction to the SPACE Principles – in hospital and prison

Caring well for people with dementia is an ambition enshrined in the Royal College of Nursing's SPACE principles, which have gradually been extended from hospitals to other dementia care environments. Ruby Fitzhenry and colleagues discuss their impact on two settings, a large NHS trust and a prison.

Cover photographs: Sincere thanks to Vamos Theatre, all involved in their performances and workshops, and Graeme Braidwood Photography



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**The Dementia Engagement and Empowerment Project** –  
people living with dementia (with Rachael Litherland)

**The 3 Nations Dementia Working Group** –  
Alzheimer's Society (with Allison Garoghan)

**Karan Jutla** – University of Wolverhampton

**David Truswell** – Dementia Alliance for Culture and Ethnicity

**Dr Nadia Wahid** – Dementia Primary Care Clinical Lead,  
Birmingham

**Kate White** – former care partner, activist, writer & researcher

# How lived experience shows us the way

by Mark Ivory



It was our 17th UK Dementia Congress (UKDC) early in November and sadly for me my last. There has always been a special atmosphere at UKDC, quite unlike that of other conferences I've attended, and this year I found myself wondering what accounted for it. I'm stepping down from the editorship of this journal after nine years, not so very long when you consider that JDC was founded 30 years ago by Richard Hawkins and Sue Benson, whose vision continues to guide everything that we do.

"There aren't any good, brave causes left," says Jimmy Porter in the classic drama *Look Back in Anger*. Well, how wrong can you be, because Jimmy clearly wasn't reckoning with dementia care and all those who fight for the cause of people living with dementia and their carers every day! It is because of all who fight the good fight that so much has changed in recent decades. "We put the person first and the dementia in second place, that's been the breakthrough of the past 30 years," as Graham Stokes from our main sponsor HC-One put it at the start of this year's UKDC.

The philosophy of "putting the person first" is what inspired this journal in the first place. Our first ever issue (November/December 1993) carried a seminal article by Tom Kitwood that laid out that philosophy but was under no illusions about the difficulty of implementing it. All too often, not just in dementia care but more widely, we are treated as objects of the professional and bureaucratic gaze to be manipulated and managed rather than understood. To put the person first, Kitwood said, was no trivial matter: "It is to be at odds with a culture, an inherited social tradition that works in many respects against the person."

I think this helps to answer my question about what makes UKDC distinct. It is profoundly counter-cultural. It does not assume that science, medicine, government and all the rest have all the answers to the problems that press down on us; instead, people living with dementia, carers and their allies set the tone of the event, talking about their lived experience and how the care system might best respond. We are reminded that, vital though science, medicine and psychology are, understanding individuals as persons is the principal thing.

No doubt we frequently still fail to put the person first. For example, our last issue was devoted to equality, diversity and inclusion (EDI), and we know that much remains to be done before we can honestly say that good dementia care embraces everybody. But, thanks to all the people who have championed this "good, brave cause," it is evident that significant progress is being made.

Tom Kitwood dared to imagine good dementia care as the microcosm of a better society, "a fragment of what may become a gentler, kinder and more understanding pattern for modern life." In its own small way, UKDC regularly shows what that might look like, and that, too, is part of what makes it special. ■

#### **Writing for JDC:**

Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? Do you have a strong opinion you would like to express? We welcome letters and contributions that promote discussion and debate about dementia care. Contact the editor, Mark Ivory: mark@dementiapublishing.community

**The Journal of Dementia Care** is a multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and residential care homes, day units and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The *Journal of Dementia Care* is grounded firmly in practice and provides a lively forum for ideas and opinions.



# News round-up

News and Resources are regularly updated on our website  
[www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)

## Raising the barriers: APPG report

As diagnosis rates continue to languish below government targets, a new parliamentary report shows that where you live has a massive impact on whether you get a timely diagnosis of dementia. The All-Party Parliamentary Group (APPG) on Dementia has published *Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England*, highlighting wide variations in regional diagnosis rates, from 88.9% in Stoke on Trent to 49.3% in Swindon. Average diagnosis rates across England hit a low of 61% during the pandemic and have risen to just 64.1% since then, still well below the government target of 66.7%.

Findings from over 2,100 people surveyed by the APPG inquiry found that transport is a major barrier to diagnosis. The report recommends that local integrated care boards increase service provision to ensure that people can get a diagnosis closer to home.

Ethnicity was another factor with people struggling to access diagnostic assessments in their own language.

“When we’re trying to understand the challenges ethnic communities face getting a dementia diagnosis, we need to look behind the headline figures,” said Dr Karan Jutla, Alzheimer’s Society ambassador and dementia lead for Wolverhampton University. “From my work I know very, very, very few people from these communities are presenting themselves to services. To be able to quantify this we need to start recording the ethnicity of people who do come forward.”

APPG co-chair Debbie Abrahams MP said the report showed that diagnosis rates were a postcode lottery, adding: “It could not be more clear now that we need integrated care boards to introduce strategic local plans to increase access to diagnostic services. Likewise, the government must significantly increase scanning capacity and workforce.”

[www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf](http://www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf).

## Creative relationships in care homes

Research from Anglia Ruskin University shows how care home staff can be empowered to provide creative activities for residents. The outcome of a four year project with care home provider Excelcare, arts charity Magic Me and four other arts organisations, the report illustrates how to build relationships between artists, residents and staff through participation in the creative arts. It finds that arts activities were powerful in fostering engagement and meaningful moments for staff with residents.

“Our evaluation found that the pandemic provided a unique challenge for the artists and staff, but meant that, when activities resumed, the sense of joy and worth were heightened not only among residents, but among staff and artists,” said Professor Hilary Bungay, who was lead investigator for the research project, called Dare to Imagine. “Collaborative working between artists and care

home staff involved embracing artists’ creative skills, human approach, and adaptability, as well as valuing the knowledge and expertise of care home staff and supporting them to take on creative roles.”

For the report, go to <https://magicme.co.uk/resource/dare-to-imagine-artists-residencies-in-care-homes-report>.

## Risk factors for ethnic groups

Research from UCL, published in the journal *PLOS One*, looked at modifiable dementia risk factors by ethnic group and found that hypertension conferred a higher risk of dementia in black people compared to white people, while a combination of hypertension, obesity, diabetes, low HDL cholesterol, and sleep disorders conferred a higher risk on South Asian people.

Compared to the effects on white people, hypertension had 1.57 times more impact on dementia risk in South Asian people and 1.18 times more impact in black people.

Lead author Dr Naaheed Mukadam said: “Dementia is a growing burden on our ageing population, and this study adds to findings that this is disproportionately affecting some ethnic minority communities. Not only are some risk factors for dementia more common among ethnic minority groups, but these factors also have greater impacts on dementia risk than among the white population. We need more prevention efforts tailored for ethnic minority communities to ensure that dementia prevention is equitable, helping health professionals become culturally sensitive and able to inform their patients about dementia risk factors.”

Previous research by Dr Mukadam found dementia rates 22% higher among black people in the UK compared to white people, with black and South Asian dementia patients dying younger and sooner after diagnosis.

## Counselling benefits: dementia and depression

Older people with dementia are missing out on vital talking therapies that could significantly improve their lives, according to the British Association of Counselling and Psychotherapy (BACP). Taking the opportunity of World Alzheimer’s Day (21 September) to highlight the problem, BACP warned that depression was often confused with dementia and that the depression was wrongly left untreated. Jeremy Bacon, third sector lead at BACP, commented: “In the early stages of dementia, it’s often assumed that all the changes we see in patients are all related to dementia, when in fact they can be symptoms of depression – which are treatable, reversible, and not part of dementia’s neurological condition. Living with dementia commonly gives rise to feelings of depression, anxiety, and loss as people struggle to adjust to changes in their cognition, behaviour and personality.”

## Young onset dementia

For the first time NHS England has released data revealing that 34,412 people in England have been diagnosed with young onset dementia (YOD). But the NHS estimates that an additional 19,194 people in this age group may be undiagnosed, putting the potential total population of

people with YOD at 53,606. “Until now, NHS England didn’t have a clear picture of how many people have young onset dementia as they weren’t fully collating diagnoses,” said Alzheimer’s Society head of national influencing James White. “With this new data, we’re on the way to building a better understanding, but we believe the numbers don’t reflect the true picture,” he added.

### **Homeshare solutions**

More should be done to offer homeshare arrangements as an option when people leave hospital, says the Homeshare Association in a new report, which identifies dementia and poor mobility as the primary drivers for seeking these arrangements. More information at the link below and see *Perspectives*, page 12.

<https://homeshareassociation.org/wp-content/uploads/2023/06/Homeshare-Association-Annual-Report-2023-for-email.pdf>

### **‘What works’ for retaining staff**

Around 390,000 people left their social care jobs in 2022/23 and around a third of them left the sector altogether, Skills for Care said in its annual *State of Social Care* report. In spite of the numbers leaving the sector, vacancy rates fell to 9.9% from 10.6% the previous year, although the reduced figure still represented 152,000 vacancies on any given day.

Skills for Care, which has promised to publish a national workforce strategy, sets out “what works” for retaining staff, boiling it down to five factors: being paid more than the minimum wage, not being on a zero hours contract, being able to work full time, being able to access training, and having a relevant qualification. Employees were twice as likely to leave their jobs if none of these applied with a turnover rate of 48.7% compared with 20.6% when all of them were the case.

There had been “some improvements” in workforce capacity, Skills for Care said, thanks to more international recruitment, more posts filled, fewer vacancies and less staff turnover. “It’s good to see green shoots for the sector and workforce in our latest report, which is testament to the hard work that’s gone into tackling the recruitment and retention challenges that we face,” said CEO Oonagh Smyth. “But the challenges haven’t gone away.”

National Care Forum CEO Vic Rayner commented that turnover rates were still “unacceptably high.” She added: “We believe a national workforce strategy cannot come soon enough, and we are committed to working with Skills for Care to ensure it hits the spot.”

### **The Filo Project—global winner**

The Filo Project, which provides an innovative model of day care for people with dementia, has been announced as one of just four global winners of a prestigious international award. Run by the Fit for Life Foundation, the awards are aimed at not-for-profit social enterprises promoting fitness and health among older people. Under the Filo scheme, carefully selected hosts welcome into their homes small groups of older people with early to moderate dementia, many of whom are socially isolated. It won the award for showing that an intimate care setting allows people with dementia to grow in confidence and reduce their risk of health issues associated with isolation.

### **Prevention: lifestyle changes**

Up to 73% of dementia cases could be prevented by lifestyle changes, a new study of 344,000 people over 15 years suggests. Researchers behind the study, published in the journal *Nature Human Behaviour*, investigated 210 modifiable risk factors and found that personal measures such as increasing physical strength, more leisure and social activities, more time at the gym, less time watching TV or a computer screen, better dental health and drinking more water all contributed to a reduction in risk.

Conversely, unemployment, low income, diabetes and high blood pressure were among factors raising risk. “We have probably under-estimated the power of prevention,” said Professor David Smith, University of Oxford, one of the study authors. “Even this figure of up to 73% of cases preventable could be higher if a person’s omega-3 and B vitamin status, measured by a blood test for homocysteine that any GP can do, were taken into account.”

### **GPs and assistive technology**

Many GPs believe that assistive technologies could bring substantial benefits to their patients with dementia, particularly devices like an intuitive app to help them navigate their community, gadgets reminding them to take medications, and smart glasses to tell them who they are looking at.

According to an Alzheimer’s Society survey, 76% of GPs worry that their patients may become trapped in their own homes because of anxiety or fear about getting lost. Two thirds of GPs told the poll, conducted by the Longitude Prize on Dementia which is funded by the Society, they would like to be able to prescribe assistive tech to their patients when diagnosed with dementia.

Other findings from the GP poll were that 88% thought people with dementia would have more fulfilling lives if they can stay in their own homes, 77% thought people would live longer if they stayed at home, and 87% believed that the majority of their patients with early stage dementia would benefit from technology designed for their condition.

### **Lifestyle coaching benefits**

Lifestyle coaching could help to slow cognitive decline in people with Alzheimer’s disease, according to a new study which found that a coaching regime that included computerised brain exercises could provide more cognitive benefit than Alzheimer’s drugs. Published online in the *Journal of Alzheimer’s Disease*, research by the Institute for Systems Biology (ISB) in Seattle compared 24 patients receiving standard care with 31 patients receiving standard care plus telephonic personalised lifestyle coaching.

“Over a two-year period, our trial showed that personalised lifestyle coaching in addition to standard care decreases the amount of cognitive decline in patients on the Alzheimer’s disease spectrum,” said ISB senior research scientist Dr Jared Roach, who led the trial.

### **Social prescribing - the power of music**

The Power of Music Fund, a scheme to promote social prescribing for people with dementia and their families, opened on 22 November for new grant applications. Musical initiatives for carers and people with dementia, such as dementia choirs, can apply for multi-year grants of

either £1,000 or £2,000 annually, depending on the size and scope of the activity. Managed by the National Academy for Social Prescribing, the fund will also award one larger grant of £500,000 for a centre of excellence. Among the academy's plans is to research and evaluate a model of provision bringing the health system and community groups together so that music can play a key role in dementia care across the country.

<https://socialprescribingacademy.org.uk>

### Blood biomarker challenge

Dementia blood tests could be available on the NHS in five years, Alzheimer's Society claims, after launching the next phase of its Blood Biomarker Challenge, a £5 million award for the research team judged most likely to deliver. Applications for the challenge, a collaboration with Alzheimer's Research UK and the National Institute for Health and Care Research, have now closed and a panel of experts is due to announce the winner in January. "It's hoped the tests will be able to diagnose different forms of dementia, such as Alzheimer's disease, earlier and more accurately than current methods," said Fiona Carragher, director of research and influencing at the Society.

### Funds diverted from social care

More than a billion pounds of the £1.7 billion committed by the government to reforming adult social care has been diverted to other care priorities, the National Audit Office (NAO) says in its report on Reforming Adult Social Care in England. The money was a downpayment on a 10-year plan to overhaul adult social care, announced in December 2021, but two years on the NAO says the plans have been scaled back and are still behind schedule. Only £729 million of the £1.7 billion is likely to be spent by 2025 as planned, effectively a 58% cut in the budget.

While there have been signs of improvement, social care remains under "significant pressure", the NAO says. Long waiting lists, up by 37% in the six months to April 2022, and adult social care vacancies up by 173% in the past decade are among the problems identified.

Calling for a long-term funded plan to reform social care, the NAO says the government must show how it will deliver. "Adult social care reform has been an intractable political challenge for decades," said NAO head Gareth Davies. "Government has set out its ambition to meet this challenge and now needs to demonstrate how it is delivering on these plans."

### Tony Husband

Cartoonist Tony Husband, a *Private Eye* satirist who also produced artwork for dementia organisations, has died in London. His work was featured in the *Journal of Dementia Care* earlier this year in an article on his book with Gina Awad, "United; Caring For Our Loved Ones Living with Dementia" (*JDC* Jan/Feb 2023). "Our work together over the past six years has been prolific," commented Awad, who also works with Exeter Dementia Action Alliance. "The shock and loss is beyond words. All the dementia charities have worked with Tony but I feel the most blessed as we did so much." See Dementia Diaries for another tribute to Tony.

### Peter Mittler – life story

A book documenting the life of human rights campaigner Professor Peter Mittler CBE has been published by the My Voice project, run by Manchester Jewish social care charity The Fed. Professor Mittler, who has dementia and has been active in the field, left Nazi-occupied Austria as an eight-year-old and came to England on the Kindertransport. He studied psychology at Cambridge University and went on to become director of Manchester University's Hester Adrian Research Centre. The book, "Let no one be excluded: A life dedicated to human rights for all," was presented to him in a private ceremony at the Belong Morris Feinmann home earlier this year. Here is a link to the book <https://myvoice.org.uk/book-name/let-no-one-be-excluded-a-life-dedicated-to-human-rights-for-all>.

### Value of early diagnosis

"We can diagnose and start to manage dementia earlier than we do currently," the Chief Medical Officer's Report on Health in an Ageing Society has admitted. Professor Chris Whitty's annual report touches on dementia in several places, including in a chapter on secondary prevention and early diagnosis in older age. "An early diagnosis and access to the right services and support can help people take control of their condition, plan for the future and live well with dementia," it continues. The report presents a comprehensive review of how people can achieve a healthier old age and the way services should be structured to support it. Fiona Carragher, Alzheimer Society's director of research and influencing, said: "We welcome the light that this report shines on the challenge of an ageing society and its recognition of the value of earlier dementia diagnosis." [https://assets.publishing.service.gov.uk/media/654cecdc5d6095000dbec88c/CMO\\_s-annual-report-2023-health-in-an-ageing-society-full-report.pdf](https://assets.publishing.service.gov.uk/media/654cecdc5d6095000dbec88c/CMO_s-annual-report-2023-health-in-an-ageing-society-full-report.pdf).

## Journal of Dementia Care Webinars

For up-to-date information and to book, go to [www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)—Events—Webinars

**Tuesday 28 November 2023, 2-3pm**

**Findings from the Memory Services National Accreditation Programme**

**Presenters:** Claudelle Abhayaratne, Project Officer, Royal College of Psychiatrists; Jemini Jethwa, Programme Manager, Royal College of Psychiatrists; Rhian Russell Owen, Senior Improvement Manager, NHS Wales Executive.

**Tuesday 30 January 2024, 2-3pm**

**Innovations in care and culture: The Montessori Way using Dementia Care Coaches**

**Presenters:** Lynne Phair, independent consultant nurse with colleagues from Milford Care

This webinar will describe how the University of Worcester FITS into Practice Dementia Care Coach programme was implemented in Milford Care to ensure cross-organisation shift of culture using the Montessori ethos. The programme is open to all staff at Milford Care and all are encouraged and trained - whatever their role, job title, abilities or background - to embrace residents as equals and use their strengths and abilities in the care setting.



# Reports from UKDC 2023 by Mark Ivory

## Celebration and concern

Aston University in Birmingham played host to the 17<sup>th</sup> UK Dementia Congress (UKDC) on November 7 & 8) and in time-honoured fashion delegates from every corner of the sector descended on the venue for a lively and thought-provoking conference and exhibition. Graham Stokes, from UKDC's main sponsor HC-One, kicked off the proceedings by reminding the audience of how much had changed in the 30 years since the Journal of Dementia Care was founded.

"Over those years we've been waiting for the great medical breakthrough on dementia and that's yet to arrive, but we do now realise that we don't define the person by their disability," said Stokes, who is the care provider's director of dementia care services. "We put the person first and the dementia in second place, that's been the breakthrough of the past 30 years."

Tim Baverstock, from our congress partner Alzheimer's Society, also pointed to the two worlds of medicine and care, although with a rather different emphasis.

"This is a crucial time for dementia with exciting breakthroughs in medical research and in diagnosis methods, yet people living with dementia and carers continue to be let down and over a third are going undiagnosed, which ought to be a national scandal," said Baverstock, the Society's head of local systems influencing.

Reflecting on the Major Conditions Strategy – the government's proposed new strategy bundling dementia together with five other conditions – Baverstock insisted that it did represent progress. "We were promised a 10 year dementia-specific plan and this is it – or not as the case may be! There are some benefits to a multi-condition approach given that 90% of people with dementia have

another condition. But there is no funding for it and with a general election due next year it does raise a worry that this will be shelved and we'll be back to square one."

## Reconsidering Dementia books launched

Open University Press's "Reconsidering Dementia" series continues to grow with four new books in the pipeline to add to the five books already published. Books forthcoming next year include Talking with Dementia Reconsidered, by Keith Oliver, Reinhard Guss and Ruth Bartlett, Living with Dementia Reconsidered (IDEAL Project), edited by Linda Clare and colleagues, and Reconsidering Young Onset Dementia, edited by Jan Oyeboode and George Rook. A further book on Dementia, Equality, Diversity and Inclusion is being commissioned by series editors Dawn Brooker and Keith Oliver.

At a launch event during UKDC, Keith Oliver said that Talking with Dementia Reconsidered would "sit proudly" with its siblings in the series. "I wanted to showcase the power of working in a committed team of both professionals and volunteers," he said. "Everyone went the extra mile and more." Professor Brooker added that all the books were inclusive of people with dementia and included cover art by them too. See photo below.

## Stigma and changing relationships

As always there was a strong academic strand to UKDC and Dr Shirley Evans from our academic partner University of Worcester spoke about the continuing impact of the pandemic on people living with dementia, whose UK numbers are now forecast to be 1.7 million by 2040, an increase of 42% on previous estimates.

It meant that the work of the university's Association for Dementia Studies (ADS), where Evans is director, would



L-R: Reconsidering Dementia series contributors Jan Oyeboode, Sam Crowe, Cathy Riley, Reinhard Guss, Hannah Church, George Rook, Dawn Brooker, Isabelle Latham, Claire Surr, Lara Stembridge, Keith Oliver and Chris Russell.

be vital with its commitment to multi-disciplinary research and the centrality of person-centred support. ADS had pioneered the development of Meeting Centres across the UK, numbers of which had now reached 70 and which now formed part of Scotland's latest dementia strategy. ADS PhD students John Bosco Tumuhairwe and Jen Edgecombe presented their research respectively exploring stigma in Extra Care and the impact of changing older adult relationships on informal caring. Tumuhairwe worked as an HIV prevention counsellor in Uganda and witnessed how people with HIV/AIDS were affected by stigma. "I'm aware that stigma of any kind affects quality of life and lowers self-esteem," he said. "We know that there is stigma towards people living with dementia in Extra Care housing and that's why I'm doing this research."

### Ground-breaking co-production

In a ground-breaking master's degree programme at Bradford University, UKDC's bronze sponsor, people with dementia have designed, written and partly taught one of the modules. Clare Mason, assistant professor at the university's Centre for Applied Dementia Studies introduced the "Understanding the Me in Dementia" module, which forms part of the MSc in Advanced Dementia Studies.

Mason showed a film featuring some of the module participants, including Chris Maddocks, who has vascular dementia, Parkinson's disease and Lewy body dementia, who says: "Don't make assumptions, see the person not the dementia and speak to them and not just the care giver."

Also in the film "Julie" says she is "very proud" to be part of the module. "I started my journey feeling on the rubbish tip of life and certainly didn't think I'd ever be involved with a university again. Working on this module has been truly life-affirming."

### Training is no magic wand

Is staff training a "magic wand" that miraculously produces results for people living with dementia? The answer from Professor Claire Surr, who gave UKDC's annual Tom Kitwood Memorial Address, was a firm "No". The thrust of her talk on dementia training and education was that effective training is not just a matter of what you learn but how you learn, the motivation to learn, and the institutional and cultural investment in learning and its translation into everyday practice.

Surr's thinking about staff training evolved from the "What Works in Dementia Education and Training?" study she led at Leeds Beckett University, the 2009 National Dementia Strategy that first made training a policy priority, and the resulting Dementia Training Standards Framework with its requirement to train staff in 16 different content areas.

"One of the challenges we found in the What Works study is that a training programme covering everything is not effective because effective training is about depth and not breadth," Surr told UKDC delegates. "Training needs to be tailored to the staff attending it; generic training that covers everybody doesn't work."

She is an advocate of "implementation science" as a lens through which to see the various factors that enter into an

effective training programme, not just the "capability" among staff to do something new as a result of it, but the "opportunity" to do it in their specific organisational culture, and the "motivation" to do it, which will be heavily influenced by the first two factors.

Among the key considerations, Surr said, was the need for good facilitators and a learning culture in which managers prioritise training and provide the conditions in which staff can implement what they have learned and try out new things.

"In the What Works study clinicians were just told to go and facilitate training sessions, which put them under huge pressure to do something that was beyond their skills base. To do it well you need the skills and resources and the investment in you to do the job.

"Supportive management is crucial as well as the mechanisms to embed new approaches. We need to think about what needs to change to make them work rather than thinking they can be put into practice by waving a magic training wand."

For more information, see Surr *et al*, 'Good dementia education and training', p25-28, *JDC* July/August 2023, and her new book with Isabelle Latham and Sarah Smith, *Education and Training in Dementia Care: A Person-Centred Approach* published by Open University Press.

### Hospital care: better training needed

Staff training in hospitals was one of several themes discussed in a plenary Q&A session in which a panel of experts answered questions put by the audience. A delegate said ward staff had been unable to distinguish her grandad's delirium from his dementia and had left the family members to feed him even though they didn't know how.

Panellist Keith Oliver, who lives with dementia, referred to his own's wife's recent spell in hospital and said that it still traumatises her. "It was the most awful experience, part of the reason being the quality of staff training on her ward."

Karan Jutla, who is head of the Centre for Applied & Inclusive Health Research at Wolverhampton University and has a nursing background, said poor training in hospitals made her rethink her career.

"When I went to work for a nursing agency, I couldn't believe what I was seeing. It inspired me to go into education myself."

Paul Edwards, director of clinical services at Dementia UK, said the Admiral nurse charity put on a free dementia summer school every year and that the high attendance rates showed up how little training there was in the acute sector. "We're not talking about high-tech skills, just basic skills such as identifying pain," Edwards said. "The pre-registration curriculum for nurses is terrible when it comes to dementia and it's the same in medicine. We have a job on to make sure that the curriculum is changed for the better."

### Research priorities

Research programmes have tended to focus on finding a disease-modifying treatment for Alzheimer's, but how can we channel more funding into research to improve care and quality of life?

Susan Mitchell, head of policy at Alzheimer's Research UK, said her charity was committed to finding more





**Enlightening presentations, networking and refreshment at UKDC. Pictured left are the team who spoke on Psychological intervention in Capgras Syndrome - a collaboration: (L to R) Christine & Christopher Mills, retired service users, Rihana Bano, City University of London and Reinhard Guss, Oxleas NHS Foundation Trust and Oxleas NHS Trust**

treatments but that it was important to avoid “unintended consequences” by overlooking other areas of research. “The bigger prize is how can we make sure there is more investment in research generally,” said Mitchell, a panellist in the plenary Q&A.

“We can develop all the disease-modifying drugs in the world but we can’t even diagnose people at the moment,” fellow panellist Tim Baverstock told delegates. “I don’t think we’ve got the balance right,” said Baverstock, Alzheimer’s Society’s head of local systems influencing, “Drugs should not be the be-all and end-all and we should consider how we can provide the right care and support to live a good life for as long as possible.”

### Work with local communities

Former Department of Health (DH) civil servant Ruth Eley – now chair of the carer involvement group tide (Together in Dementia Everyday) – gave short shrift to the government’s proposed Major Conditions Strategy (MCS), a combined strategy for dementia and five other conditions including cancer and heart disease.

While at the DH Eley had a leading role in the development of the 2009 National Dementia Strategy: “Now here we are doing it all again,” she said. “Yawn, yawn, dementia is not going to get its voice heard with the MCS. We need to work with our local communities, that’s what’s going to bring about change.”

Working with local communities, groups of family carers and professionals, is a core task for tide as it seeks to involve carers as equal partners in supporting people with dementia. Engaging carers in “co-production” is key, partnering professionals and peers in creating solutions to their own needs and those they care for.

“We offer practical advice and tips, and a safe space where people can share things and know they’ll be understood,” Eley said. It was neatly summed up on film by a carer called Debbie from Ayrshire:

“You can feel very lost navigating your way around services. When the co-production ship sails up to you, it throws a lifebelt to you, pulls you on board and throws its

arms around you. It promotes an empathetic connection between people that is so important when carers are feeling alone. My advice to professionals is hold your hand out to carers, let the carer tell their story, throw the lifebelt and be there to administer the hug at the end.”

### Staff development and culture change

Care providers contributing to a session on staff development said that culture change was essential for training to make a difference.

Lynne Phair, who has worked with East Midlands care home group Milford Care, said introducing the Montessori Way in dementia care had “transformed the culture” of the organisation.

“We agreed that all staff needed to be trained in the Montessori Way; it’s not an activity but a way of life, an ethos for the whole care home regardless of role,” Phair said. “Whether a director or a Saturday afternoon potwasher, everybody has to buy in, otherwise the culture does not change.”

### Prescribing non-pharmacological interventions

The power of non-pharmacological interventions to improve wellbeing was illustrated by a project to find out the causes of distressed behaviours and respond accordingly. Clinical psychologist Joanna Marshall and OT Susannah Thwaites spoke about their project to prescribe music, robotic pets and sensory items instead of anti-psychotic medications.

Marshall and Thwaites are part of the Care Home Liaison Hub, an NHS multidisciplinary team that provides support to 116 care homes across the north-east of England with distressed behaviour referrals. In their project during 2021, 338 non-pharmacological interventions were prescribed successfully for 171 patients.

“Prescribing non-pharmacological interventions improved quality of life and reduced behaviours that challenge, and the vast majority of residents were maintained in their care home placements,” Marshall said. “Not everything works for everybody and funding is an



issue, but it is clear that mental health teams need to be able to prescribe a range of non-pharmacological interventions as well as medications.”

### **Sleep problems and solutions**

Sleep is a significant problem for people with Lewy body dementia – 40% of people with Alzheimer’s have sleep problems, compared with 90% of those with Lewy body dementia. So said Rachel Thompson, who presented with her colleague Rachael Webb, both Admiral Nurses specialising in the Lewy body variant of the condition. Changes in the brain, undetected pain, medication side-effects were among the factors responsible, Thompson said, and the effects included poor mood and concentration, lower quality of life, plus high blood pressure, heart disease, diabetes, stroke, cognitive decline. and anxiety and depression in the longer term.

“It really impacts on how people cope,” she added. “What makes for a bad night makes for a bad day.”

Webb offered some tips for better sleep, although she pointed out that there is no single fix. More daily exercise, less daytime rest, and more exposure to natural light to reduce sleep-inducing melatonin during the day were among those on her list. “Try not to nap too late in the day and keep the house bright till bedtime on dark evenings,” she suggested.

### **Award-winning Hear Well project**

Hearing loss has been identified as a major modifiable risk factor for dementia with a Lancet study suggesting that 8% of dementia cases could be prevented with proper hearing loss management.

Care UK’s Hear Well project aimed to find out whether residents with hearing problems, who account for 20.4% of all those living in the company’s care homes, could be helped by nurses trained in otoscopy and ear wax removal.

“We suddenly realised that none of our 9,000 residents had had their ears checked since the pandemic and perhaps for longer than that,” said Care UK’s head of nursing care and dementia Suzanne Mumford.

Outcomes included significantly improved interaction with residents, who came out of their rooms more often and exhibited less distressed and agitated behaviour, which resulted in less use of psychotropic drugs for them. The project won the Nursing Times Social Care Award in November.

### **Intergenerational community**

Belong Chester offers dementia care with a distinct difference, in that it is part of an intergenerational community in which there is a 25-place nursery alongside independent living apartments, day care and 24 hour support “households”. “There’s a real sense of community in Belong villages and the impact of the Chester nursery is just incredible,” says the charity’s head of dementia and care quality Caroline Baker. “I did wonder whether people with dementia might become distressed with youngsters running around, but in fact there is a great connection. I met Bill in one household whose wife had passed away and he was struggling with his grief. Now he’s a different man, glowing all the time and participating in the community thanks to the nursery.”

## **Perspectives**

by **Caroline Cooke**



### **Homeshare and dementia: the invaluable matches**

The homeshare movement has changed the way that people live for the better. As a circle of support, homeshare matches younger people (the average age of a sharer is 39) who need an affordable place to live, with older people (the average age of a householder is 84) who need some extra support to remain living independently in their own home. It can be a lifeline across generations, and people with dementia are among those most likely to benefit – as revealed in the Homeshare Association’s *Homeshare Report 2023*.

There are several reasons that homeshare works so well for people with dementia. Importantly, as a bespoke service, people are carefully paired to create strong connections - such as placing an elderly medical professor with dementia with a medical student, ensuring common interests. Yet it isn’t necessarily about a sharer having specific dementia experience; it’s about matching sharers with the right manner, empathy and patience. Another example of a good match is of an 82-year-old former music teacher with dementia who was calmed with a “sing-song” around the piano with her musical sharer who was also a teacher.

Homeshare is incredibly flexible, sitting well alongside other support services; householders often have visits from carers alongside their homesharer. Equally, it works well for individuals and couples. For instance, we currently have a married couple homesharing - the wife has dementia, and having a homesharer enables her husband to balance his time caring for his wife alongside arranging to meet up with his friends for social events.

In recent years, the number of people with dementia in homeshare arrangements has significantly risen. One of the reasons is that some people may not need, or be ready for, residential or full-time live-in care. The kind of support a sharer offers is reassuring to someone with dementia, whether it be preparing an evening dinner, helping to find misplaced items, or simply as a companion to chat with. These can all help relieve any frustration and anxiety and sharers are also great at providing a gentle nudge for people’s daily routines, or trigger reminders to take medicine or remember social commitments.

Having a companion in the home offers a greater capacity for independent living. It reduces the risk of falls and improves wellbeing by reducing social isolation and loneliness. It increases social engagement as genuine, strong friendships are built and both parties become like family to each other. Share and Care Homeshare are founding members of the Homeshare Association, and its recent report revealed that 100% of respondents would recommend homeshare or already had, and 100% also reported a positive impact on their health and wellbeing.

Important, too, is the impact on families who may live far away and be unable to provide instant support. With homeshare comes peace-of-mind that parents or loved ones are not alone.

The next steps for the homeshare industry are to make the concept more widely known to those who would benefit the most from these arrangements, including people with dementia. As the *Homeshare Report 2023* identifies, more needs to be done to offer homeshare as an option when people leave hospital. We need to reach those with dementia earlier, as a preventative solution.

**Caroline Cooke is founding member of the Homeshare Association and director of the community interest company Share and Care Homeshare.**

# Dementia Diaries

On Tuesday November 14 there was the funeral of Tony Husband. More than 1,500 people turned out to pay their respects to a much-loved man, who did so much for people living with dementia. **Steve Milton** recalls how his kind, attentive personality touched the lives of Dementia Diarists, and how his exceptional, sensitive work made people think differently about dementia

A lot has been written about Tony in the last few weeks, and rightly so. His contribution was enormous. I'd like to take this opportunity to say a few things about Tony, and how his work touched the lives of Dementia Diarists.

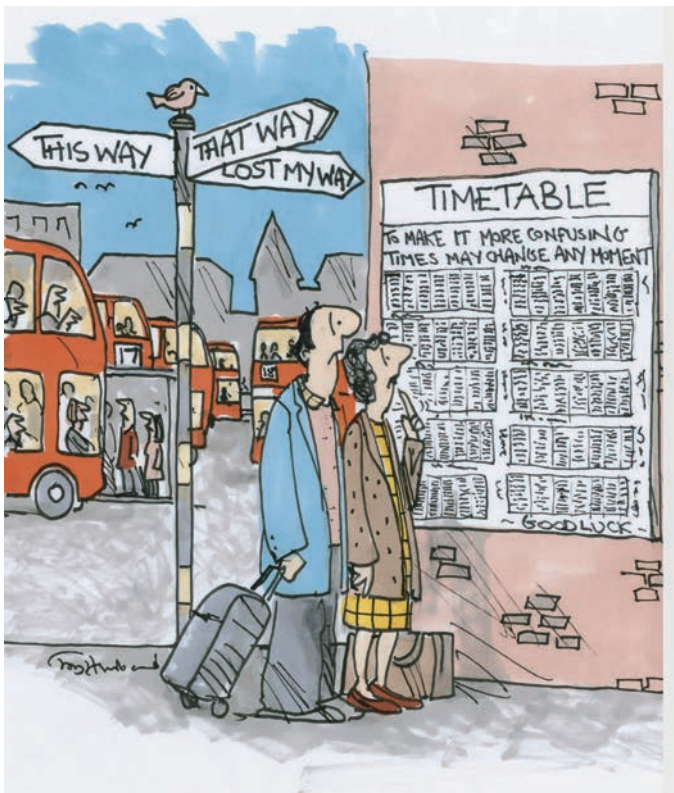
The first time many Diarists came into contact with Tony was through his involvement with the IDEAL project at Exeter University. Tony, together with poet Ian McMillan and photographer Ian Beesley, worked with many diarists through their respective DEEP groups to produce banners portraying a different way of looking at dementia. Tony's cartoons formed an important part of these banners, reflecting the stories and experiences that people with dementia shared with him.



In this diary, Wendy describes her involvement in the early days of the project.

<https://dementiadiaries.org/entry/7746/wendy-reporting-from-york-where-they-have-been-creating-an-our-right-to-get-out-and-about-banner-with-two-other-groups-tony-husband-and-ian-beasley/?highlight=Husband>

You can see some of the banners that people with dementia created with help from Tony, Ian and Ian here: <https://clock.uclan.ac.uk/23352/1/The%20Dementia%20Banners.pdf>



...and here's a cartoon (below, left) that Tony drew after hearing people's experiences of the difficulties they encountered whilst out and about.

People loved working with Tony. He was attentive, kind, and generous to a fault. He had the ability to make people feel like they were the most important person in the room.

Tony listened to people with dementia, and not just listened, but took on board what they said.

On one occasion, the Dementia Diarists' Zoom group had a reservation about one piece of wording on one of Tony's cartoons about dementia. I took this to Tony, and he simply changed it, without hesitation. Not a hint of preciousness, nor of defensiveness, he just listened to what people with dementia had to say.

Another piece of work that Diarists were involved with was "Let's Talk About Death Shall We?" People with dementia worked with Tony and psychologist Polly Kaiser on a booklet to encourage people to talk about their death.



You can download the booklet here:

<https://www.dementiavoices.org.uk/wp-content/uploads/2020/01/6707-Dementia-end-of-life-leaflet-Cartoons-FINAL.pdf>

Diarists that took part included Jacqui Bingham, who spent much of her working life as a funeral director, and Dory.

Having had the opportunity to really think about her own death, with the support of Tony and Polly and her peers with dementia, Dory recorded this diary:

<https://dementiadiaries.org/entry/7490/dory-says-i-would-like-to-die-doing-something-i-enjoyed-that-would-be-my-perfect-death/?highlight=death>

A little while after the project, Dory received something in



the post that captured her feelings and wishes about her own death. Here's the diary <https://dementiadiaries.org/entry/16763/tony-husband-has-crafted-a-lovely-poem-about-dorys-dying-wishes-this-is-simply-beautiful/?highlight=death>



....and here's the cartoon (right).

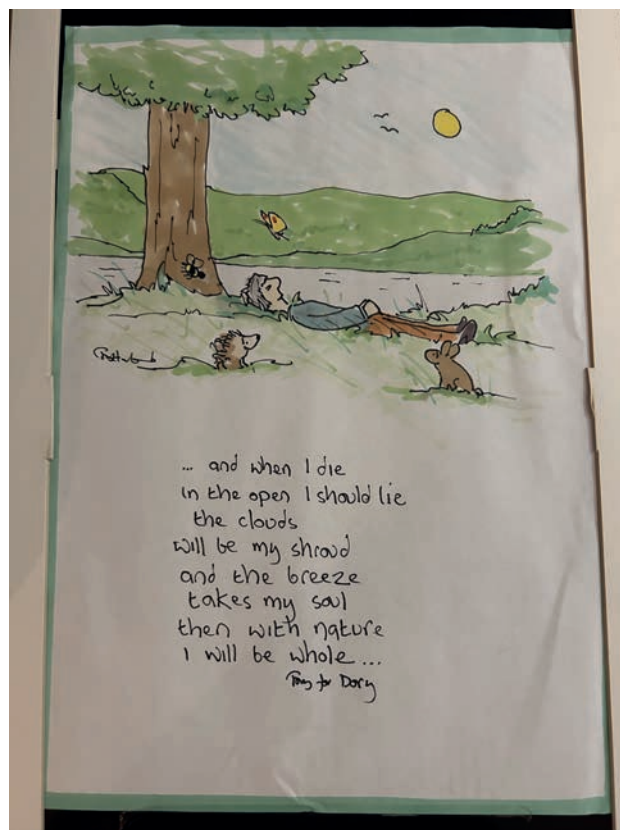
What a perfect illustration of the kindness and generosity that was so characteristic of Tony, and which touched the lives of so many people affected by dementia.

His work did so much to humanise the experience of dementia, often communicating with a few lines from his pen something which we'd struggle to communicate in mere words. His work made people think differently about dementia, made people more aware, less afraid, and less alone.

Thank you Tony for everything you did, and for everything that you were.

Cheers Mate x

*Steve Milton, director, Innovations in Dementia*



## Alzheimer Europe conference in Helsinki

### Anti-Stigma Award

At its 33rd annual conference in Helsinki last month (16-18 October) the winners of Alzheimer Europe's 2023 Anti-Stigma-Award were announced.

First prize went to Touchstone's BME (Black and Minority Ethnic) Dementia Service in Yorkshire, UK, which provides specialist support to people living with memory problems or a diagnosis of dementia and their carers/family members from Black and Minority Ethnic communities, predominantly the South Asian community, living in and around Leeds.

Second prize was awarded to Rainbow Neighbours, Brighton and Hove LGBT Switchboard's initiative which takes a creative approach to addressing the stigma, loneliness and isolation that can be experienced by LGBTQ+ people living with dementia, particularly those who are living in residential care settings. Switchboard is a charity for LGBTQ people looking for a sense of community, support or information.

The third place went to by Hogeschool Windesheim (Windesheim University of Applied Sciences, Netherlands) for its campaign "Assess your assumptions".

### Improving cultural inclusion

In a plenary presentation on Achieving Cultural Inclusivity in Dementia Care, Dr Karan Jutla, Head of Health Research Centre & Dementia Lead for the University of Wolverhampton, discussed ways for improving cultural inclusion to reduce inequalities in dementia and ensure widespread accessibility to care becomes a reality. She emphasised that co-production is integral to achieving equitable access to support services for people with

dementia and their family members and carers. She invited the audience to consider how culturally-inclusive care can be achieved, via a person-centred approach.

### Digital technology

The potential of digital technologies such as wearables, sensors, mobile apps and cameras to improve the assessment of Alzheimer's disease was highlighted at the conference. The RADARAD7 consortium has published a series of 7 videos explaining the project's work and results (information on Alzheimer Europe website).



### Helsinki Manifesto

At Alzheimer Europe's AGM before the conference (participants pictured above) the Helsinki Manifesto was adopted. It sets out the current position of dementia in Europe and calls for actions in four main areas: health, research, disability and social rights, and informal carers.

*More information on Alzheimer Europe's website and in forthcoming issues of JDC.*



# JDC asks:

**Asking for information about life story as a person living with dementia moves into a care home is common practice, but how can we use it to foster relationships and resilience?**



**Left to right: Tanya Clover, Caroline Baker, Stuart Wright, Isabelle Latham, Jane Ward**

## **Tanya Clover, head of dementia and personalisation at Porthaven Care Homes:**

Human beings have been coming together to share stories around the campfire since the dawn of time. While the seating around the fire may have changed, our need to gather and share our stories hasn't.

When a person living with dementia shares any part of their story, the people around their campfire have a duty to protect the story and what it means to the person.

Sometimes a person can become disconnected from their own story, unable to recall or recognise snapshots from their life. When this happens, we around the fire have a responsibility to hold the story, maintain its integrity, and share it back in a way that makes sense to the person and that enables them to live the way they would choose.

As care providers, we must also hold a person's stories up against the care that is offered. Upholding who the person is and continually reaching to support who they wish to be should be the benchmark and not just the aspiration of today's social care.

But are we true to the precious stories that we hold? Too often still I see an individual's narrative separated from their experience. Actions that speak of resourcefulness and resilience dismissed as a manifestation of a condition.

I struggle to say that we should "use" a person's stories wisely, as the word implies that we as care providers own the person's narrative. This must never happen. But we must ensure that we truly see the person in the story. Step into, not over, their narrative.

We are all story tellers gathered around the fire. At Porthaven, we plan to blend the powerful conversations of person-centred planning with the visual impact of storyboards.

## **Caroline Baker, head of dementia and care quality at Belong:**

How often do we return to a particular restaurant because they either remember our name or our preferred table, meal or drink? We feel drawn to people because they remember something about us and it helps us all to feel special. On the other hand, how annoyed can we get when we are asked the same question over and over by

somebody we consider to know us quite well? I for one become frustrated every time I visit my hairdresser of 20 years who asks me which side my parting is on!

Of course, we should always encourage choice at every opportunity but we should also know the key elements of people's lives to enable us to understand how they may be feeling or what may help them to express themselves.

Being able to talk to a person living with dementia about their own life, their family and friends and things that they enjoy can help both the person you are supporting to feel safe and confident that you know them well, but it will also enhance the relationship and confidence of the person who is providing the support.

Nothing brings me more joy than when I have read somebody's life story and I visit them on the household and begin to talk to them about elements of their life story with them and they respond with a smile or further information about themselves.

Knowing is showing ... that you care.

## **Stuart Wright, dementia care lead at Brunelcare:**

Life story work is often seen as the domain of those providing activity and giving care staff opportunities to engage in reminiscence. But life stories can also afford us greater insight into ways in which we can support wellbeing for that person, provide clues as to how to meet needs that are not so obvious and highlight possible interventions around dementia symptoms.

A deeper understanding of a person's history fosters empathy, enabling carers to connect with the person on a more meaningful level, leading to greater emotional support. Dementia can erode a person's sense of self. Sharing and acknowledging their life story can help validate their identity, allowing them to maintain a sense of self-worth and dignity. This can promote resilience by reinforcing a positive self-concept.

Knowing a person's life story can aid communication. Understanding their preferences, triggers, and past interests can help health care professionals communicate in a way that is more comfortable and effective for the person with dementia. This can reduce frustration and anxiety, improving overall wellbeing. A person's life story can help

identify potential triggers for dementia symptoms. Caregivers can work to avoid or mitigate these triggers, reducing stress and distress for both the person with dementia and those around them.

Understanding a person's life story as they transition into a care home can be a powerful tool for creating a more person-centred and supportive care environment. It can help build relationships, maintain a sense of identity, reduce anxiety, and promote resilience in individuals living with dementia.

### **Isabelle Latham, researcher-in-residence at Hallmark Care Homes:**

Listening to the experiences of residents and team members in our care homes it is clear that, while life story information is important, as with most things it is what you do with it that matters most. To ensure life story information fosters relationships and resilience we have to remember that life story is a thing to use, not a thing to "do". Rather than a static snapshot of a person's life stored in a book or electronic record, it should be viewed as a living thing, spanning the past, present and future.

A team member from one of our care homes shared the following lovely example of this the other day, emphasising how passionate staff combined with helpful technology and resources could take a small piece of information about the past, use it in the present and influence the future, fostering relationships along the way.

During a passing conversation, a resident asked the team member about a local beauty spot, near where they used to live. While the team knew a little bit of back story they decided to find out more, sending a message on the app the home uses to communicate with relatives. Within two hours, the resident's daughter had responded explaining the significance of the location, including some old photographs.

The photographs were used over the following days to prompt many conversations with the resident. The icing on

the cake, however, was the flurry of messages on the app a week later sharing video of the resident visiting the location with a team member and updating her photo album!

### **Jane Ward, charity lead at Dementia Friendly Hampshire:**

Knowing information about someone's life story is key to understanding who they are; it tells us about their likes and dislikes, where they have been, what they've achieved, and about the people they've loved.

I created three volumes of photographs for mum; the first, focused on her childhood, was filled with family and friends and told the story of her early years through photos of the people and places in her life at that time. I relied on her friends and older family members to help me collect photos, then identify people, places, occasions and the special stories they portrayed.

Putting this volume together gave mum many happy hours interacting with everyone involved and increased my understanding of her as a person rather than as my mum. A second volume focused on my childhood giving me a different insight into our relationship, and the third on her homes, gardens and our family pets.

All of the stories we collected were added to these volumes; either printed up or simply handwritten on a post-it and proved invaluable. We started adding suggestions for prompts and questions as her memory deteriorated to help us initiate conversations. The books proved to be an incredible resource useful for family and strangers alike.

When you are able to confidently engage with someone using photos and story prompts, it forges a much better relationship with them; we are more naturally drawn to people who appear genuinely interested in us. Life stories support us in understanding the person's emotional needs and provide means to identify things which may upset them and memories we can use to cheer them up. Life stories let us see beyond dementia to the person.

## **JDC Asks Challenge: Equality, Diversity and Inclusion**

### **Tell us what you are doing to make dementia care more inclusive**

The September/October 2023 *Journal of Dementia Care*, was a special issue on Equality, Diversity and Inclusion in dementia care. It includes many examples of excellent initiatives which are helping to make dementia services more inclusive. We know there are lots of other brilliant projects going on, and we would like to hear about them.

Are you, as a practitioner or researcher, or the organisation you work for, making an effort to reach out and co-create opportunities for effective support to individuals and communities who tend to be under-represented and under-served in dementia services?

You might have made quite a small change which has made a big difference, you might have undertaken a stand-alone project, or you might have been involved in a major initiative to refocus your organisation's vision and

mission. What challenges have you faced, and what have you achieved? Please write to tell us what you have been doing, by answering the following question in no more than 250 words:

***What have you or your organisation done to make your dementia practice or service inclusive and responsive to the needs of different communities?***

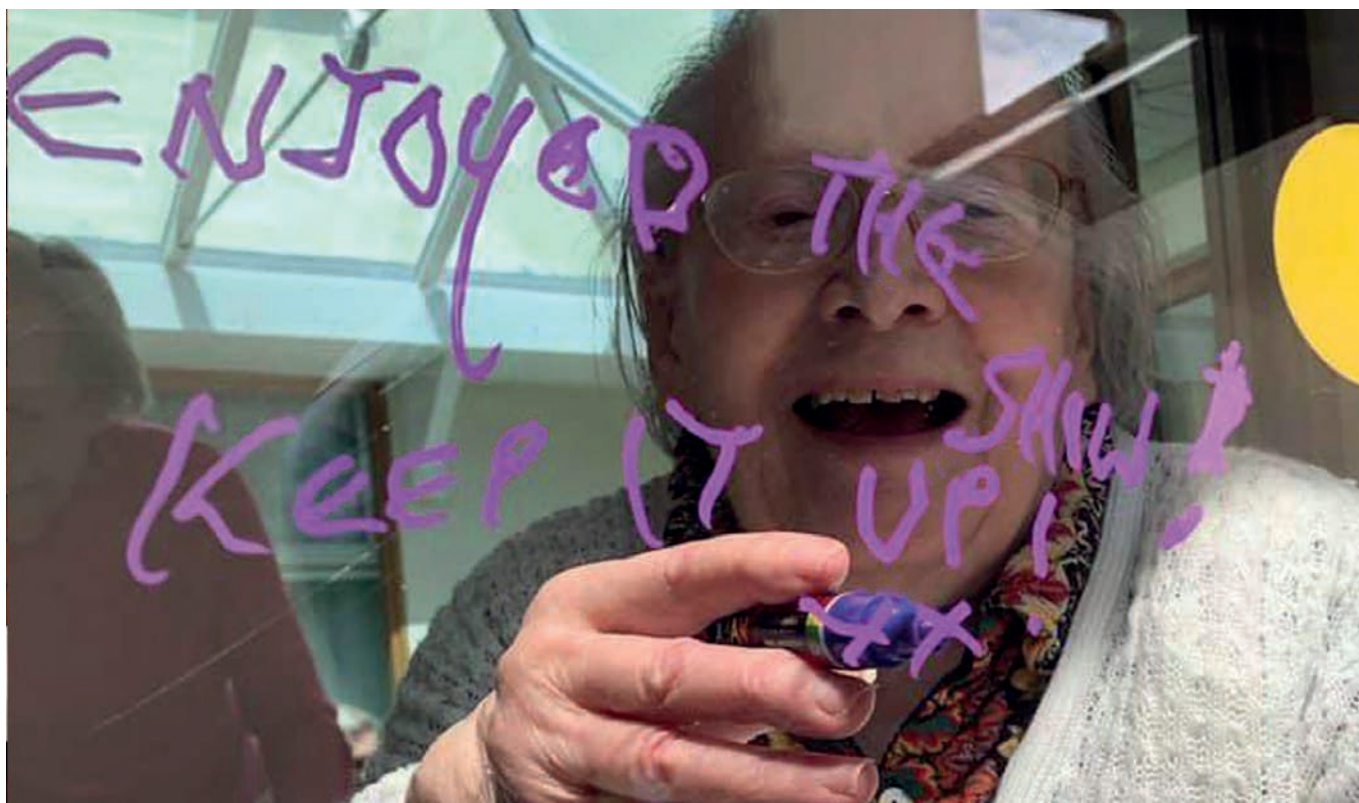
Please also give your name and describe your role in one sentence. Send your replies to Sue Benson at [sue@dementiapublishing.community](mailto:sue@dementiapublishing.community) by 15 December 2023.

The replies we receive will form the basis of our regular JDC Asks topical section in the January/February 2024 issue of the *Journal of Dementia Care*.



# Love Through Double Glazing

Innovative work by Vamos in the pandemic and beyond



Vamos is a full mask theatre company known for its performances and workshops exploring and supporting people living with dementia. **Janie Armour** highlights the innovative work it has done recently, particularly during the Covid 19 pandemic

Vamos Theatre is the UK's leading full mask theatre company and we've been creating performances, workshops and training since 2006. Our national and international touring shows are wordless, using movement and body language to tell stories, and this means it's highly inclusive and accessible to many more people than language-based performing arts. With our company ethos emphasising empathy and shared humanity, we've focussed a great deal of our work on supporting the health and care sectors, and specifically people living with and working with dementia (Hoskins 2018).

In 2019, we were honoured to be awarded Arts Council England National Portfolio Organisation funding: a huge development meaning we could extend our existing work around dementia, developing *Sharing Joy*, our interactive performance for care homes, and our training for carers, *Listening with your Eyes*, to make them even more impactful, with feedback of audiences and participants.

In 2020, with only weeks to go on our national tour of *Dead Good* (a show about end of life), the pandemic happened. The tour stopped of course, and like everyone, we were left wondering how we could function, never mind continue to make an impact. We were lucky enough to almost immediately be chosen as one of only 25 Culture in Quarantine commissions by the BBC, seeing us making a 20-episode full mask visual story about pandemic isolation, which was featured on the BBC iPlayer.

## Reaching out to care homes

But it was clear by this time that where people were truly experiencing isolation was in care homes. Things were incredibly tough for residents and staff, and one thing we could do was try to find a way to reach people in enforced isolation. But, of course, physical interaction was out of the question. ▷



**Love Through Double Glazing** was performed entirely outside while residents and staff watched safely from inside. Credit: Graeme Braidwood Photography.



▷ Over the next months, we worked on a new production, *Love Through Double Glazing*, featuring Cirque de Soleil clown, Sean Kempton, Vamos Theatre's Artistic Director Rachael Savage, and her little white dog, called Norah. *Love Through Double Glazing* was performed entirely outside with residents (many living with dementia) and care staff watching safely from the inside. Completely wordless, it was as interactive as ever – residents ate cake as Maurice the chef baked, joined in with Geoff the Fitness Instructor and wrote messages on the windows (with wipe-off pens).

*Love Through Double Glazing* did just that – it brought love, hilarity, joy, silliness and naughtiness to care homes who really needed it, through the windows. Care home director Richard White commented, “*Love Through Double Glazing* made us laugh more than we have laughed in a very long time”; Care home resident, Eileen, said, “We fell in love with you through our double glazing”; Gemma, a staff member, added, “After these very long months, it lifted [residents'] hearts,” and finally Beattie, 101, said, “it made me feel alive again”.

As things opened up, we further developed *Listening with your Eyes*, our workshop supporting carers and others working in dementia care. This workshop helps develop skills of empathy, insight, listening and trust-building, and offers an opportunity for participants to see the powerful effect of non-verbal techniques and their benefit in helping us make real and honest connections.

Since the pandemic, we've been successful at extending the reach of the workshop to other professions who interact with people living with dementia, such as police officers, GPs, transport drivers, nurses, occupational therapists, and theatre front-of-house staff, and it's proving really impactful.

For example, GP trainer, Dr Catherine Kelly, called it, “everything a GP needs, to practise medicine with humanity”, and Detective Constable Clare Harrison of Greater Manchester Police said, “I want all my officers to attend this workshop - we need to learn how to communicate in this amazing way”. And Josefa MacKinnon of the Royal Shakespeare Company commented, “Vamos training goes the extra mile in dementia training and should be essential for all front facing teams.”

### Making mischief

Most recently we've created a brand-new show for people with sensory issues, learning disabilities, and living with dementia. *Mischief* is a 60-minute interactive performance, workshop and celebration featuring comic characters, interactive sensory play, and a special mask theatre workshop. As with all our work, we're developing the show with feedback from participants and are honing it to be able to respond in the best way to everyone's needs.

This fun-filled show gives participants, regardless of their sensory differences, the opportunity to play, interact and immerse themselves, to explore their capacity for happiness and laughter and models diverse ways for carers to encourage improvisation, spontaneity and creativity.

*Janie Armour is head of communications at Vamos Theatre*



**Listening with Your Eyes workshops for staff, now extended to others including police officers, GPs, transport drivers, OTs, nurses and theatre front-of-house staff. Credit: Graeme Braidwood Photography**

Samantha Poxon of Sense Birmingham told us, “It's amazing how a group of people can come together and gain joy and fun from such an experience.”

We've got big plans for the next three years. Having been awarded National Portfolio status once more, we'll be touring a new production in early 2024 – *Boy on the Roof*, which explores ADHD, loneliness, ageing, hearing loss, connection and community, and we'll be keeping our work with the health and care sectors central to what we do.

Meanwhile, *Mischief* and *Listening with your Eyes* are available for booking, and in 2025 we'll be taking *Sharing Joy* back out to care homes. In the same year, we'll be re-touring the show that started it all off – award-winning *Finding Joy*, our international touring production that tells the story of Joy, who lives with dementia, and her carer grandson, Danny.

Through this, and all our performances and workshops, we hope to widen understanding of living with dementia, to continue to invite and include people living with dementia into our performances and workshops, and to show the incredibly positive effect that interaction with the arts can have on people living with dementia and those who care for them.

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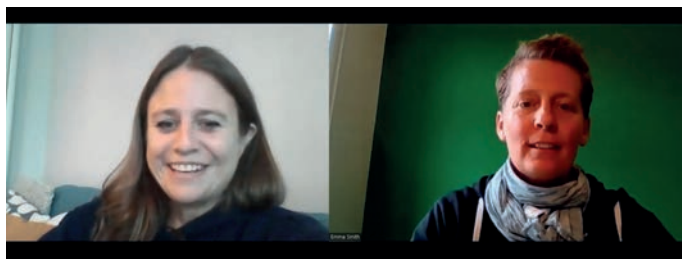
Hoskins H (2018) Loudly (but silently) finding and sharing joy. *Journal of Dementia Care* 26(2) 12-13.

For more about Vamos Theatre, visit:  
<https://www.vamostheatre.co.uk/arts-in/arts-in-health/>

# Grief and dementia:

## In conversation with Dr Esther Ramsay Jones

We are familiar with the idea of grief after death, but a carer may also experience “anticipatory grief” while a loved one is still alive. In conversation with **Emma Smith**, psychotherapist **Esther Ramsay Jones** (left, below) explains what it means



**Emma Smith:** Why is it important to think about death and dying?

**Esther Ramsay Jones:** One of the things I’ve learned about working with bereaved families and people living with dementia is that grief, often after a person has died, puts a sharp focus on the value of relationships. In psychotherapeutic work, we offer up space for people to explore anticipatory grief while a cared-for person is alive. This enables people to recognise how important someone has been while there is time to communicate this. This is not about idealisation; a space in which honest conversations can take place allows for the difficulties, tensions and more ambivalent feelings associated with the partnership between carer and the person they care for.

One of the most difficult things is the revision of the relational dynamic. As the disease progresses one will become more dependent. That can be a very frightening place for the person with dementia, particularly if their attachments with their own primary caregivers early on in life have been wobbly. It can be equally frightening for a family caregiver; they might have looked after their own parents as children - a reversal of roles - and so looking after a partner with dementia might stir up resentments. Consideration of dependency, dependency needs and experience of dependency is vital in this context, for both caregiver and cared for. For those in a caring role, seeing someone who was once able and relatively independent shift over time to greater states of dependency can be frightening. If spaces are not provided to consider these areas of emotional complexity, fragility in the person with dementia may not be fully responded to.

**Emma:** Can we avoid thinking about death?

**Esther:** From a philosophical perspective, Heidegger noted that when we live with the awareness of our endpoint in mind we are able to make more authentic daily choices. If we are less in denial that dementia is a terminal

*Emma Smith is project manager at Empowered Conversations, Age UK Salford.*

### Esther Ramsay Jones: Career background

Esther Ramsay Jones is a researcher and psychodynamic psychotherapist with a background in dementia care. She has worked as a psychotherapist in palliative care and currently supervises hospice at home teams. She also lectures in counselling and psychotherapy at Birkbeck, University of London, and on the Open University’s Death, Dying and Bereavement module. She is the author of two books, *Holding Time: Human Need and Relationships in Dementia Care* and *The Silly Thing: Shaping the Story of Life and Death*.

condition, we might have some of those trickier conversations about relational dynamics, fears and hopes, earlier on in the disease trajectory.

We want to ensure that as much agency in the person is accessed as possible. We might tentatively start having conversations around what someone might want for the rest of their time, how they want to be treated, cared for, thoughts around advance care planning. This may open up opportunities for the sharing of stories and grief.

**Emma:** Can you talk more about what anticipatory grief is?

**Esther:** For a person with dementia there might be a sense of mourning oneself in advance, the fear of what is going to become of me, what more am I going to lose? De Masi (2004) said that “our death as individuals is an experience of separation unlike any other experience of mourning”. It is the most profound separation, being disconnected from the world around us, disconnected from those in our relational field and also disconnecting ourselves from ourselves. It’s almost an impossible task to imagine that we’re going to be no longer. What I’ve often noticed in very unwell people is that part of their anticipatory grief is wrapped up in imagining the grief of those around them. It’s not uncommon for people living with dementia towards the end of their lives to begin to grieve earlier losses, the experience of facing one’s own endpoint brings earlier deaths back into consciousness. This can be a very painful process. People with dementia might be psychologically at a different developmental point to their physical age, there might be moments of deep awareness that a mother or father – who emotionally somehow feels within reach – is in fact absent. A reminder, albeit short-lived, that the present time is populated with significant lost attachments: this is something that I witnessed in a care home. ▷

▷ **Emma:** How might a person with dementia express their grief?

**Esther:** I've noticed particular symbols of grief that I've found in people with dementia. One woman always used to tell me her hair was fraying, wayward, that it was in front of her eyes, she couldn't see anymore, and that was very much in evidence. But I think she was also telling me that she felt that she was becoming fragmented, she couldn't see things clearly, indicators perhaps that someone is grieving an earlier, more integrated sense of self.

Care home residents would tell me in research interviews that they'd lost their babies or they'd left babies on buses - possible signs of the desperate and painful loss being experienced. Sometimes it was about feeling that they could no longer mother anyone, they weren't competent to care for another person or sometimes that they'd lost parts of themselves that they felt needed care.

In terms of daily care practice we might recognise that someone with dementia is grieving their identity, and in these situations small acts of care can be reassuring. If you think of "signatures of appearance" as a marker of self, my mother, who died of brain cancer, always wore mascara and used the same perfume even as she became bedbound. Attuning to these signatures of appearance allows someone to continue to exist and to be held in mind.

At funerals we share these wonderful memories about the person that has died. Thinking that time is finite, can we honour someone while they're alive by sharing memories and stories.

**Emma:** What is ambiguous loss?

**Esther:** It can be difficult for others to see how someone can be grieving a person who is still living and therefore empathise with the extent and intensity of these losses. The experience of ambiguity is around the desperate uncertainty of what's going to be lost next in the person, in our relationship. Can we go to the park again, take a holiday, what does our future look like?

It might feel that grief is not justified because the person still exists. Ambiguous loss can become a disenfranchised experience of grief and feelings of isolation. Pauline Boss suggests finding the meaning within this ambiguity, which is incredibly difficult when you are caring 24/7 for a person, but there might be times where you notice a deep sense of connectedness, such as finding meaning in listening to music or a short dance. Connecting with others who've found a way around some of the difficulties of ambiguous loss can help.

It's difficult for those living with ambiguous loss to try to discover new hope, imagining there could be a future beyond the current situation. It leaves someone feeling guilty, as if they no longer want the person with dementia to be in existence. It's important to explore ambivalent feelings, because there can be a real tension with ambiguous loss. It's likely you don't want the person you're caring for to be no longer here but you're also exhausted, overwhelmed and in need of rest. This is why those ambivalent feelings should be explored: the fact that you might be resentful on one level, but also deeply fond and loving towards someone, can be hard to reconcile.

## Implications for practice

- Anticipatory grief is a major factor in dementia, the fear of what is going to become of the individual and family members, as well as grief related to the reality of everyday losses and a reliving of losses from earlier life points.
- The experience of ambiguity that surrounds what is lost in dementia and what may be lost in the future can stir up feelings of profound uncertainty and misunderstanding, particularly for those in positions of care.
- Acknowledgement that dementia is a terminal condition allows family caregivers and professionals to have earlier trickier conversations about death and dying.
- A recognition that time is finite can help us to share our appreciation and gratitude for what is most important to us about our relationships.
- While there are certain universal characteristics of grief, no one ever knows how this process will unfold and each person and family will respond differently, with a unique way of experiencing and expressing loss.

**Emma:** Should we talk to people with dementia about death?

**Esther:** The people that I've worked with living with dementia have certainly felt grief. We have these relational fields which exist both outside and inside our mind, we know that something or someone has gone missing. There's a lot of debate about whether we explicitly mention to someone with dementia that somebody has died. The question we have to ask ourselves is, what's getting in the way of saying, "I can see you're in a lot of pain, can you tell me what's going on?"

**Emma:** What helps us to grieve?

**Esther:** There is no one way to grieve, there is something about oscillation and movement in grief that's helpful. Community makes a difference, ritual and honouring, remembering the dead makes a difference. Moving our bodies: very often grief gets located in the body, it weighs us down, so walking, dancing, any mode of physical expression particularly in the aftermath of a physical death can help. Being in nature reminds us of life's impermanence, the changing nature of existence: there are shoots of beginnings among the evidence of endings.

Grief can teach us very profoundly about relationship, the nuances, how another person has informed our life. It tells us where we've made mistakes, what we failed to notice, and how we may wish to try to notice more in our current lives. Yet we've got to be compassionate with ourselves and forgiving in our mistakes. While grief can be complicated and debilitating, for some the experience may also be transformative, though of course it doesn't have to be!

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# Evaluating a reminiscence project (RYCT) in a residential care home

As a well known arts-based reminiscence programme, Remembering Yesterday Caring Today has traditionally been delivered in community settings. **Sandie Woods** set out to discover how it would work in a care home, and shares her findings

Reminiscence therapy has usefully been described as discussing events and experiences from the past to evoke memories, stimulate mental activity and improve a person's well-being, supported by tools such as videos, music, pictures, objects and memory books (Harrison Denning 2022).



The Cochrane systematic review into reminiscence therapy (RT) for people with dementia (Woods *et al* 2018) found some evidence that RT can improve quality of life, cognition, communication and mood. Woods *et al* and Saragih *et al* (2022) supported the use of RT in care homes to promote quality of life.

One major approach to RT was pioneered as Remembering Yesterday Caring Today (RYCT), which had previously been delivered in community settings. The opportunity arose to pilot and evaluate the delivery of the programme in a care home setting (residential, nursing, respite or palliative care) for residents of Jewish heritage living with dementia and complex needs.

RYCT aims to stimulate communication, contribute to building positive relationships and improve quality of life (Schweitzer & Bruce 2008). The programme is structured around a life course, building on the skills people have and using a strengths-based approach (SCIE 2020).

Care home staff and volunteers were invited to attend a two-day training before the start of the programme to engage them in the sessions and upskill them to deliver reminiscence activities during and following the 10-week programme.

## Evaluation

The weekly programme ran from August to November 2022. Different approaches were taken to gather information and evaluate during the delivery and at the end of the programme.

Residents were asked for verbal feedback during the sessions. Weekly evaluations were also undertaken with facilitators, staff, an apprentice and volunteers. Notes were taken and the information gained shaped the design and delivery of subsequent sessions.

At the end of the programme a questionnaire (online and paper) was provided for volunteer and staff feedback. Three volunteers, who attended on a regular basis, completed the questionnaire and rated the programme as

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## Summary

Remembering Yesterday Caring Today (RYCT) is a reminiscence programme which focusses on creative arts-based reminiscence work, multisensory stimulation, and verbal and non-verbal channels of communication.

RYCT was delivered in a care home setting (residential, nursing, respite and palliative care) for residents of Jewish heritage living with dementia and complex needs. RYCT had previously been delivered in community settings. Facilitators delivered 10 weekly sessions supported by staff, an apprentice and volunteers, and the programme ran from August to November 2022.

The evaluation incorporated verbal and written feedback from residents, family members, and volunteers. The value of social engagement, relationships, communication, participation and the use of arts-based approaches featured highly in the feedback.

Adaptability and flexibility to the environment, structure of the programme, and design of the sessions was important to meet the needs of the group. A high ratio of supporters (facilitators, staff or volunteers) was needed to promote inclusion for residents with multiple long term conditions.

Different methods of evaluation need to be used to gain maximum feedback. Developing staff and volunteers to sustain the provision was important.

excellent. Staff gave feedback during weekly sessions but due to work pressures it was not possible to get written feedback at the end of the programme.

An evaluation sheet was provided during the last session for attendees and family members to complete together. Eight attendees/family members provided feedback and rated the programme as excellent or good (excellent= 6, good= 2). From the evaluation a number of themes were identified, as follows:

## Social engagement

Building a rapport and getting to know each other was a key part of the programme. In the first session group members found different ways of greeting each other using gestures and words.

Five residents commented on the social aspects of participating in the reminiscence group. Three of them focused on the enjoyment of being together and said:

*"I think it was best when we all came together. I loved being with everybody."* ▷

▷ *“Just enjoyed being together.”*

*“Enjoyable”.*

One resident commented on the atmosphere:

*“Friendly and stimulating.”*

And another enjoyed not only participating but also:

*“Watching all the people in the group and listening to what they had to say.”*

The importance of relationships was evident in the feedback:

*“The most enjoyable part of the programme for me was witnessing my husband’s evident pleasure in participating in and watching the activities.”*

Another relative added:

*“I’ve been coming to see my mum every day and seeing most of your group here. It’s lovely to see them like this, engaging.”*

One resident summed up the mood when seeing one of the facilitators:

*“When I see you, I know I am going to have a good time”* (session 9).

The programme was adapted to facilitate new members joining during the 10 sessions. A member of staff commented on the benefits during a weekly evaluation:

*“People can fit in for a one-off session”* and *“Each session feels like its own thing”* (session 2).

### Arts-based approaches

The sessions incorporated drama, art, singing, artefacts, activities and storytelling with the goal of promoting inclusion for all. Volunteers shared their skills and talents and Jewish customs, traditions, celebrations, poems and music were incorporated into the sessions.

One volunteer said:

*“I found that singing the occasional song brought a lot of pleasure to the residents.”*

Residents also commented on singing in the sessions:

*“Singing with the group brought back happy memories,”*  
*“Singing, being with others and remembering childhood memories (not forgotten).”*

### Communication

Volunteers reflected on the importance of communication skills when working alongside the residents and commented:

*“Important to focus on the person and listen to what they are trying to tell you, encourage the use of photos and talk about them. Also if family members are present it is important to record what family reminiscences they may have.”*

*“Not to use the words ‘Do you remember...’”*

A member of staff remarked on the interactions:

*“There were some really in-depth conversations in the small groups”* (session 2).

### Memories

Flipcharts with words and pictures assisted recall of what had been covered in the previous week and the theme for the session. Artefacts positioned on tables, generated interest as the group members arrived. Volunteers noted:

*“Bringing small items relating to the subject, and the residents being able to hold them in their hands, made a huge difference to their memories. The memory books were excellent.”*

### Key points

- **Adaptability:** Be observant and ready to adapt the content and delivery of the sessions. Continue with the life course design but plan sessions so that new members can join.
- **Carers:** Engage and support family carers throughout the programme.
- **Communication:** Use verbal and non-verbal communication methods. Incorporate a range of arts-based approaches to promote interest and inclusion (drama, photographs, music, artefacts and memory books).
- **Environment:** Ensure the environment has wheelchair access, good acoustics, is a familiar space and has suitable lighting, heating and seating.
- **Social engagement and interaction:** Have a high ratio of support (ideally 1:1 or 1:2). Include small groups as well as large group activities. Gather relevant information and be alert to topics that could be challenging or upsetting.
- **Sustainability:** Use different methods of evaluation to gain maximum participation. Provide training for staff and volunteers and RYCT apprenticeship opportunities to promote the continuity of the provision.

Two residents reflected on what they had enjoyed and said:

*“There was a lot to do, I like remembering,”* one said, while the other liked *“Remembering things from the past.”*

Two other members of the group commented:

*“The importance of recalling happy memories,”* and *“To cherish good memories.”*

Memory/scrapbooks were provided for each group member to populate. Relatives, staff and volunteers supported residents in telling their stories which were captured through words, pictures and photographs. Family members also brought in photographs and artefacts and the books were revisited and developed each week.

A resident observed:

*“Many things have been brought to my mind, but they weren’t exactly new, just dormant.”*

Four residents shared how they enjoyed including memories of childhood and school days. They talked about *“remembering early childhood”, “remembering school days”* and *“I remembered doing remedial writing.”*

Holidays generated lots of interest with hats, sunglasses, swimsuits, shells and more. The stories shared were captured in the memory books.

One member of the group recorded in the evaluation how she enjoyed sharing

*“Our holiday in Mauritius.”*

Working in pairs hobbies were demonstrated through mime. During the evaluation a resident remembered how *“I liked knitting.”*

Memory books acted as a weekly reminder of what had been covered in previous sessions and something to take



away at the end of the programme. One resident wrote:

*"I'd like to show my scrap book to the grandchildren."*

Some group members had experienced the impact of war and the Holocaust and the team were sensitive to the emotional impact that may arise from some topics.

### Conclusion

The evaluations undertaken during the programme and at the end of the 10 sessions demonstrated that RYCT could be delivered successfully in a care home setting with residents living with dementia and complex needs.

Adaptability and flexibility, planning and organisation were essential as residents' health and abilities changed over the 10 sessions. To gain maximum participation a high level of support was needed from staff, facilitators or volunteers.

A range of evaluation methods was needed to capture the voices of residents, family members, staff and volunteers. Gaining feedback at the end of sessions as well as the end of the programme was important to promote recall and capture as many voices and viewpoints as possible.

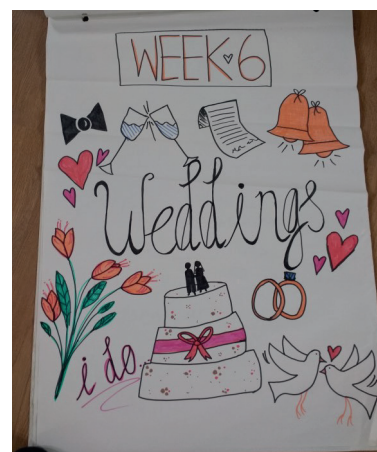
Training and preparing staff and volunteers to continue with reminiscence activities when the programme is finished is an integral part of RYCT.

### Acknowledgements

I would like to acknowledge the contribution of RYCT programme director Pam Schweitzer MBE, director of the European Reminiscence Network, [pam@pamschweitzer.com](mailto:pam@pamschweitzer.com); lead facilitator Caroline Baker, who trained and works in theatre and special needs education in Australia and the UK, co-facilitating

### RYCT topic outline (10 weekly sessions)

Childhood and family life  
School days  
Starting work and working lives  
Going out and having fun  
Weddings  
Homes, gardens and animals  
The next generation, babies and families  
Food and cooking  
Holidays and travel  
Celebration



reminiscence and arts with RYCT; and facilitator Annie Pownall who works in creativity for people living with dementia, reminiscence with the creative arts, dance and movement and laughter yoga.

Thank you to all the staff and volunteers who gave their time, shared their talents, and engaged with such enthusiasm and commitment.

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## Turning a crisis into an opportunity: taking dementia training online

Lockdowns during Covid gave the charity Understanding Dementia a chance to rethink its approach to training. Interactive online courses now provide a cost effective means of training family carers and professionals, turning a crisis into an opportunity, says **Shirley Pearce**

Bridging the gap between dementia awareness and a real understanding of the condition takes careful planning. Our interactive online courses for professionals and family carers, developed during the pandemic lockdowns, have shown how this can be achieved.



The aim of our charity, Understanding Dementia, is to provide training on dementia, how it affects people and how to lessen the impact. We began training domiciliary care staff in Berkshire via one-off sessions in 2018. However, with no follow-up it was hard to assess

their effectiveness. Moreover, our counter-intuitive approach requires time to become embedded before it can be used in crisis situations where it is most needed.

Understanding feelings and developing communication skills are the focus of the courses. This type of training is best absorbed in bite-sized amounts, with time for practice and reflection between lessons, making face-to-face delivery prohibitively expensive. ▷

Shirley Pearce is a retired occupational therapist and founder/CEO of the charity Understanding Dementia [www.understandingdementia.co.uk](http://www.understandingdementia.co.uk).

▷ On the other hand, online training can reach many people at minimal expense, but it is not always effective. Even some safety-related courses require no engagement from trainees, with assessments demanding the correct multiple choice answer before the next question is displayed. Full marks achieved by trial and error are unlikely to lead to meaningful change.

But an alternative solution presented itself in 2020 when we learned to use virtual meetings. During the lockdowns, the sudden closure of face-to-face services left family carers unsupported, and made in-person training impossible. Through local social media, our charity advertised three identical stand-alone virtual meetings at different times for family carers, which included an introductory presentation and group discussion. We offered a follow-on series of sessions which evolved into an eight-week course; feedback was overwhelmingly positive, so we videoed the presentations and repeated the course each term. A closed Facebook group provided ongoing peer support, with trainer input as required.

The following year we started a parallel paid-for course for health and care professionals. Trainees included occupational therapists, nurses, care workers, dementia advisors, care managers and a chaplain, working in hospitals, care homes, hospices, domiciliary care and community services, for statutory, commercial and third sector providers. Trainees reported improved client outcomes, reduced behavioural issues and increased job satisfaction.

### Barriers and facilitators

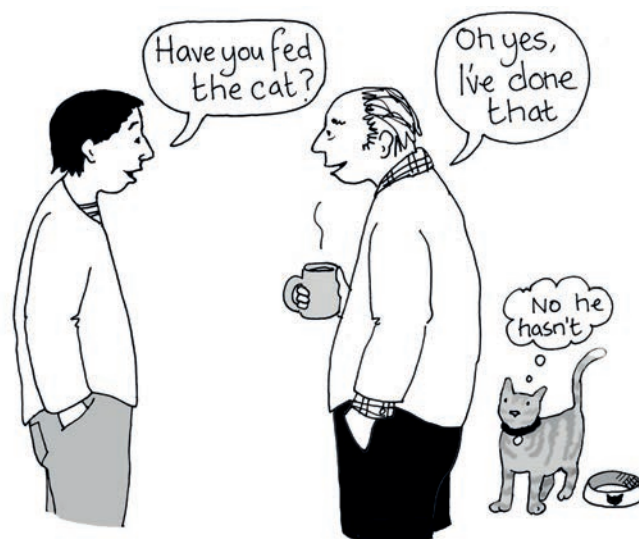
Distance became no object and participants only required internet access, with no need for transport, parking or substitute care. In case of emergency, they could mute or leave the call, returning once things had resolved, or we could send them a link to watch the video presentation later.

Family members could set up online meetings for a tech-hesitant parent, and then take the person with dementia out or to another room during the sessions. Recently a carer with no internet connection participated from the office of a local befriending charity. Another trainee, who had been supporting her aunt from a distance, went to stay with her when a crisis arose during the course. She joined the session from her aunt's room, using headphones and the chat facility for privacy.

Each cohort has its own WhatsApp group for quick and easy communication between, or even during, sessions. When a carer has experienced connectivity issues, we have on occasion provided telephone support throughout the process of leaving a call, rebooting their computer and re-joining the session.

Professional trainees complete reflective homework via online surveys, using anonymised examples from their caseload to embed their learning and provide evidence of their understanding.

Wokingham Borough Council commissioned us to run courses locally after hearing that Understanding Dementia was the only organisation providing support to family carers during lockdown. We now run several carers' courses concurrently, in morning, afternoon or evening sessions, and hold one face-to-face course in a different




**Taken from Understanding Dementia's training presentations, this drawing illustrates the pointlessness of some of the questions we ask people living with dementia**

venue each term across the borough. A train the trainer programme is helping to build our training team and further extend our reach.

With no transport, parking and venue costs or travel, room preparation and clear-up time, our online courses can be priced competitively for professionals, and delivered free of charge to family carers. Trainees can participate safely while isolating, and have even joined in from their holiday. Geographically scattered families can train together or join different sessions according to daily routines, shift patterns and time zones. Health professionals can usually plan an hour in their weekly timetable or, if they are training independently of work, before or after their shift.

### Conclusion

Interactive online dementia courses, originally developed in response to Covid lockdowns, have given Understanding Dementia a cost-effective means of training both family carers and professionals. Thus a potential training crisis has become an opportunity to support many more people with dementia through those who care for them.




Understanding  
Dementia  
and lessening its impact

## Dementia Training

The charity Understanding Dementia offers interactive online training for Health and Care Professionals that can be accessed from anywhere.

- 9-week courses, appropriate for any level of experience
- £195 including training booklet, e-handouts and a CPD certificate
- Start dates in January and April 2024 with choice of daytime or evening



For details and booking visit  
[www.understandingdementia.co.uk](http://www.understandingdementia.co.uk)



# Re-inventing a space for intergenerational use

A former day care centre next to Suffolk care home “the Dell” has been reinvented as an intergenerational space where care home residents socialise with tenants of Dell View, independent living for people with learning disabilities.

**Joy Henshaw** shows how the programme is proving beneficial for older and younger generations

Intergenerational mixing has a host of benefits for people of all ages, providing an opportunity to socialise, improve cognitive stimulation, help develop a sense of purpose, and improve the mood of all involved.

For people living with dementia, this is no different, and intergenerational mixing can potentially help to slow down the progression of the disease. Dementia can be a very isolating condition and it can be difficult for individuals with the condition to connect with others. Encouraging interactions between different generations can enhance mental and emotional wellbeing for the individual while also enriching the lives of young people.

Playing games, doing puzzles, or engaging in other activities with children or younger adults helps stimulate the brain and create new neural connections for those in the early stages of dementia. Residents might even find themselves with a renewed sense of purpose and value as being able to share their knowledge and experience with younger people can be incredibly rewarding.

Even in the late stages of dementia, individuals can still benefit from interaction with others. Although their cognitive abilities may be severely impaired, social engagement can provide emotional comfort and a sense of connection. Simple gestures like holding their hand, speaking softly, or playing familiar music can elicit a response and convey a sense of presence and companionship.

## A new role and purpose

At the Dell, a care home in Suffolk which forms part of the Wellbeing Care group and provides residential, dementia and respite care, we had a day care centre that was once open to the public. However, the decision was made to close it at the start of the pandemic when it was unsafe to have outside visitors on site. After sitting vacant for several years, it has since been reinvented for internal use for intergenerational mixing in conjunction with Wellbeing Care’s Dell View, which specialises in assisted living services and apartments for independent living for people with learning disabilities.



*Joy Henshaw is regional Director at Wellbeing Care*

## Key points to consider

- **Safety and supervision:** Ensure that the care home has appropriate safety measures in place to protect all generations, and that there is sufficient supervision to ensure that interactions are positive and safe for all involved.
- **Staff training:** Provide staff with training to ensure they are equipped to manage and facilitate intergenerational interactions, such as strategies for effective communication, behaviour management, and conflict resolution.
- **Age-appropriate activities:** Plan age-appropriate activities that are suitable for all ages. Activities should be tailored to the interests and abilities of both groups and should encourage interaction and communication.
- **Physical space:** Consider the physical space available in the care home and whether it is suitable for intergenerational activities. It may be necessary to update areas of the home or create dedicated spaces for activities to take place.

One of the biggest misconceptions about intergenerational mixing is that it only happens between the elderly population and very young children – when in fact, it extends beyond this and encompasses all generations in between. For us, we take advantage of the adults living at Dell View and the unique contributions that they bring to the residents of the home such as energy, ambition, and innovative ideas.

## Renovation needed

While we were lucky enough to have this pre-existing building to use, it was in need of renovating and modernising to make it fit for purpose. After being empty for so long, it needed bringing back to life with a fresh lick of paint and new furniture, which took longer than expected as sourcing contractors and supplies, especially



**All parties enjoy delicious food and conversation at the breakfast club**

heading towards the festive season, was difficult.

Finally, we re-opened the building in January 2023 and it was a great feeling to have something new to kick off the year. It gave the residents something to look forward to and helped to create a feeling of excitement and anticipation. The financial cost and the waiting time were both greater than expected, but the results and impact have made it all worthwhile.

We now have a space that will be utilised for years to come, with a fully operational kitchen and activities area. It is not to say that without this building intergenerational mixing could not happen, but it is nice to have space specifically designed for that. Other areas that could be used for generational activities include communal areas, lounges and the kitchen.

### **Breakfast club and bingo**

The centre now operates a popular twice-weekly breakfast club and bingo afternoons – simple but engaging activities which are relatively easy to organise, and which everyone can enjoy. This gives the residents the opportunity to get together outside of the typical care setting and engage in conversation over a game or some delicious food. It depends on the mood and health of the residents on the day as to who takes part but ideally we would have equal residents to tenants to ensure everyone has someone to interact with.

Although implementing an intergenerational programme does not necessarily require specific qualifications, we offered additional support and training to staff to ensure smooth implementation. We arrange brainstorming sessions with staff from Dell View to share best practice, exchange ideas, and discuss successful strategies previously used to make the most out of the weekly sessions in the Wellbeing Centre.

Lee Lambert, a tenant from Dell View, has found

himself a new job helping to prepare and cook breakfast for the residents. He then enjoys serving it to them sitting at the table, and takes pride in his role. For the residents of our care home, they love getting out, albeit a short distance across to the centre, and they also love the fact that it's the tenants from "down the bottom" serving them. They wanted to know so much about them and they are really inquisitive, which is great for stimulating the brain, especially for people with dementia.

Rather than labelling people with a learning disability and saying they can't mix with other people or separating older people from society, it's been lovely seeing them interact together. We can't wait to see all of the wonderful things that this space will bring to our residents and tenants in the coming months.

Evaluating the success of something intangible can be challenging but not impossible. We continually assess the impact and effectiveness through feedback from residents, families, staff members and tenants at Dell View. Our main objective is to reduce loneliness, improve wellbeing and impart joy, so seeing the residents happy, laughing, and talking about the interactions for days after is a clear indicator of its success and that we are getting things right.

### **Future plans**

There are also some exciting plans for the future with coffee mornings, fetes and other feel-good activities on the horizon. We hope there will come a time when we can re-introduce the public to our new space, which will also help to break down the stigma of dementia in the local community, and help reintegrate people back into society and alleviate the loneliness that the condition can sometimes bring. This would include reaching out to local schools, scout groups, Women's Institute branches and other community groups.



# Making a diagnosis of dementia using DiADeM

## (Diagnosing Advanced Dementia Mandate)

### in Dartford, Gravesend and Swanley

DiADeM is a tool for diagnosing advanced dementia when it is neither necessary nor appropriate to involve local memory services. **Mark Kitchingham** (top) and **Kevin Tan** describe a project to extend its use from care homes to people's own homes

The DiADeM tool was developed by the Yorkshire and Humber Dementia Clinical Network (2015) to support GPs in making a diagnosis of advanced dementia in care homes. The acronym stands for "Diagnosing Advanced Dementia Mandate" and the tool enables a diagnosis to be made where a memory service referral is neither feasible nor desirable and may be distressing.

National Institute for Health and Care Excellence dementia guidelines NG97 (NICE 2018) recommend that assessment in primary care should involve a detailed history, including from an informant known to the patient where possible, physical examination and blood testing and use of a basic cognitive tool such as 6-CIT or GPCOG. The DiADeM tool consists of five parts: functional impairment, cognitive impairment, corroborating history, investigations and exclusion criteria. A diagnosis of dementia can be made with a high degree of certainty if all five criteria are met.

The benefits of a timely diagnosis of dementia are well established (Burns 2012), such as providing an opportunity to review any exacerbating factors and medications (including antipsychotics) and non-pharmacological treatments, enabling tailored support for individuals and families, informing advance care planning, facilitating access to the right support at the right time, and allowing consideration of MCA/DoL's issues. The traditional memory assessment service (MAS) pathway locally in Dartford, Gravesend and Swanley involves an initial assessment with a nurse/OT within four weeks, then referral for a brain scan, followed by an appointment with a doctor for diagnosis within 18 weeks.

The NICE dementia guidelines, however, suggest that specialist involvement does not have to be in a clinic setting; the person could be seen and assessed in their own home or care home with advice from a specialist where needed. A specialist could be a secondary care clinician, eg, old age psychiatrist, or a community clinician, eg, an advanced nurse practitioner or GP with additional skills and expertise.

*Mark Kitchingham is advanced clinical practitioner/independent prescriber, Dartford, Gravesend and Swanley (DGS) Community Mental Health Service for Older People, Kent & Medway NHS & Social Care Partnership Trust (KMPT). Dr Kevin Tan is Dartford, Gravesend, and Swanley HCP clinical lead GP (frailty and dementia) and director of clinical services of DGS Health GP Federation.*



#### Key points

- DiADeM is a tool developed for assessing advanced dementia in care homes where referral to the memory service is likely to be distressing and unnecessary
- DiADeM stands for "Diagnosing Advanced Dementia Mandate"
- Benefits of a diagnosis include opportunities for physical health and medication reviews, signposting for support, MCA/DoLS issues and advance care planning
- There is a similar cohort of elderly, frail, housebound patients who may be suitable for diagnosis using the DiADeM tool
- There is therefore an opportunity for cross-service working with the frailty team to reduce duplication and make a diagnosis supported by the memory assessment service (MAS)
- DiADeM can improve quality by improving access to timely diagnosis and deliver this in the most appropriate setting for the individual
- Future challenges are around workforce and replicability in other areas

NICE's guidelines recommend offering structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.

Our project sets out to extend the use of the DiADeM tool from people living with suspected advanced dementia in care homes to those elderly and frail people living in their own homes who were housebound.

The diagnosis rate in Dartford, Gravesend and Swanley (DGS) has been historically low, not meeting the Prime Minister's Challenge on Dementia 2020 (Department of Health 2015) ambition that two-thirds of people with dementia should receive a diagnosis and appropriate support. Consequently, there were many individuals with dementia who had not had the opportunity to receive a formal diagnosis and access support.

There is increasing demand for memory assessments post-Covid and standard waiting times between referral and diagnosis lengthened from 13 to 17.7 weeks after 2019, according to the National Audit for Dementia (Royal College of Psychiatrists 2021). Although these assessments were originally designed for use by GPs, there is an acknowledgement that there are gaps in skills, knowledge, confidence and resource for making a diagnosis of dementia in primary care. ▷

	Diagnosis rate (February 2023)	Diagnosis rate (February 2022)
<b>Dartford, Gravesham and Swanley</b>	63.2	60.2
<b>National</b>	61.85	62.66
<b>Regional</b>	60.63	61.50
<b>Kent and Medway</b>	57.66	58.89

▷ Therefore, the aim of this project is to improve quality by ensuring that individuals with suspected advanced dementia at home are seen in a timely manner in the most appropriate setting for them, reducing time to diagnosis and support compared with the traditional MAS pathway.

Working with the local community frailty team run by DGS Health GP Federation across service boundaries, a new pathway has been developed to enable DiADeM to be completed as part of the frailty assessment by the frailty nurses. Given that there is a link between frailty and dementia, one effect of this initiative is to reduce duplication.

Training for the frailty nursing team from the MAS advanced clinical practitioner on using DiADeM was the first step. If no diagnosis of dementia is already in place and there are concerns about cognitive impairment in moderately and severely frail (ie, scoring 6 or above on the Rockwood Clinical Frailty Scale) housebound elderly patients, the frailty nurses complete the DiADeM tool as part of their comprehensive geriatric assessments (CGA). A thorough functional and cognition history has already been taken as part of the CGA, so this requires minimal extra resource.

If significant cognitive impairment is indicated, the possibility of a dementia diagnosis is discussed with the patient or next of kin and a referral made to the dementia coordinator at the Alzheimer's and Dementia Support Service for pre-diagnosis support. An internal referral is then made to a one-hour multi-disciplinary team virtual meeting held every six weeks between frailty nurses and the MAS, fitting in with the government's target of six weeks from referral to initial assessment (Department of Health 2015), and increasing the number of individuals receiving a diagnosis and treatment within six weeks of referral (National Collaborating Centre for Mental Health 2018). The MAS then produces a report to be sent to the GP for record keeping, including the ICD-10 diagnostic coding if appropriate. In the case of mobile patients, where screening shows that they have a mild or moderate cognitive impairment, we will divert them on to the usual MAS pathway.

Our project has already led to nine new diagnoses of advanced dementia being made using DiADeM in the first six months. The average age of diagnosis was 87.1 years (range 70-95), seven individuals living in their own homes and two living in a care home. In every case a diagnosis was made within six weeks of the regular MDT meeting.

Analysis of the diagnoses shows that seven were of unspecified dementia, one of mixed type dementia and one of dementia in Parkinson's disease. DiADeM has also given an opportunity to review physical health and medication for each patient and prescribe cognitive enhancers (in one case), while the support service

dementia coordinator has enabled support and signposting. In the three patients subsequently followed up by the advanced clinical practitioner, the diagnosis of dementia was confirmed in all cases, strengthening confidence in the DiADeM pathway diagnosis.

As the table (left) shows, there has been an improvement in the local diagnosis rate with Dartford, Gravesham and Swanley outperforming local, regional and national figures. However, it should be acknowledged this is just one of a range of innovations to increase the diagnosis rate, including the use of "GP's with extended roles" and a reconfiguring of MAS assessment clinics so a diagnosis can be made on the same day if appropriate and treatment can be started.

Examples of the feedback we have received include:

*DiADeM diagnosis helped as... "Mum gets very anxious about medical appointments" (carer).*

*"It is simple for people with advanced dementia, comprehensive and easy to use" (frailty nurse).*

*"It has avoided unnecessary scans and hospital visits" (paramedic practitioner).*

*"It has opened the door for support" (carer).*

The DiADeM pathway has reduced waiting times and allowed a diagnosis in the most appropriate setting for the individual while being more efficient and minimising duplication of assessments. The pathway requires minimal extra resource from the MAS when considering the time saved compared to traditional pathways. Quality is maintained by following NICE dementia guidelines (NICE 2018).

Among other benefits have been opportunities for building relationships and learning across service boundaries and multi-professional discussion to promote holistic assessment. Some individuals referred to the MAS have been redirected to the frailty team for diagnosis with DiADeM, freeing up capacity to deal with more complex diagnoses.

Even so, diagnosis should be viewed as a beginning to unlock support rather than as an end in itself. Correct coding in primary care is vital for ensuring appropriate follow-up. In the future, it is hoped that this pathway can be rolled out to the whole trust, although there will be challenges with replicability and workforce issues.

In the meantime, this project has demonstrated that using DiADeM to diagnose advanced dementia in elderly, frail, housebound patients may be a viable alternative to a traditional MAS assessment.

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# Digital technology as a tool for predicting deterioration in frail older people: A case study

Digital technology can provide a comprehensive picture of a care home resident's health and wellbeing and identify any signs of deterioration.

**Anita Astle** explains how this was done in her care home

Digital “ecosystems” are what is created when you interconnect digital technologies in certain ways. It sounds very technical, but it has the potential to revolutionise the care provided in social care settings for people living with dementia.

In the context of a care home, digital ecosystems enable seamless communication and data sharing between different digital tools, offering a comprehensive view of a resident's care needs and delivery. At my nursing home - Wren Hall, a dementia specialist home in Nottinghamshire - we undertook a project aimed at utilising digital technology to proactively meet and improve the health needs of residents living with dementia.

By leveraging digital care planning software and remote monitoring devices, and collaborating with technology providers, we aimed to identify signs of deterioration by optimising care interventions. Here, I will explain what digital ecosystems are, explore the lessons learned from our project and shed light on the potential benefits and obstacles of implementing digital ecosystems in a care home environment.

## What are digital ecosystems?

When implemented correctly, digital ecosystems have the potential to benefit residents with dementia by enhancing the coordination and effectiveness of their care. Integration of various digital technologies within a home enables seamless communication and data sharing among different systems, allowing care providers to more accurately assess and address the specific requirements of residents with dementia. The nurse call system, for instance, can monitor a resident's behaviour and promptly record any significant observations. This data can then be integrated into the planning records, ensuring that caregivers have a real-time understanding of the resident's condition and potential deterioration and can respond accordingly.

These technologies also enable more efficient and streamlined care processes. For instance, medication administration can be automated and synchronised with the electronic system, reducing the risk of errors, which is particularly important for residents living with dementia in whom cognitive function and memory may be impaired. They may be unable to remember and communicate their medication schedules or accurately follow instructions.

Certain medications for symptoms of dementia, such as antipsychotics or sedatives, may have specific dosage requirements or potential side effects that need to be closely monitored. Careful oversight ensures that residents receive the appropriate medication in the correct dosage as an effective response to symptoms while minimising



## Project learning points

- **Intrusiveness:** We constantly considered how our interventions would be felt and tolerated by residents. The main aim was to capture data without staff having to physically disturb residents but it took a while to get to that point.
- **Costings:** There are huge benefits to implementing a digital ecosystem in a care home but you have to be mindful of the cost of new technology, maintenance, training, etc. It might be a case of implementing one piece of new technology at a time, when the budget allows, building up eventually to a fully integrated system. Looking for funding and donations may be an alternative.
- **Staff training:** It is essential to provide comprehensive training programmes that cover the functionalities and operation of the new technology. Ongoing support and refresher sessions should also be provided to ensure that staff members feel confident and competent in utilising the new technology effectively. It's important to remember that this will also be an extra cost.
- **Technical issues:** It is inevitable that technical problems will arise when adopting new technology in a care home. It is important to have a dedicated IT support team to promptly address any technical issues that arise. Creating contingency plans, providing staff training on basic troubleshooting, and establishing clear communication channels for reporting and resolving technical problems can help mitigate the impact.
- **Staff motivation:** Some staff members may be resistant to change and prefer sticking to familiar routines and processes. The introduction of new technology may take them out of their comfort zone, leading to reluctance or scepticism. Additionally, staff members may perceive new technology as a burden or an additional workload, but it's important to reiterate the benefits and motivate staff to work together towards a positive outcome.

*Anita Astle is owner and manager of Wren Hall, a specialist dementia care nursing home in Nottinghamshire.*

adverse reactions. Medication monitoring also allows health care professionals to assess the effectiveness of the prescribed medication and make necessary adjustments as the resident's condition changes over time.

### **Our project**

To facilitate our project we introduced digital care planning software from the company Person Centred Software (PCS). Under this system care and catering staff record their interactions with residents, allowing for data analysis and report generation. Initially, baseline data was manually collected using traditional apparatus such as sphygmomanometers, stethoscopes, thermometers, and oximeters. However, the project highlighted the need for devices that could remotely and non-invasively monitor vital signs.

This led us to contact Ascom, another company focusing on digital information systems. We discussed the potential for remote monitoring of physical measures including blood pressure, pulse rate, respiratory rate, oxygen saturation, and temperature. All this was feasible, but we needed an algorithm to make digital identification of deterioration possible.

So we also engaged with Feebris, a mobile-based software platform, powered by AI and helping users to detect and triage deterioration. Feebris were very supportive of our project and generously provided all the necessary equipment required to facilitate the monitoring process. Feebris collaborated with PCS to make sure that data obtained from their equipment seamlessly integrated with the PCS system. Our staff undertook specialist training on how to access and interpret the data, allowing for efficient and effective remote monitoring.

### **Lessons and outcomes**

Since the project began we have learned how to use our care planning software to analyse health data from our residents and identify significant trends. Weekly data analysis means that we can promptly refer residents to appropriate professionals, such as dietitians, falls teams, community psychiatric nurses and GPs.

By collaborating with these multidisciplinary teams more effectively, action on behalf of our residents has been more timely. For example, medication changes have been initiated more promptly and medication-related issues have been detected at an earlier stage. As a result, we have observed a reduction in behavioural incidents, accidents like falls, and occurrences of infections, as well as a visible improvement in residents' wellbeing.

We observed that the indicators of deterioration in each individual are specific and consistent. For instance, a particular person may exhibit a pattern of increased falls, heightened distressed reactions, withdrawal, or reduced food and fluid intake during periods of deterioration, and they may exhibit the same pattern every time. By recognising these unique signs in each individual, proactive interventions can be implemented to mitigate the adverse effects of deterioration.

By identifying each person's individual response to deterioration, we can have a major impact in supporting their wellbeing day to day. We can add it to their care plan and train our staff to notice what is happening beyond

clinical observations. An increase in falls is relatively easy to notice but withdrawal to one's own room or from activities is often a more subtle change which is harder to notice in a timely manner. Our new digital software is helping to plug the gap.

### **Challenges**

Our primary hurdle has been ensuring effective communication with the entire team at Wren Hall. We wanted the team to be well informed about the project's objectives so as to maximise the benefit to residents. As the project progressed, changes were needed to the way staff recorded information, such as in how registered nurses and nursing associates documented the prescription of antibiotics in our computerised care planning software.

This was crucial to facilitate seamless data analysis, but we encountered challenges in motivating all nursing staff to adhere to the new recording procedures. We dedicated time to encouraging and prompting staff to provide more comprehensive written reports, which meant familiarising them with each resident's deterioration plan and emphasising the importance of recognising and recording specific signs of deterioration for each individual.

The project coincided with a period of staff turnover and new recruits, many of whom had little to no prior experience in social care. They faced the hard task of understanding and meeting the project's requirements because of all the new information they had to absorb. Staff shortages exacerbated the situation, as fewer staff members on duty led to increased pressure and limited time for project reporting.

While our initial project was funded by the Queen's Nursing Institute, the cost of implementation could be prohibitive for other institutions that might not have the appropriate funds. For travel expenses, the purchase of new equipment, staff training and new software, the project cost over £8,000. Implementation of further technology, refresher training courses, new updates and maintenance of the technology will be additional costs down the line.

As our project focused on those living with dementia and significant associated cognitive impairment, it was difficult to seek their opinions throughout this study to be able to assess the project's impact. We had to rely on established evidence-based observational tools such as Dementia Care Mapping and the Quality of Interactions Schedule. We used these as a check on residents' wellbeing and to be sure that interventions were not detrimental.

### **Moving forward**

Our project demonstrated the potential of digital technology in predicting and identifying deterioration in frail older individuals with complex needs, such as dementia. By recognising unique signs of deterioration, timely interventions can be implemented, minimising the negative impact on residents' wellbeing.

As the project continues, the focus remains on individualised care and ongoing improvement in detecting and responding to changes in residents' health. While the initial project focused on five residents within the home, we intend to roll it out to all residents and evidence our findings on a larger scale.



# Introduction to the SPACE Principles - in hospital and prison

Caring well for people with dementia is an ambition enshrined in the Royal College of Nursing's SPACE principles, which have gradually been extended from hospitals to other dementia care environments. **Ruby Fitzhenry** and colleagues discuss their impact on two settings, a large NHS trust and a prison

Caring well for people with dementia has been a long-standing ambition in hospitals and the principles developed by the Royal College of Nursing (RCN) have gradually been extended to other settings such as care homes. These principles – known as the SPACE principles – are enshrined in the RCN's report *Commitment to Care of People Living with Dementia* (2012), outlining the key requirements for improving care in hospitals. Here, we will explain the principles, say how they have been implemented in our NHS trust, and describe our ground-breaking project to extend the principles to a prison setting.

The launch of the SPACE principles had a significant impact on hospitals, partly because they were simple and easy to follow, but also because it was the first time the acute sector had been given a roadmap of what needed to be done. Piloting the principles in eight hospitals from 2014-16, Wessex Academic Health Science Network reported that the hospitals were “able to systematically improve their approach to dementia care” (Wessex AHSN 2016).

When Dr Dawne Garrett, then the RCN's professional lead for older people, updated the principles a few years later, she recognised that they could be used across a wider range of services such as care homes and other residential settings (RCN 2019). Work soon commenced with care homes and again resulted in success stories, while in hospitals the principles became a foundation on which organisations could build improvement and allow services to evolve.

## Imperial implementation

Imperial College Healthcare NHS Trust is large NHS trust based in central London with five main hospital sites. At any one time, 25% of patients accessing services, both inpatient and outpatient, are living with dementia or cognitive impairment. Across the organisation, Imperial has adopted trust values – kind, collaborative, aspirational and expert. The SPACE principles noticeably share these

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## Summary

We explore the experiences of clinicians from two vastly different clinical areas - Imperial College Healthcare NHS Trust and HMP Oakwood – of implementing the Royal College of Nursing's SPACE principles for caring well with people with dementia.

Imperial College Healthcare NHS Trust have implemented SPACE principles across their hospital sites successfully, integrating them with trust values and allowing a small team to make a big impact on patient care.

SPACE principles were adapted for prison settings in 2019. HMP Oakwood have actively applied these principles, and here we detail the challenges and successes they have achieved in an environment which can be unpredictable.

Both institutions demonstrate the adaptability and effectiveness of SPACE principles and the far-reaching positive impact for people living with dementia.

values and that has helped the transition to these principles at Imperial.

As will become clear, SPACE is an acronym standing for Staff, Partnership, Assessment, Care and Environment.

**S**taff who are skilled and have time to care  
**P**artnership working with carers  
**A**ssessment and early diagnosis  
**C**are that is individualised  
**E**nvironments that are dementia-friendly

Here is a brief summary of Imperial's implementation process:

## Staff who are skilled and have time to care

Tier 1 dementia training is part of core learning and all clinical staff are required to complete it. Our dementia care team delivers a face-to-face dementia study day which is open to all staff. We focus on person-centred care, with the onus placed on staff that training is not about teaching them how to manage people living with dementia, but to help patients living with dementia manage staff, the environment, and the experience of hospital care. ▷

▷ Our small team works hard to ensure visibility and has built strong working relationships with staff in all areas across the trust. There is an open referral system and staff are encouraged to contact the team with queries and concerns. Staff are also aware they can refer relatives and carers of patients living with dementia who they feel need expert input and support.

### **Partnership working**

Imperial has committed to working in partnership with carers, with the use of the “Carer’s Passport” widespread throughout the trust. Carers’ passports are for a nominated person who acts as a carer for a person living with dementia, learning disability, or at the end of life, and allows the carer to attend the ward at any time. Carers are not to be seen as visitors and the trust’s visiting policy reflects this.

Instead, carers are encouraged to support their loved one in whatever way is appropriate for them; this may be hands-on care such as personal care or emotional support, whatever the patient needs. This is obviously hugely beneficial for the patient, but the impact is also significant for the carer. Beardon *et al* (2018) found that carers often experience anxiety and distress when their loved one goes into hospital, so the flexibility of the carer’s passport is essential in supporting their needs also.

The dementia care team embraces a collaborative approach to supporting inpatients, and carers are often contacted to provide additional information. This information is imperative in ensuring care is person-centred, as well as supporting carers to feel involved while their loved one is in hospital. Carers are encouraged to bring in items from home which are familiar and comforting, while wards actively involve carers in best interests meetings regarding care and discharge planning.

### **Assessment, early identification of dementia and post diagnostic support**

Evidence shows that diagnosing dementia should be avoided while a person is an inpatient in hospital due to the potential impact of cognition of illness and an unfamiliar environment (Taylor *et al* 2015). It is recommended that patients who have suspected dementia but have not yet received a diagnosis should be referred to a memory clinic for specialist assessment (NHS 2020). On discharge, patients are handed over to their GP to be followed up in a memory clinic in the community.

But other assessments are necessary in hospital and these are based on the SPACE principles. An example is the assessment of pain, which is frequently not recognised and under-treated for people living with dementia, often exacerbated by communication difficulties. We use PAINAD - Pain Assessment in Advanced Dementia Scale (Warden *et al* 2003) - as it does not rely on verbal communication and is suitable for patients with significant communication deficits such as expressive dysphasia.

We also used the Observational Scale of Level of Arousal (OSLA) which is recommended by the National Institute for Health and Care Excellence for the assessment of delirium in dementia (NICE 2018). OSLA is designed to be used following a brief interaction and can accurately identify hypoactive and hyperactive delirium, even with no

verbal response from the patient.

Our policies for both dementia and delirium are easily accessible for all staff. There is a clear pathway for escalating and referring a patient who is distressed or a patient with delirium to the dementia care team for additional support.

### **Care and support plans which are person-centred and individual**

Gathering a succinct life history is essential for ensuring care is person-centred (Brooker & Latham 2016). At Imperial, a document called “What matters to me” has been developed to record key details, including what the person likes to be called, likes and dislikes, and who is important to them. It is designed to be left at the patient’s bedside, so it is accessible for all staff, as well as carers, and enables staff to get to know their patients better and develop a relationship conducive to good quality care. It is invaluable for creating bespoke, person-centred care; it informs care plans, helps to decide appropriate equipment and resources are provided to the patient and ensures that patients are seen for the person they are, not a hospital number.

Specialist input is provided by the dementia care team and care plans are drawn up with information gathered from in-person patient review, patient notes and discussion with relatives and carers as well as members of the wider multidisciplinary team. It is vital that care plans cover a range of domains, including physical health such as continence, pain, sleep and nutritional needs, and mental health such as emotional needs. Family and carer support and personal history, including trauma-informed care, should also be part of it.

### **Environments that are dementia friendly**

Dementia friendly environments can be logistically complex in large organisations. Our trust is no different in this respect, with multiple different sites and buildings built in different periods over the last two centuries. In this context, creating truly dementia friendly environments has not been without its challenges!

Wards in medicine for the elderly have had significant refurbishments, with the most recent completed in April 2023. The team has worked with architects and builders to ensure that these new environments are dementia friendly using the King’s Fund Enhancing the Healing Environment Dementia Friendly assessment tool (2014).

Particular attention has been paid to flooring and avoidance of designs which could confuse patients with visual perception issues. There are large, clear signage welcoming patients to the ward, bright colour schemes for bays, yellow doors to identify toilets and coloured high contrast toilet seats. On one ward in particular the trust charity arts team worked with the dementia team and commissioned an artist to paint murals (see photo on page 36). This hospital site has high numbers of black, Asian and minority ethnic patients, particularly from the Caribbean, and the artist was chosen for her use of bold, bright colours and Caribbean-themed landscapes.

Items brought from home by relatives and carers, such as photos and items of special significance, help to maintain familiar environments, while any hobbies brought by them



help to maintain regular routines. Patients are also encouraged to sit out of bed as much as possible during the day to differentiate between day and night, and to utilise day rooms to watch TV and engage in other activities.

### SPACE in prison settings

By 2020 attention became focused on vulnerable adults who were in the justice system. The number of prisoners over the age of 60 had increased by 243% between 2002 and 2020 (House of Commons 2020) and dementia diagnosis rates were 5% in prisons compared to 68.7% for older people in general at that time (Age UK 2019).

In evidence to the House of Commons Justice Committee, the Prison Reform Trust stated that “people with dementia cannot be well cared for in a prison environment” (House of Commons 2020) and an example

from the same report illustrates the challenges a prisoner living with dementia will experience in prison:

“Mr X has severe dementia and every day he believes he has a taxi arriving to take him home to his wife. Consequently, he refuses to return to his cell until the staff tell him to get his coat because his taxi has arrived. He then enters the cell to get his coat upon which the door is slammed. He then spends many hours, including during the night, banging the door trying to get out to reach his taxi.”

In view of this, the principles were adapted again, this time for prisons and justice settings (RCN 2020). A benchmarking tool - Transforming Dementia Care – gave staff the opportunity to chart their progress and the adapted principles, produced in collaboration with *Inside Times*, the prison newspaper, have the voices of people living with dementia threaded throughout (see table below). ▷

	SPACE principles	Adaptations for prisons
S	Staff who are skilled and have time to care	This has included the importance of hearing the views of not only the person living with dementia and the family but also the wider prison community who will be living with that person.
P	Partnership working within the prison community	This acknowledges that a person in prison has a different community and that the circle of support might not include family, but might include prison staff and other people living in prison.  The importance of ensuring records accompany the person during transfers between prisons is emphasised, along with ensuring the availability of comparable services in the new prison.
A	Assessment, Early Identification of dementia and post diagnostic support	Highlights the lack of parity in assessment services for those living in prison. Warns against attributing behaviours to lack of liberty rather than a possible cognitive impairment.  Highlights the danger that persons who are disinhibited due to an undiagnosed dementia might be at increased risk of imprisonment and how important screening is.
C	Care and support plans which are person-centred and individual	A greater emphasis is placed on safeguarding. The safeguarding needs and responses to both the person and others they come into contact with, both within prison and on release, should be carefully planned.  All staff must have safeguarding training on induction and the opportunity of regular refreshers. Health care staff should have training in line with the intercollegiate documents for both adults and children and young people.  There should be strategies in place for communication of care and support plans during transitions across health and social care settings, prison facilities and release and resettlement from prison.
E	Environments that are dementia friendly	These should be dementia friendly and support independence and wellbeing. A risk assessment should inform where people are situated in prison.  Their sensory and mobility needs and ability to navigate must be taken into consideration.  Where accommodation is shared, the person with dementia should be protected from abuse or manipulation and their human rights upheld.  Health care staff should be involved in the environmental planning of the prison estate to ensure clinical needs are taken into consideration, drawing on the best available evidence.  Evidence-based design features should be included in all new builds and refurbishments of prison health care facilities and older people's wings such as appropriate flooring, lighting, signage, contrast and technology.  Regardless of facility, individuals should have access to items they recognise as their own.  Risk assessment should be undertaken to ensure the appropriateness of those sharing accommodation.  <i>“I have seen an elderly man with dementia being allocated a cell with a much younger man who assaulted him badly”</i> (Comment from 45-year-old man living in an open prison).  Settings should ensure people have access to rehabilitative opportunities and activities to maintain functional independence and social interaction. The person should have access to social interaction with people who understand the nature of dementia, such as a peer system or buddy arrangement.

### Key points

- The SPACE principles for caring well for people with dementia have been successfully employed in hospitals including Imperial College Healthcare NHS Trust
- They can be adapted for different environments such as care homes and prisons
- There is an increasing need for dementia care in prison settings as the prison population ages
- Seen as roadmap for better care, the principles can be used to kick-start improvements in dementia care
- HMP Oakwood shows how the principles were used to develop a successful in-reach service for prisoners with dementia.

#### ▷ HMP Oakwood implementation

HMP Oakwood is a Category C prison located in Featherstone, Staffordshire. It is one of the largest prisons in the UK, with a capacity to house 2,134 male prisoners. The prison is operated by G4S, a private security company that manages several prisons.

Prisons are not typically equipped to handle the unique needs of individuals living with dementia. They can be noisy and confusing places, which can exacerbate dementia symptoms and make it difficult for people to understand and follow rules. Additionally, a prisoner with dementia may be more vulnerable to abuse or neglect.

When the RCN adapted the SPACE principles to promote dementia care in prisons, a pilot scheme was initiated to implement them at HMP Oakwood. Assisting in this project were two of this article's co-authors, an advanced nurse practitioner (Deanna Mezen) at HMP Oakwood and a dementia in-reach nurse (Edwina Gould) from the Midlands Partnership University NHS Foundation Trust.

The SPACE principles help services and staff assess the quality of dementia care delivered in the prison. From this baseline assessment, prison communities can work together on improving specific aspects of care. The principles can be used with a wide range of training packages, quality improvement methodologies and practice development activities. While the evidence base drawn upon is for the care of people with dementia, there are potential benefits to people with other cognitive difficulties.

The primary objective of the prison's dementia in-reach service is to provide prisoners with the same level of dementia-related care as would be available to the community population. The service offers routine cognitive screening clinics for over-50's, diagnostic clinics for dementia assessment and diagnosis, follow-up/review clinics, liaison with other professionals, training and teaching, and the offer of supervision sessions for frontline staff in understanding and managing dementia in prison.

Dementia care in prisons can be challenging because specialised care and support are needed, yet difficult to

provide in this context. Consequently, we made an individual spider graph for each of the five principles, highlighting areas for improvement and in particular the need to offer training and education to staff. We aimed to assist staff with understanding and delivering care, as well as the implementation of assessment to aid early identification of dementia. The graph was then revisited a year later and showed definite improvements in most areas, in particular a clear referral pathway and access to a dementia specialist services. "Before" and "After" spider graphs for the "Assessment" principle are shown on page 35.

This piece of work highlighted the importance for prisons of having protocols in place to properly assess individuals with dementia, provide appropriate care and support, and ensure their safety and wellbeing. There continue to be challenges which are outlined below.

#### Physical environment

Prisons are designed with security in mind, which can create a hostile and unfamiliar environment for someone with dementia. The physical layout of the prison can also be confusing, causing some people with dementia to become disoriented and lost. It can help if the individual can give consent for prison officers to be informed of their diagnosis and how it may affect them. A "buddy" allocated to them, who is another prisoner, can support with daily activities, such as attending appointments or taking them to collect medication and ordering food and provisions from the kiosk (which is a touchpad screen and potentially hard to navigate).

Noise from things like loud alarms, intercoms, and other sounds can be distressing. Conducting post-diagnostic dementia reviews in the healthcare building where possible has been advantageous, as it is quiet space allowing privacy for thoughts and feelings to be discussed.

As part of our project we provided end-of-life care for a man diagnosed with dementia. His wishes were to remain on the wing and so the officers and other prisoners were respectful in trying to keep noise levels down. For example, prisoners changed the way that they queued for meals to avoid standing outside the patient's door.

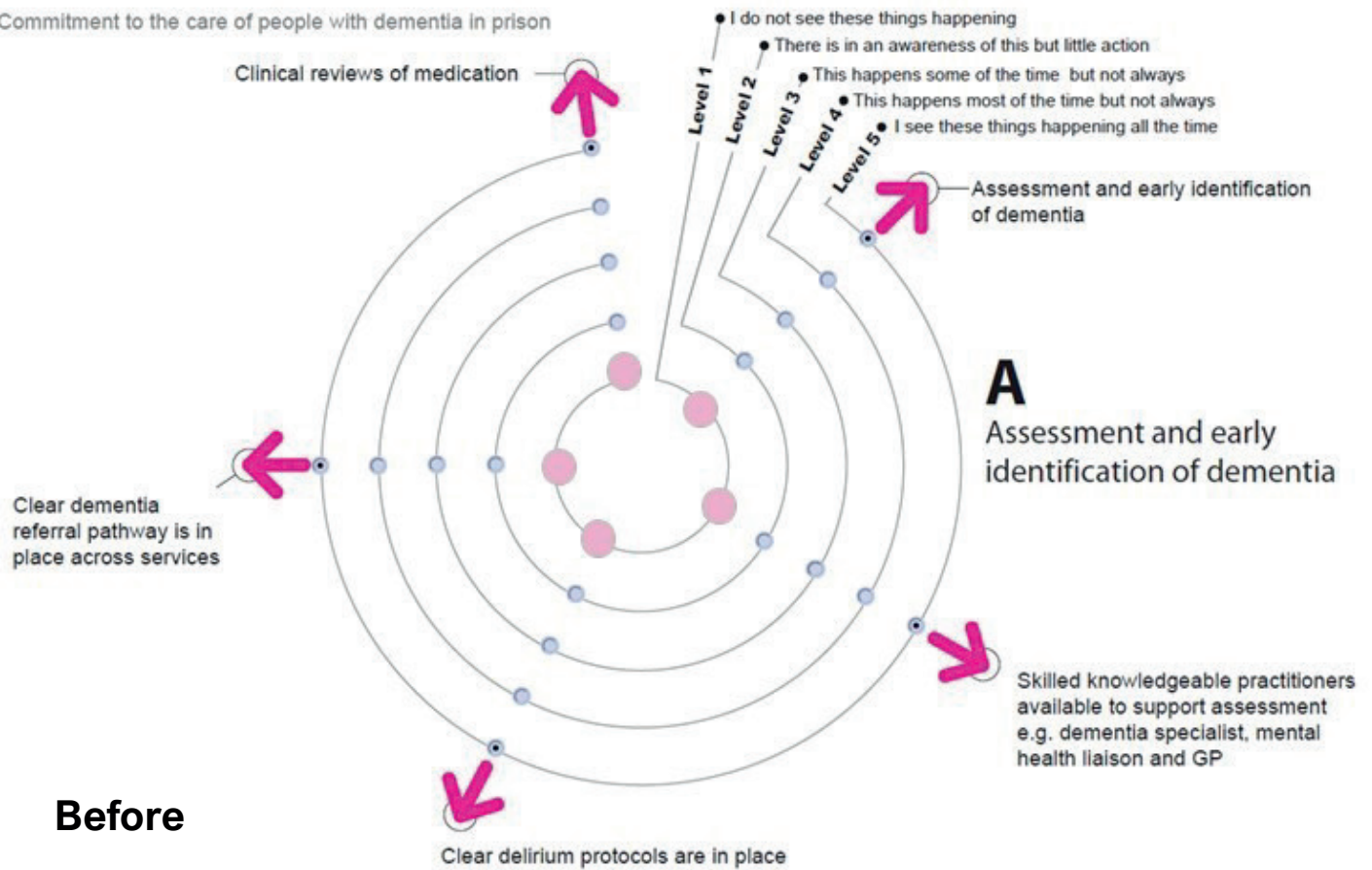
#### Lack of stimulation

Prisons can be boring and lack stimulation, leading to feelings of depression and anxiety in individuals with dementia. HMP Oakwood encourages social activities on the wing, such as playing pool, using gym equipment, cards, dominoes, attending chapel and for the men who are ex-military, attending the veterans' meeting. Time outside is also encouraged in the exercise yard.

#### Lack of personal space

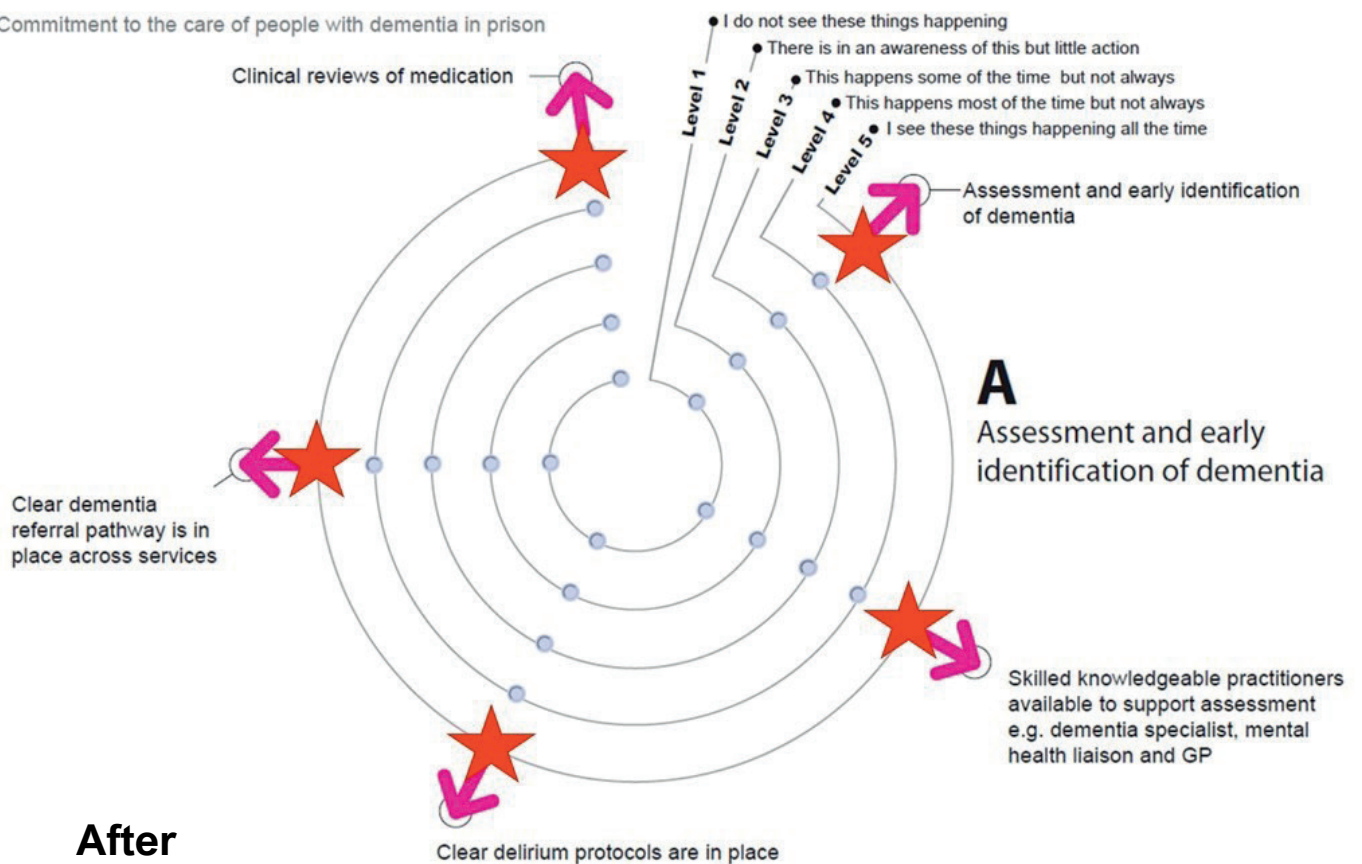
Prisons are often overcrowded, and prisoners with dementia may not have access to a private room or space, which can be overwhelming and cause further confusion. At HMP Oakwood a patient with a diagnosis of Alzheimer's disease was struggling in a shared cell owing to the small space and his cellmate talking and telling him what to do. The issues were discussed with the health care team and he was transferred to a single cell, which helped to alleviate his anxiety and levels of distress. ▷

Commitment to the care of people with dementia in prison



**Before**

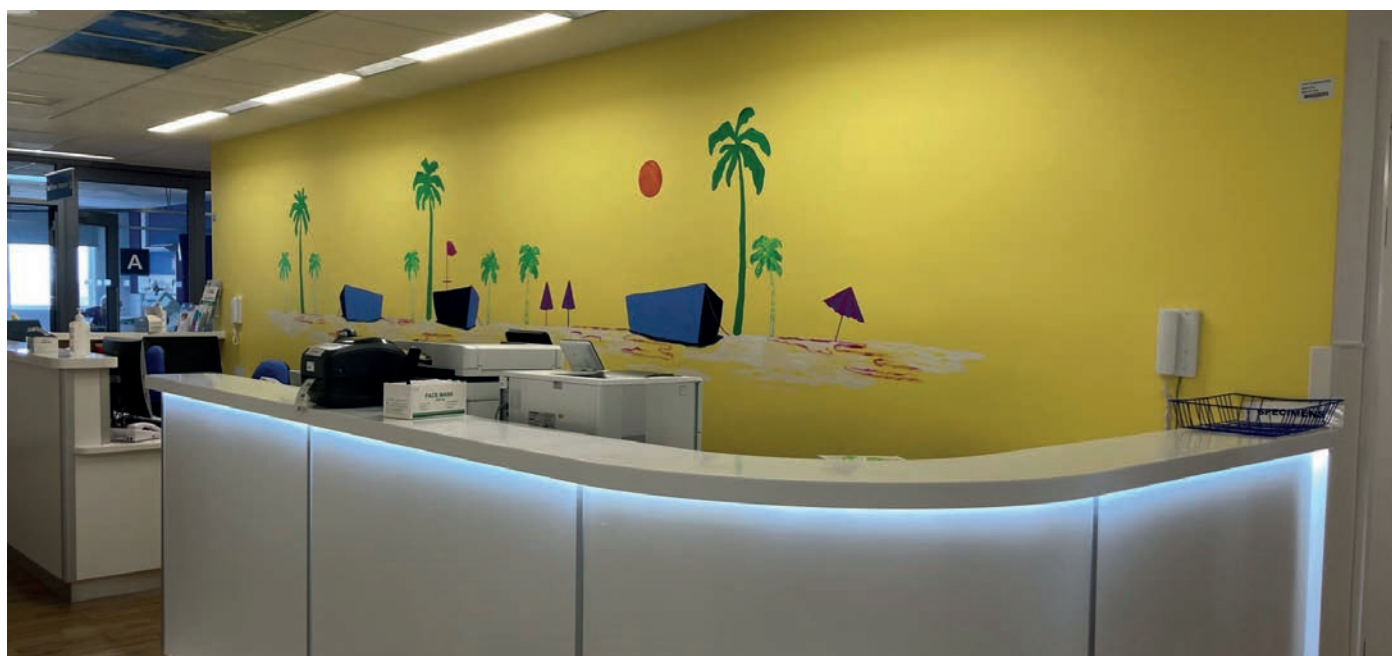
Commitment to the care of people with dementia in prison



**After**

Spider graphs for “Assessment” principle, before (top) and after. Pink dots and red stars are the markers.





**Mural welcoming patients to the ward, in a hospital that has high numbers of black, Asian and minority ethnic patients, particularly from the Caribbean. The artist was chosen for her use of bold, bright colours and Caribbean-themed landscapes.**

### ▷ Limited staff training

Staff in prisons often lack the necessary training to give adequate care to people with dementia, potentially resulting in inappropriate or even harmful interventions. Dementia awareness training at HMP Oakwood has been delivered to staff in health care, pharmacists, managers and porters, although it has been harder for prison officers to find time for these teaching sessions and this is something that continues to require input.

Another benefit of the project is that we've been able to contribute to prisoners' release planning. Release planning may mean a move to "approved premises", which can be an unfamiliar place in an unfamiliar area with a requirement to abide by a curfew. This can pose a substantial risk for released prisoners who are significantly cognitively impaired, in terms of their health, safety and a potential breach of their licence conditions, which would result in a recall to prison.

Instead the dementia in-reach service has been able to liaise with the Probation Service and social care to enable some prisoners to be identified as requiring 24-hour care to meet their needs, meaning that they can be released into the community safely.

Overall, it is important to recognise that individuals with dementia in prison have unique needs that require specialised care and support. By addressing these challenges and working to provide appropriate care, we can improve their quality of life in prison and ensure their safety and wellbeing.

### Conclusion

We have indicated the incredible flexibility of the SPACE principles and their commitment to good care. They can be adapted for almost any setting with a little thought and collaboration as has been powerfully illustrated in the work done by Imperial and HMP Oakwood. Improvement can happen, it can be meaningful, and, whatever the primary purpose of the institution is, it is always possible.

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# Evidence for practice/Research news

This section aims to keep readers up to date with research in dementia care and the current best evidence to support practice. We aim to provide a channel of two-way communication between researchers and practitioners, so that research findings influence practice and practitioners' concerns are fed into the research agenda.

We welcome contributions such as:

- Information on recently-completed studies that are available to readers
- Notice of the publication (recent or imminent) of peer-reviewed research papers with practical relevance to dementia care
- Requests or offers for sharing research information and experience in particular fields of interest
- Short comment on important research papers recently published, drawing readers' attention to new evidence and key points that should inform practice.

The research papers summarised here are selected for their relevance and importance to dementia care practice by the section editors, Hazel Heath and Theresa Ellmers. We welcome suggestions of papers to be included: please contact [sue@dementiapublishing.community](mailto:sue@dementiapublishing.community)

## Communication through unspoken narratives

Qualitative research involving people with dementia tends to be word-based and reliant upon verbal fluency. This study sought to understand movement as a vital means of communication for older people with dementia in a general hospital ward. It shows that people with dementia have narratives to share, but that these do not fit the bio-medically constructed model generally expected from patients. Utilising a 'mobilities' lens enabled the narratives to be understood as layers of language. The first layer is the words, the second layer is gestures and movements that support the words and the third layer is micro movements. These can support the words, but in some cases, they tell a different story altogether.

Collins P, Bridges J, Bartlett R. Gaining access to unspoken narratives of people living with dementia on a hospital ward – A new methodology. *International Journal of Geriatric Psychiatry*. 38, 8, e5987. Published Aug 16 2023. <https://doi.org/10.1002/gps.5987>. Open access.

## The challenges of co-produced research

Despite general consensus that service users need to be meaningfully involved in research, for people living with dementia this remains limited by academic structures, frameworks, language and funding processes. This paper reflects on the experiences of researchers and people with dementia experienced in research. Providing novel insights, it concludes that creating a collaborative environment in dementia research requires extensive time, resources and emotional support. The authors highlight the importance of embracing the tensions of research contexts as researchers strive towards learning, growth and more equitable ways of working in co-produced dementia research.

Warran K, Greenwood, Ashworth R *et al*. Challenges in co-produced dementia research: A critical perspective and discussion to inform future directions. *International Journal of Geriatric Psychiatry*. 38, 9, e5998. Published Sept 6 2023. <https://doi.org/10.1002/gps.5998>. Open access.

## Also:

Despite the consensus that service users need to be actively involved in systematic reviews, this paper highlights that usually only healthcare professionals are involved; also there is currently no framework for the active involvement of people living with dementia and those from their social network. These researchers will develop such a framework in collaboration with a range of members of the public and healthcare professionals. The framework will later be made available to the public free of charge.

Rommerskirch-Manietta M, Manietta C, Hoffman AL *et al*. Participatory development of a framework to actively involve people living with dementia and those from their social network and healthcare professionals in conducting a systematic review: the DECIDE-SR protocol. *Research Involvement and Engagement*. 9, 52. Published July 11 2023. <https://doi.org/10.1186/s40900-023-00461-2>. Open access.

## Barriers to person-centred care in care homes

Interviews with managers in highly person-centred homes sought recommendations for overcoming the multi-level barriers to person-centred care. They conclude that, in order to increase a common understanding of person-centred practices, stakeholders, policy and organisations need to offer person-centred education initiatives and continuing supervision. The authors highlight that person-centredness needs to inform the functional design of nursing homes, and that residents' needs and preferences for a good life should frame economic, regulatory and health care policies.

Backman A, Ahnlund P, Lövheim H, Edvardsson D. Nursing home managers' descriptions of multi-level barriers to leading person-centred care: a content analysis. *International Journal of Older People Nursing*. Published Oct 20 2023. <https://doi.org/10.1111/opn.12581>. Open access.

## Physical rehabilitation

Research into rehabilitation after hip fracture often excludes people with dementia, especially those in more

advanced stages, so the most appropriate interventions remain unknown. Using nominal group technique, highly specialised physiotherapists achieved consensus on core considerations for the multidisciplinary expertise needed to effectively deliver rehabilitation to people with advanced dementia who fracture their hip. They conclude that people with dementia require highly skilled and trained professionals, providing holistic and person-centred approaches to deliver rehabilitation interventions. While the focus was on hip fracture, the authors suggest these statements can be used for people with advanced dementia who have a variety of other conditions.

Hall AJ, Manning F, Goodwin VA. Physical rehabilitation for people with advanced dementia who fracture their hip – expert consensus process. *Disability and Rehabilitation*. Published Sept 21 2023. <https://doi.org/10.1080/09638288.2023.2260739>. Open access.

#### **Also:**

This restricted access paper debates what is, or should be, rehabilitation's role in progressive neurological conditions and what are the policy and practice implications for the care of people living with neurological conditions such as dementia.

Faieta J, Ebuenuy ID, Devos H et al. The Role of Rehabilitation for Early-Stage Alzheimer's Disease and Related Dementias: Practice and Priorities. *Archives of Physical Medicine and Physical and Rehabilitation*. Published Sept 26 2023. <https://doi.org/10.1016/j.apmr.2023.09.013>. Restricted Access.

#### **Dementia-friendly television videos**

This study aims to understand the perspectives of nurses and healthcare providers on the potential function and practice considerations of using TV videos for people with moderate to severe dementia. It identified that TV videos could help to calm individuals in emotional distress, form connections, bring people together, facilitate Activities of Daily Living and help people connect with their past. The authors conclude that TV videos should be designed to match the person's cognitive abilities, interests, and cultural and linguistic backgrounds. The findings supplement Kitwood's model by identifying the person's cultural and language needs.

Hung L, Lok K, Wong Y. The Perspectives of Nurses and Healthcare Providers on the use of Television Videos with People with Moderate to Severe Dementia. *Canadian Journal of Nursing Research*. Published Oct 16 2023. <https://doi.org/10.1177/08445621231208220>. Open access

#### **Dementia care education**

This study used nominal group technique to identify priorities and reach a consensus on student nurses' learning requirements and the teaching strategies best suited to dementia care. Prioritised learning requirements included theoretical understanding of dementia, communication, caregivers' needs, comprehensive assessment and ethical practice. Experiential learning was identified as the best-suited teaching strategy. The findings could support nurse educators to design and deliver better dementia education. Cariñanos-Ayala S, Zarandona J, Durán-Sáenz I, Arrue M. Identifying undergraduate nurses' learning requirements and teaching strategies in dementia care education: A nominal group technique. *Nurse Education in Practice*. 71. Aug 2023, 103711. <https://doi.org/10.1016/j.nepr.2023.103711>. Open Access.

#### **Physical activity to prevent cognitive decline**

This systematic review aimed to summarise evidence on the cost-effectiveness of physical activity (PA) for the prevention and management of cognitive decline. It concluded that PA interventions implemented before or during the early stage of cognitive impairment may be cost-effective in reducing the burden of dementia but more research is needed to investigate the cost-effectiveness of PA interventions in managing dementia.

Li W, Kim K-WR, Zhang D et al. Cost-effectiveness of physical activity interventions for prevention and management of cognitive decline and dementia—a systematic review. *Alzheimer's Research and Therapy*. 5, 159. Published Sept 25 2023. <https://doi.org/10.1186/s13195-023-01286-7>. Open access.

#### **Social isolation in hearing loss**

The consequences of living with hearing loss can include social withdrawal and reduced communication opportunities. This study examined patterns of communication and the perspectives of residents, staff, and relatives within two UK care homes. This enabled an understanding of how communication environments contribute to social isolation. It observed a range of examples of social isolation, not always associated with the severity of hearing loss but rather communication ability. Simple interventions such as staff dining with residents and focussing on improving communication could reduce social isolation.

Dhanda, N., Pryce, H. An ethnography study exploring factors that influence social isolation in care home residents living with dementia and hearing loss. *BMC Geriatrics*. 23, 593 2023. Published Sept 25 2023. <https://doi.org/10.1186/s12877-023-04296-0>. Open access.

#### **Young Onset Dementia services**

Through interviews with commissioners and service managers in diverse areas and contrasting services, this study concluded that improvements in provision for people with young onset dementia (YOD) and their families needs to be built on understanding of service-level and interpersonal influences as well as on understanding of YOD itself. The findings highlight a set of facilitators which need to be in place to establish and sustain high-quality YOD services that fit the local context.

Oyebode J, La Fontaine J, Stamou V et al. Establishing and sustaining high quality services for people with young onset dementia: the perspective of senior service providers and commissioners. *International Psychogeriatrics*. First View 1-10. Published Sept 21 2023. Doi: <https://doi.org/10.1017/S1041610223000443>. Open Access

#### **Characteristics of dementia friendly hospitals**

This review highlights the need to consider resources, funding options, influencing factors, and the current culture of care provided by hospitals before implementing Dementia-Friendly Hospital characteristics. In addition to the involvement of professional dementia experts and various health care professionals, the involvement of other stakeholders, such as people with dementia and their relatives, is identified as necessary.

Manietta C, Purwins D, Reinhard A et al. Contextualizing the results of an integrative review on the characteristics of dementia-friendly hospitals: a workshop with professional dementia experts. *BMC Geriatrics*. 23, 678. Published Oct 19 2023. Open access. <https://doi.org/10.1186/s12877-023-04312-3>.



## Blogs I'm Watching

By Mark Ivory

In Scotland the role of occupational therapists and other allied health professionals (AHPs) in dementia care is taken seriously, perhaps more seriously than elsewhere in the UK. The Alzheimer Scotland blog Let's Talk about Dementia regularly carries stories from qualified and student OTs on their experiences and perceptions of dementia care while emphasising the crucial role of occupation in helping people live well with the condition. This message is regularly reinforced by the AHP dementia webinar series, hosted by Alzheimer Scotland, and now by a book entitled *Occupational Therapy and Dementia: Promoting Inclusion, Rights and Opportunities for People Living with Dementia*. Edited by Fiona Maclean, Alison Warren and colleagues, the book aims to "inspire occupational therapists of today and tomorrow to be future leaders, innovators, researchers and rights-based practitioners in dementia." An ambition worth pursuing not just in Scotland but south of the border too.

<https://letstalkaboutdementia.wordpress.com>

Most services are provided to spouse and partner on the assumption that this also takes care of the person living with dementia. So contends George Rook, except, as he points out, that assumption is "NOT TRUE". George's blogpost issues a stern reminder that one third of people with dementia live on their own. And, in any case, he thinks that there's an over-reliance on the carer's point of view rather than that of the person with dementia. To take just one example, Admiral Nurses support carers to support the person living with dementia, but someone on their own may be denied the service. "That is unfair, and if the solo person living with dementia is having trouble navigating the system to obtain help and support, they need the services of an Admiral Nurse all the more," George argues. "I am working to get this changed, so that contracts with commissioners are drawn up differently."

<https://georgerook51.wordpress.com>

Actor Timothy West talks about his wife Prunella Scales' dementia diagnosis in the Alzheimer's Society blog, drawing inspiration from his new memoir *Pru and Me*. He knew something was wrong when he saw Pru falter over some lines on stage in 2001 but it wasn't until 2013 that she was diagnosed with vascular dementia. Pru no longer appears on stage but theatre continues to play an important part in their lives, Timothy says. He admits to not being "very aware" that there are dementia-friendly theatres and performances but agrees that it is "a positive step". What really matters, though, is "enduring love". In the book, he says: "[We] have exactly the same conversation every day of the week and it's something I never tire of. Repetition doesn't really exist in Pru's world and the look on her face when she enters the room and sees me sitting there on the sofa waiting for her makes me realise just how much I love her."

[www.alzheimers.org.uk/blog](http://www.alzheimers.org.uk/blog)

## Resources

A trio of 'Knowledge is Power' resources is now available for people diagnosed with dementia. Innovations in dementia have launched their England edition of their 'Knowledge is Power' post-diagnostic support resource.

The booklet, like the Scotland and Wales editions, is written by people living with dementia for people living with dementia and contains a wealth of information, resources, and support for anyone with dementia and people around them.

You can find the full trio of booklets at these links:

England: [https://www.dementiavoices.org.uk/wp-content/uploads/2023/09/Knowledge\\_is\\_Power\\_England.pdf](https://www.dementiavoices.org.uk/wp-content/uploads/2023/09/Knowledge_is_Power_England.pdf)

Scotland: [https://www.dementiavoices.org.uk/wp-content/uploads/2021/04/Knowledge\\_is\\_Power\\_English\\_booklet\\_single\\_A5\\_pages\\_AW.pdf](https://www.dementiavoices.org.uk/wp-content/uploads/2021/04/Knowledge_is_Power_English_booklet_single_A5_pages_AW.pdf)

Wales: <https://www.dementiavoices.org.uk/wp-content/uploads/2023/10/knowledge-is-power-en.pdf>

Care home provider KYN have worked with Innovations in Dementia to produce new guidelines on the language we use about dementia. Emma Hewat, Head of Dementia at KYN said: "We wanted to draw upon people's lived experiences of dementia to create a new set of guidelines that was inclusive of their views, experiences and expectations of how they are portrayed in the media. The guideline creation is an example of how including the perspectives of people affected by dementia can be successfully utilised in educating the media and broader society."

Allison, Dory, George, Gerry, Julie, Lorraine and Steve from Innovations in Dementia worked with KYN, supported by Philly Hare, to produce these guidelines, which can be found here: <https://www.kyn.co.uk/assets/files/uploads/kyn-lets-talk-about-dementia-guidelines.pdf>

Palliative care charity Marie Curie has produced a new resource for local health and social care boards to help with the legal requirement to provide palliative care to those who need it across England. Called the ICB Inspire Resource, aimed at NHS and local authority integrated care boards, it will support ICBs in their duty to commission good palliative care and includes examples of best practice. <https://view.pagetiger.com/bbqohwx/1/?ptit=83923831D4B3A3C0942CF>

Derby Theatre has published Nicky Bellenger's new play "Everywhere", to be performed by young people but exploring and shining a light on dementia in a sensitive, stigma-reducing way. Available free, the play is also intended as a resource for all ages to support a greater understanding of the dementia. "Everywhere" is the result of a creative and compassionate collaboration between Bellenger, attendees to Derby Theatre and Universal Services for Carers in Derby Carers Café and members of Derby Theatre's Youth Theatre.

<https://derbytheatre.co.uk>

Funding from the National Institute for Health and Care Research (NIHR) has been announced for developing a brain health app. Worth £1.9 million, the funding will

enable work to begin on the REACTIVE app, which will monitor brain health in older adults through regular cognitive tests while also providing a brain training programme for them. The aim is to identify mild cognitive impairment in people who are not currently seen by a GP or memory clinic and ensure that they get the help they need. Anne Corbett, study lead at the University of Exeter, said: "Computerised tests of brain health are far more sensitive and accurate than traditional paper-and-pencil tests and using an app means we can reach large numbers of people in an affordable way."

<https://news.exeter.ac.uk>

Co-created by people affected by dementia, a new film released by the IDEAL research project focuses on the importance of effective communication around dementia. Titled "The World Turned Upside Down," it looks at the reality of living with dementia and caring for someone with the condition through a dramatic composition. People affected by dementia were involved in creating the drama, which explores scenarios at different points of characters' experiences with dementia from diagnosis and sharing the diagnosis with family to caring for a loved one with dementia.

[www.alzheimers.org.uk/blog/watch-world-turned-upside-down-film-about-dementia-and-communication](http://www.alzheimers.org.uk/blog/watch-world-turned-upside-down-film-about-dementia-and-communication)

An easier way to administer an established treatment for Alzheimer's disease has been developed by Luye Pharma. The twice weekly Zeyzef rivastigmine transdermal patch is said by the company to be simpler than the daily rivastigmine patches already in circulation. It is also 52%

less expensive than some other patches, the company says. "We know that transdermal delivery can be advantageous to both patients and carers and having a patch that only has to be applied twice a week, will significantly reduce the carer burden and also potentially improve compliance," said Luye Pharma general manager Andy Farrant.

<https://luye.co.uk>

The World Alzheimer Report 2023 is now available from Alzheimer's Disease International (ADI) focusing on risk reduction and the ways in which dementia risk factors are experienced around the world. Case studies highlight how risk reduction is undertaken in various parts of the world, such as eating healthily, physical exercise, learning, socialising and much else. In her foreword to the report, ADI CEO Paola Barbarino says the report offers a lot to those who want to take action, despite a "global dereliction of duty" by governments. "Wearing hearing aids really works, as do dancing, physical and mental exercise... many things can be helpful at a presymptomatic stage, and even after a diagnosis," she writes.

[www.alzint.org/u/World-Alzheimer-Report-2023.pdf](http://www.alzint.org/u/World-Alzheimer-Report-2023.pdf)

Young Dementia Network (YDN) has created a short animation explaining what YDN is, what it does and how to join up. The narrator in the "What is the Young Dementia Network" video, available on the YDN website and on its YouTube channel, talks from the perspective of someone with young onset dementia and the typical issues that they encountered as a person with the condition.

<https://youtu.be/5lOcfX7lxDw?si=eZInRQKJRi5gapAB>

## Book review

### Education and Training in Dementia Care: A Person-centred Approach

*Claire Surr, Sarah Jane Smith and Isabelle Latham,  
Open University Press, ISBN 9780335251124, £25.99*

If you are involved in providing dementia education and training in any shape or form, this book is a "must read".

The ambition to improve understanding of dementia and develop a skilled, confident and competent workforce has received much attention and investment. However, providing education and training for a diverse and changeable group is complex. Those providing care have differing learning needs, dementia can be diverse and people may be cared for in a variety of settings.

Despite educational frameworks and a variety of resources, delivery of dementia education and training can be inconsistent and outcomes often unclear. How refreshing it is, therefore, to see this book bringing together theories, research and evidence about what works best in providing effective education and training in dementia.

The first section provides a comprehensive introduction to design and delivery of training, learning theories and methods. It also considers the essential role of informal learning which it points out "happens all the time".

Chapters 3-8 address the learning needs of those in different settings including care homes, primary care, acute care and the community. Barriers to learning as well as facilitators of successful training are identified. Caution is highlighted about over-reliance on e-learning and a variety

of approaches to education and training are recommended.

Key messages include ensuring information is relevant to both the setting and learners needs, learning from those with lived experience and exploration of real-life situations. Availability of skilled facilitators and clinical leaders to encourage interaction and reflection is also emphasised.

I particularly like the inclusion of practical case examples, and useful tools and resources for each setting.

Chapter 9 covers implementation and provides an important reminder that training alone will not lead to improvements in dementia care. Models to support understanding of organisational culture and readiness to change are introduced which should possibly be at the start of the book. Measuring and evidencing the impact of training is addressed in chapter 10 and reminds us to consider carefully what we are trying to achieve and choose appropriate tools.

Each chapter helpfully includes a summary of implications for those delivering training, managers, staff and for those directly affected by dementia. However, I would recommend readers explore relevant chapters in full if they want to get the full benefit.

With often limited opportunities to provide dementia education and training, getting it right is crucial. This book provides an essential guide to those investing in this important task.

*Rachel Thompson, consultant Admiral Nurse for Lewy body dementia*

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