

The Journal of DementiaCare

For all who work with people with dementia

Vol 31 No 1 January/February 2023



**Also inside
this issue:**

- Access to dementia care in the Travelling community
- The IDEAL Living with Dementia Toolkit
- Prison garden project

NEW FOR 2023:

The Journal of **DementiaCare** WEBINARS



Following the success of 2022's UK Dementia Congress, we are bringing some of the best sessions to you live online, with extra time for questions and discussion.

Register via Eventbrite with the links below or from our website
www.journalofdementiacare.co.uk

Tuesday 28 February 2-3pm

EQUALITY, DIVERSITY AND INCLUSION: **Actions not words**

Services must change, become more flexible and listen and respond to the voices of marginalised communities. In this webinar Trish Caverly and Roxanne Holton will describe how the Bristol Dementia Wellbeing Service (a partnership between Alzheimer's Society and Devon Partnership NHS Trust) radically opened up its access to Deaf BSL service users - building up networks and trust in the Deaf BSL community, consulting about barriers, improving communication and internal practices.

Chair: **Lucy Whitman**

<https://www.eventbrite.co.uk/e/493704632847>

Monday 20 March 2-3pm

IMPROVE CARE AND COMMUNICATION WITH PEOPLE WITH DEMENTIA

How 'Talking Mats' can improve care and communication with people with dementia in care homes

Isabelle Latham, Researcher-in-residence, Hallmark Care Homes will report on an evaluation of the communication tool Talking Mats, their benefits and the barriers to effective use in practice.

Chair: **Suzanne Mumford, Care UK**

<https://www.eventbrite.co.uk/e/503233644377>

Monday 24 April 2-3pm

RESPONDING TO PEOPLE WITH DEMENTIA IN DISTRESS

Helping staff to be more confident and competent in communication skills: use of the CAIT online program

Ian James, Clinical Psychologist CNTW NHS Trust, will explain the Communication and Interaction Training (CAIT) an online person-centred training program designed to help care staff understand the skills they already have and use to communicate with people with dementia, especially when responding to distressed behaviour, and how they can build on these skills. Ian James has written the British Psychological Society's new guidance in this field (due out soon).

Chair: **Paul Edwards, Dementia UK**

<https://www.eventbrite.co.uk/e/503270213757>



Save the date:

The **13th National Dementia Care Awards** will be held at Winchester Cathedral on Thursday 13 July 2023 (a lunchtime event).

If you are interested in sponsoring an award please contact Dr Richard Hawkins: richard@dementiapublishing.community

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Inside this issue...

■ United: Caring for our Loved Ones Living with Dementia 12

Author **Gina Awad** and cartoonist **Tony Husband** teamed up to produce a new book relating true stories about the challenges of dementia care faced by families. Gina tells how *United: Caring For Our Loved Ones Living With Dementia* came to be written.

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How to stay safe and well, stay connected, stay active, stay positive and keep a sense of purpose. **Allison Batchelor** and colleagues describe the development of a new Living with Dementia Toolkit, a freely available website for people with dementia and carers.

■ Forget-me-Not garden project Collaboration between a prison and a care services team 24

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■ The importance of support for people living with dementia who are experiencing 'sundowner syndrome' 28

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■ Voices from the frontline: Turning research on care homes and Covid-19 into theatre 32

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Cover photos: Sincere thanks to Alison Teader and all involved in Napa's
National Day of Arts in Care Homes 2022



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The Journal of DementiaCare

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**Call Richard Hawkins on 07947 640724 or
email richard@dementiapublishing.community**

Successfully launched by Hawker Publications almost thirty years ago, JDC has become the leading publication and events team for professionals working within the dementia sector. JDC has now been bought by a not-for-profit Community Benefit Society, Dementia Publishing, of which we are directors. As the new owners we are committed to providing you with all that is so loved and valued at JDC, plus a lot more: the journal itself of course, now in an electronic format (still ably edited by Mark Ivory), a much more extensive website, www.journalofdementiacare.co.uk, and dementia-focused newsletters and events including the UK's largest annual event in our dementia care world, UK Dementia Congress.

A charitable Community Benefit Society is a relatively new model, whose purpose is to support a 'community of interest', funded by social investment (and in the case of a publication, subscriptions too). This makes it highly appropriate for JDC and the UK Dementia Congress: we are a community, built up over many years, bringing together practitioners, researchers, family carers and people with dementia themselves – everyone who cares passionately about dementia care and the vital importance of supporting all who work in the field. This support is needed now more than ever, in the current climate of intense pressure on services and staff.

We hope that our friends old and new will join us in supporting this venture, so that our work can continue with the journal and we can resume, as we plan to, the important meeting of minds, refreshment and renewal that was the UK Dementia Congress. We are delighted that all members of our JDC Editorial Advisory Board and UKDC Planning Committee will continue to advise and guide us on the journey ahead. We also very much welcome your thoughts and ideas – through the opportunities for comment and discussion that will soon be available on our website, or meanwhile by email: sue@dementiapublishing.community.

To find out more about joining our community by investing (which includes a subscription) please see final pages of this issue or email sue@dementiapublishing.community

**(L to R) Sue Benson, Richard Hawkins and Barbara Stephens
Directors, Dementia Publishing Community Benefit Society**





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The Journal of Dementia Care is published six times a year by Dementia Publishing Community Benefit Society

Registered address; 16 Broad Street, Eye, IP23 7AF

© Dementia Publishing

ISSN 1351-8372

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Dr Nadia Wahid – Dementia Primary Care Clinical Lead, Birmingham

The voices of experience

By Keith Oliver



The start of the New Year is an ideal time to revisit or reconsider what has gone before and what might lie ahead. It seems quite unbelievable that 12 years ago, when I was diagnosed with Alzheimer's disease, I could not find any books written by or with a person with dementia. I had initially read *My Bonnie* by John Suchet, and it was through Reinhard Guss that I was introduced to *Dancing with Dementia* by the Australian Christine Bryden, and this book in many ways changed my life back in 2011.

Christine's book enabled me to see the authentic words of someone whose life in many ways reflected my own, conveyed in a readable, balanced, heartfelt way which left me feeling positive and hopeful about my situation. Later I met Richard Taylor, an American whose book *Alzheimer's From the Inside Out* I read. It seemed strange to me that I could not find any books written by people living in the UK.

Since then a number of us have put our heads above the parapet and attempted successfully to tell our stories in print, while offering others a sense of hope and positivity through our lived experience over a number of years with the many challenges that dementia presents us with.

So, when Dawn Brooker approached me to share the editor role with her on a new series of books aiming to take Tom Kitwood's legacy of person-centred care, and putting the person with dementia at the centre I jumped at the opportunity, and with the support of Dawn. Sam Crowe and Hannah Jones at Open University Press embarked on the ground breaking project of a multi-book series on dementia inspired by the *Dementia Reconsidered Revisited* book.

Soon into the editor role I decided that I wanted to co-author one of the titles in the series. Since first encountering Kitwood I have been an advocate for his work, particularly the Kitwood Flower model, so in harness with my co-author, clinical psychologist Reinhard Guss, we planned a book which would involve him and me as a person with dementia conducting semi-structured hour-long conversations by Zoom or in-person with 15 people from around the UK about their life with dementia using the Kitwood flower as the structure.

Everyone clearly expressed what people with dementia need to live as well as possible – a theme picked up brilliantly in the article on the *Living with Dementia Toolkit* by Allison Batchelor, Rachael Litherland and colleagues in this issue of JDC (p20). All those we interviewed were unique, authentic and inspiring when revealing a rich vein of fabulous thoughts, experiences and realism, while offering hope, encouragement and guidance to others affected by dementia.

It is a truly exciting prospect for the New Year, and not only for us and our intended audience. Writing has become more challenging for me, so for support I enlisted two teams of four undergraduate psychology students who had been on placement working with myself and others with dementia. My hope is that this will help inspire them to be outstanding members of the dementia workforce of tomorrow. ■

■ See Dawn and Keith's article on the book series on p18.

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.

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

News round-up

Promising drug results

An Alzheimer's drug from the Japanese pharmaceutical firm Eisai has been shown to slow down patients' decline in memory, thinking and function in the final stage of trials. The drug, called lecanemab, demonstrated promising results in a phase 3 trial and works by removing Alzheimer's trademark amyloid protein from the brain.

Early results indicated that things like memory, orientation, judgement and problem-solving deteriorated 27% more slowly in those taking the drug compared with those who weren't. The trial, called CLARITY AD, involved 1,795 people with either mild Alzheimer's or mild cognitive impairment.

But some participants have had severe side effects. The main one is called ARIA, "amyloid-related imaging abnormalities", which result in swelling or bleeding in the brain. Just over one in five participants experienced this.

According to Alzheimer's Research UK, it remains to be seen whether the benefits of the treatment last longer than 18 months. "The benefits of taking lecanemab in the trial were modest, but the challenge and opportunity remains within dementia research to build on these findings into an era where we're developing multiple treatments against different aspects of Alzheimer's disease to slow and stop the disease," said ARUK director of research Dr Susan Kohlhaas.

"It's safe to say that the NHS is not ready for a new era of dementia treatment. We estimate that unless there are drastic changes in how people access specialist diagnostic tests for Alzheimer's disease, only 2% of people eligible for drugs like lecanemab will be able to access them.

"We recommend, through the new Dementia Mission, the government take urgent steps to bring together regulators, industry, clinicians and decision-makers in our health system to put a clear plan in place to ensure people in the UK are among the first in the world to access new treatments once they are licensed."

Results were published in the *New England Journal of Medicine*.

Unfair to care

Social care workers are paid 41% less than their NHS equivalents, contributing to an unprecedented rise in vacancy rates. This is the verdict of a new report called *Unfair to Care*, commissioned by the charity Community Integrated Care, which demonstrates that social care workers earn more than £8,000 less than their NHS counterparts.

Social care vacancies rose by an unprecedented 52% in 2022, the report finds, and there are now 165,000 vacancies on any given day in social care. Care providers are having to plunder their cash reserves to pay their workers more in a bid to stop them leaving for better paid work, the report suggests.

"This current system serves no one. It is entirely wrong that this sector has 165,000 vacancies on any given day, significantly impacting the quality of life of people who should, rightly, expect reliable support built upon

consistent relationships," said Community Integrated Care's chief people officer Teresa Exelby.

For the report, go to www.unfairtocare.co.uk

New Year Honours

Tony Jameson-Allen and Chris Wilkins, co-founders of the dementia reminiscence charity Sporting Memories, have been awarded MBEs in the New Year Honours. They started the charity in 2011 and there are now more than 100 Sporting Memories clubs supporting older people across England, Scotland and Wales.

Wilkins, CEO of Sporting Memories, said the clubs used the power of sport to engage people through reminiscence and inclusive physical activities.

"I'd really like to dedicate this award to all of the wonderful people that have been part of the Sporting Memories journey over the past 12 years, including our staff, our partners, our funders but most important of all, our incredible volunteers, club members and carers," he added.

Also awarded MBEs were Jill Quinn, CEO of Dementia Forward, which provides services and support to people with dementia and carers in North Yorkshire, and Martin Jones, CEO of care company Home Instead.

Professor Deborah Sturdy, the government's chief nurse for adult social care, and Jane Townson, CEO of the Homecare Association, were awarded OBEs, while Nadra Ahmed, chair of the National Care Association, was awarded a CBE.

New blood test

A new blood test developed at Pittsburgh University may hold the key to diagnosing Alzheimer's disease relatively inexpensively.

Results published in the journal *Brain* show that the test reliably detects a biomarker called "brain-derived tau", using an antibody that selectively binds this protein found specifically in the blood of people with Alzheimer's.

"At present, diagnosing Alzheimer's disease requires neuroimaging," said senior author Thomas Karikari.

"Those tests are expensive and take a long time to schedule, and a lot of patients don't have access to MRI and PET scanners," he said, adding that the development of simple tools detecting signs of Alzheimer's in the blood promised to improve the accessibility of diagnostic tools.

A larger-scale study of the effectiveness of the blood test is now planned.

Diagnosis rates

Alzheimer's Research UK (ARUK) has accused the government of a "worrying lack of focus and urgency" in dealing with the drop in dementia diagnosis rates resulting from the pandemic.

Diagnosis rates – now hovering around 62% – are at a five year low, said ARUK, and the government's target of 67% had not been met since before Covid-19 struck.

Dr Susan Mitchell, ARUK's head of policy, said

government plans to reduce care backlogs with new diagnostic centres and an elective recovery taskforce were welcome, but called on health secretary Steve Barclay to expedite his promised 10-year plan for dementia.

“This must be backed by targeted investment in NHS diagnostics, to enable greater access and availability of brain scanning equipment, along with the rapid development of diagnostic blood tests that can help provide an early and more accurate diagnosis. People living with dementia can’t be left in the dark any longer,” she added.

‘Inadequate’ ratings

A sharp rise in the proportion of dementia care homes rated “inadequate” or “requires improvement” has been recorded by the Care Quality Commission (CQC), according to an exclusive story in the *Guardian*.

It shows more than 50% of care homes offering dementia care in England and subject to inspection were rated in these categories in 2022 and 2021, up from under 40% in the previous three years. In 2022 and 2021 8.8% and 8.6% respectively of dementia care homes were rated “inadequate”, a substantial increase from 3.7% recorded in 2020.

Dismay over funding

Aspects of the government’s 2022 autumn financial statement, delivered by chancellor Jeremy Hunt in November, have been greeted with dismay by the care sector. While the chancellor said funding for the NHS and social care would be increased by up to £8 billion and help to double the number of hospital discharges in 2024, he also said that the promised cap on social care costs would be postponed: “I fear that for the remainder of this parliament, the ambition for reform of social care has been put on the back burner,” said National Care Forum CEO Vic Rayner. “There is little in this budget that talks to the vision of developing care with people at its heart... Whilst discharge is vital, great social care changes lives and matters to us all.” She added that the crucial issue of workforce pay had been ignored.

Dementia UK said the extra support for hospital discharge was welcome but inadequate in isolation. “Sadly, hospital discharge is often fragmented, rushed and not reflective of need, contributing to poorer experiences of care and worsening health outcomes,” said head of policy Andrew Pike.

Anchor pay rise

Housing and care provider Anchor has become a Real Living Wage employer, agreeing to pay staff a minimum of £10.90 an hour outside London and £11.95 within London. The provider employs over 9,000 staff across the country and claims to be the largest to achieve accreditation as a living wage employer by the Living Wage Foundation. Anchor has also signed up to the Age-friendly Employer Pledge, part of the Centre for Ageing Better’s campaign to support businesses to improve conditions for older workers and attract more of them back to work as a solution to the recruitment crisis.



Hallmark raises pay and benefits

Family-run care group Hallmark Care Homes are paying all staff at or above the Real Living Wage as part of a £1.3 million initiative to help them through the cost of living crisis. The company said that a full-time member of staff on the Real Living Wage outside London would receive £3,200 more than someone on the statutory national minimum wage, while within London it would be more than £5,600. All 2,300 employees will also be able to access a £250,000 “stronger together” winter support fund, plus special health benefits, a pension, Blue Light Discount Card and Hallmark Rewards if they need help with the rising cost of living.

Award for Stuart Wright

Brunelcare dementia care lead Stuart Wright has won the 2022 Hennell Award for innovation and excellence in dementia care. The award, presented by the University of Worcester’s Association for Dementia Studies, (ADS), recognises people who have significantly contributed to promoting person-centred care. ADS’s Dr Chris Russell commended Wright’s “clear and inspirational leadership qualities”. Wright, who is dementia care lead at the Bristol-based housing and care charity and has implemented a highly regarded human rights framework there, said that he was honoured to receive the award given in memory of Brian Hennell. “I appreciate this recognition of my work and also the recognition it brings to the work of my colleagues across Brunelcare who each day strive to deliver the very best care they can.”

New genetic findings

A genetic alternative to the dominant belief that Alzheimer’s disease is caused by a build-up of toxic proteins known as amyloids has been put forward in research published in the journal *Nature*. A quarter of the population carries one copy of the gene known as APOE4 and this inheritance from one parent doubles the risk of getting Alzheimer’s. For the 2-3% who have two copies inherited from both parents, the risk of dementia increases about tenfold. Research on mice shows for the first time that APOE4 prevents the proper development of oligodendrocytes in the brain, cells that produce myelin helping to prevent the neuron degradation thought to cause the symptoms of Alzheimer’s. Researchers also found that a drug, cyclodextrin, when applied to oligodendrocytes cultured in a dish, provided better myelin and, when given to mice carrying APOE4, improved learning and memory. These results suggest the possibility of a new treatment path.

Award for online partnership

Vibrant Communities and Keychange have been awarded “Highly Commended” for their Praise, Prayer and Togetherness online community. They won this recognition as part of the Great British Care Awards (South West Region). The partnership between the two charities was nominated under the “Putting People First” category and scooped the award after competing with 12 other organisations and individuals. “Vibrant Communities’ digital groups have enabled Keychange to enhance wellbeing and provide meaningful experiences for those we support,” said Keychange care provider Martin Farrow. “A more impactful outcome would be hard to find.”

Parkinson’s: training campaign

Charity Parkinson’s UK has launched a campaign for better training of social care staff on Parkinson’s-related dementia. Carers of people with the condition signed more than 1,200 postcards delivered to Whitehall as part of the charity’s “Nobody Really Knows Us” campaign. It urges the government to allocate some of the £500 million it has earmarked for upskilling the social care workforce to prepare them for providing high quality care for people with Parkinson’s-related dementia. A Parkinson’s UK study showed that just 14% of health professionals felt that their training had prepared them well to provide high-quality care for people with Parkinson’s-related dementia. A further 58% said their training was adequate but they needed more.

Call to fix ‘broken’ social care

In his New Year message Archbishop of Canterbury Justin Welby called for action to fix “broken” social care while praising the work of carers. Speaking during a visit to MHA’s Bradbury Grange care home in Whistable, he also flagged up the forthcoming *Care and Support Reimagined* report, due to be published on 24 January by the Archbishops’ Commission chaired by Dr Anna Dixon, which he said would offer a new vision for social care. “We know our care system is broken, but it doesn’t have to be. We can rise to the challenge of fixing it. That means action from all of us; you, me, families, communities, and government,” Archbishop Welby said in his video message.

ADI medication campaign

Alzheimer’s Disease International (ADI) has applied to have anti-dementia medications placed on the World Health Organisation’s Essential Medicines List. ADI said that the move, made alongside Newcastle University and the LSE, would ensure everyone everywhere had equitable and affordable access to dementia medications.

Award for Karen Murrell

Local dementia friends group Dementia-friendly Alton, in Hampshire, has been presented with the Queen’s Award for Voluntary Service. Nigel Atkinson, the Lord Lieutenant of Hampshire, presented the award to Karen Murrell, Dementia-friendly Alton’s coordinator and a founding volunteer.

Perspectives

by Mark Ivory, JDC editor



Challenge ahead

Now that the US medicines regulator has granted accelerated approval for the Alzheimer’s drug lecanemab, the way is clear for similar approvals in the UK and Europe. We have been here before, of course, when the American Food and Drug Administration gave qualified approval two years ago to another monoclonal antibody drug called aducanumab, which was then denied a licence on this side of the Atlantic because the European Medicines Agency decided that the potential harms outweighed the potential benefits.

Lecanemab, in contrast, seems to have more going for it. Results from what was named the CLARITY AD trial indicated that things like memory, orientation, judgement and problem-solving deteriorated 27% more slowly among the 1,795 subjects with either mild Alzheimer’s or mild cognitive impairment.

Given the hoopla when aducanumab first emerged with some apparently impressive results, we should perhaps temper our enthusiasm a little, especially as lecanemab can have serious side effects just as its predecessor did. But after a long lean period with no medicinal advances, hopes of a breakthrough with a monoclonal antibody treatment targeting amyloid plaques in the brain look well founded. So it is worth asking what would happen if lecanemab were to be licensed by the UK regulator.

It is a glaringly obvious question whether the NHS would be equipped to deliver the treatment, not just to pay for it but to diagnose people early enough to make it effective. It was estimated that a course of aducanumab could cost upwards of £100,000 a year and with abundant and rising demand anything similar for lecanemab could make a considerable dent in the NHS drugs budget. Our health system’s struggles to meet existing demand are headline news and it is hard to see how the budget could be made to stretch.

At the same time diagnosis rates have actually fallen because of the pandemic and people can face waits of up to two years in any case. At present, a diagnosis sufficiently early in the progression of Alzheimer’s would have to rely on formidably expensive, thinly spread and time-consuming brain-scanning technology. A simple blood test may come to the rescue, such as the one covered in this issue of JDC, which reliably detects a biomarker called “brain-derived tau” (News, p6).

Either way, investment in diagnostics will be essential if new drugs are to be administered quickly and comprehensively, as well as a focus on developing blood tests as a cheap, efficient way to identify Alzheimer’s. None of this should come as a surprise to the government, but we are still awaiting a strategy to get us from where we are now to where we will need to be in a few years’ time. It broke its promise to publish a 10 year plan last year, which would have replaced a strategy that expired three years ago. When confronting the implications of dementia for our health system, the government’s nerve has too often failed. In 2023, at last, it should square up to the challenge.



Dementia Diaries

This is something of a departure from our usual Dementia Diaries column.

At the end of 2022 we held a week-long festival as a culmination of DEEP's 10th Anniversary.

It comes as no surprise that Diarists popped up regularly across the 21 events that we organised over the week.

Dementia Diarists have their own virtual DEEP group which meets once a week. Many diarists are involved in other aspects of DEEP, not least as facilitators of their own local groups.

We'll be writing a lot more about what came out of those events in the months to come, but for now I'd like to focus on one specific element of our celebration. I think it touches on something that is absolutely central to the work that the Diarists do, and the work that DEEP does.

As we looked back over 10 years, there was a lot to think about... but probably the words that most readily sprang to mind weren't the ones we would have imagined when we started:

- **Warmth**
- **Friendship**
- **Love.**

None of which lend themselves to the usual metrics of evaluation. What's the score on the love-ometer?

But we see it every day in our work with people with dementia. So when I was asked to put together a piece of music celebrating DEEP, it was to this that I turned.

My main inspiration came from a Dementia Diary recorded by Dory, in which she reads from the wonderful "The Boy, the Mole, the Fox and the Horse" by Charlie Mackesy.

You can hear Dory's Dementia Diary here:

<https://dementiadiaries.org/entry/14249/dory-reads-chapter-4-of-the-boy-the-mole-the-fox-and-the-horse/?highlight=horse>

These words in particular captured so perfectly what for

me has been the most amazing thing about DEEP, and about Dementia Diaries:

"Sometimes I feel lost," said the boy.

"Me too," said the mole. "But we love you and love brings you home."

"You fell, but I've got you," said the horse.

"Everyone is a bit scared," said the horse.

"But we are less scared together."

What beautiful words, especially:

"I've Got You"

It's the support, encouragement, inspiration, solidarity, warmth, friendship and love *between* people with dementia that defines the very essence of DEEP for me. It's been the most remarkable, largely unmeasurable, and absolutely uncontainable outcome of all.

It's for this reason that "I've Got You" became the inspiration, and working title for the music.

I worked with Chris Norris and Paul Hitchmough to put together a musical celebration of DEEP.

They provided both musical inspiration and the bedrock of the piece.

Extracts from Dementia Diaries run throughout the piece.

Not only that, but 80 individual people with dementia also contributed with audio and video recordings of them saying "I've got you".

Not only that but a mass meeting in Northern Ireland all saying it in perfect unison.

.....not only that but three singing groups lent their lungs to the cause.

You can watch "I've Got You" here:

<https://www.youtube.com/watch?v=H3EHg3JdOM0&t=15s>

Please share as much as you can....

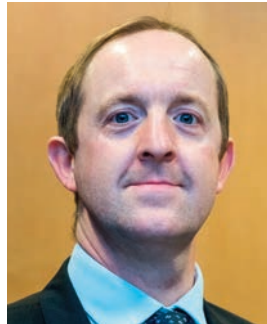
Now, where did I put my Love-ometer?

Normal service will be resumed in the next JDC.

Steve Milton is a director of Innovations in Dementia

JDC asks:

Diagnosis rates are down, care providers are closing, and waiting lists for social care needs assessments are growing. What will it take to rebuild dementia care?



Left to right: George Rook, Colin Capper, Maxine Groves, Graham Stokes, Teresa Atkinson

George Rook, a Dementia Diarist living in north Shropshire:

“Rebuild” implies that there was previously a structure that collapsed. But there has been no such structure, universally in place across the UK, to provide meaningful care and support for those affected by dementia. Ever.

We need mandatory minimum scaffolding that is in place everywhere (not “recommended”, or “guidance”), within which people choose what they need. We need a new paradigm, in which dementia has equity with other diseases. (Think cancer...) And by implementing a universal, legally mandated model we can reduce the huge spending on picking up broken people later.

Dementia is caused by physical disease. It is terminal, though with hugely varied life expectancy. But people can, and do, live meaningful, positive lives with dementia, given a little (or more) appropriate support when needed.

We need a properly paid, professional care workforce. We need unpaid caregivers to be supported when they need it (ie before they break). We need radically different training for health care professionals, so they understand the life needs and realities of those living with the disease.

We need to enable, rather than disable, people living with dementia. We need automatic entitlement to benefit funds when diagnosed. And we need the costs of care, when needed, to be shared across the population, in the same model as the NHS.

We need all social and health care staff and resources to exist within a single, coordinated system, working together around individuals

We need the whole structure to be funded from the taxes we pay. (We may have to pay more now to save in the future.)

Then, and only then, will we be a society that is compassionate and fair to those who develop this disease.

Colin Capper, associate director of evidence and participation at Alzheimer’s Society:

I’ve been around care homes all my life. Initially because my mother worked in them, and currently in my role at

Alzheimer’s Society. My conclusions then are the same as now – care must be person-centred. The 10-year plan for dementia that we’re fighting for would deliver that.

But the system as it stands doesn’t put the person receiving the care first. Only 120,000 out of 900,000 people with dementia said their care review was helpful.

People with dementia are often in and out of hospital. As one third of these admissions are for one night, they may not have needed acute health attention but could have been supported through community care. We could decrease costly admissions and worse outcomes for people with dementia through post-diagnostic community support, reducing pressure on general practice and acute care.

Research brings hope. In 2022, we got the news of a drug that slows cognitive decline for people with early Alzheimer’s. But this breakthrough will mean little to people with dementia while diagnosis rates remain low. These drugs work when people are diagnosed early and accurately, but targets haven’t been met in four years.

To realise that hope, we need to see a 10-year plan that sets ambitious aims for dementia care. Disappointingly, at Alzheimer’s Society, we’ve received 22 responses of “in due course” from the government on when we’ll see their plan. But 900,000 people know that dementia doesn’t wait for “due course”. We must unite to call on the government to deliver on their promise.

Maxine Groves, a local authority specialist commissioner of dementia care services:

Dementia care has never been “right”: the question for me is, how can we create a safe and responsive system that properly recognises the complexity of dementia care – the plethora of challenges that people living with the effects of dementia and their families experience from before diagnosis to the end of life and beyond?

The impact of the pandemic and the economic crisis have worsened the situation in health and care. The gaps have become much more apparent and the holes in the system emphasised. The National Dementia Strategy (2009) and the Prime Minister’s 2020 Dementia Challenge

set out laudable goals, but the political will to deliver on these policies diminished.

While the five-year forward view and the 10-year plan for mental health recognise the needs of older people, they don't give dementia a high priority. As a result the debate about where dementia sits in the system has led to a move away from dementia specialist commissioning in favour of a generic approach.

The recipe for effective dementia care requires commitment from government to prioritise and invest in dementia care, supported by robust policy, and the impetus, wherewithal and resource to implement the policy.

Plus - we need to do things differently – by including third sector providers as equal partners in the health and care system and recognising social care models as being valid and effective.

Integration is key: to ensure that systems can be streamlined, we need to overcome fears and share power. This is one of the biggest barriers preventing effective integration of health, social and community care.

Graham Stokes, director of dementia care services at HC-One

We know that investment is greatly needed in social care provision. Then the heroes of three years ago, when Covid-19 emerged, can work in care homes and domiciliary services that are appropriately and fairly funded; services that nowadays are caring for people living with increasingly complex care needs.

Yet professional carers are leaving the social care sector at a rate close to 40% a year, and hence not only must the response be to support learning and development, it must also enable carers to enjoy a sustainable career as practitioners in dementia care.

As well as this investment in the welfare of people we know are living with dementia, diagnostic services need both investment and greater ingenuity. Diagnosis is crucial for understanding and meeting people's needs. Three years on from when the NHS became consumed by the pandemic, dementia diagnosis rates have fallen to a five-year low. Alzheimer's Society estimates there are around 30,000 people in England living with dementia who would have been diagnosed had the pandemic not happened.

The result is that people are deteriorating unknown to services, while their unsupported caring families struggle to cope. There needs to be an immediate funding injection to tackle the growing diagnosis backlog, but also a re-think about how memory assessment services can become more accessible, responsive and – through collaborative partnerships – ensure post-diagnosis support and review.

However, as we enter 2023, there is still no sign of any publication date for the government's standalone 10-year dementia plan, which it committed to producing before the end of 2022. With the social care costs for people living with dementia currently standing at £15.7 billion and set to treble by 2040, funding for the social care sector to support people living with dementia is vital.

There is a moral obligation to protect the most vulnerable in society. This isn't a choice; it is a responsibility.

Teresa Atkinson, senior research fellow at the Association for Dementia Studies, University of Worcester

Shelter is a basic human right. We all need somewhere to live where we feel safe and can be sustained; to live our best lives.

Imagine living in a world that is not "fit for purpose" but made to feel as though you are the problem? People with dementia must "up the ante" to work harder and harder to remain connected with their world, to engage with that world, to feel safe within that world; working within a world of stigma and misunderstanding which can be exhausting.

Now imagine a world where someone with dementia can thrive. Isn't that what we are all working towards? What would that world look like?

In 2021, the All-Party Parliamentary Group (APPG) Report on Housing and Dementia set the bar – "every decision about care, is a decision about housing". For people with dementia to live their best lives, housing should be, and must be, appropriately designed, appropriately resourced and appropriately staffed.

Housing is not some miracle cure that will enable people with dementia to live well. Housing is as much an umbrella term as the diagnosis itself; as diverse and as complex. What kind of house would you wish to live in if you developed dementia? One where you are enabled to thrive, to remain connected, to be yourself?

We need to ensure the right person is in the right housing at the right time, with access to the right relationships, support, and activities in order to maximise the ability to live well. A house is merely a shelter, what happens in that house makes it a home.

Open Space

Imagine the future of our dementia care community

Open Space Zoom meetings began in Spring 2022 and ran monthly through the year, culminating in live meetings at the UK Dementia Congress in November 2022. We are very grateful to Chris Gage (Ladder to the Moon/Vibrant Communities) for proposing, initiating and hosting these lively meetings—they have proved a valuable melting pot of voices and opinions from all aspects of dementia care. This was one of our chief aims, but we also hoped to make progress in defining the future mission and purpose of Dementia Publishing—and that is still a 'work in progress'. We are pausing for thought, but will revive the Open Space zooms later this year. Meanwhile, we are pursuing the aims agreed at a fruitful Open Space meeting last summer:

- Open Space meetings will continue to welcome all comers to open, general discussions, as well as focusing on specific ways we can play our part in improving dementia care and services.
- The board of Dementia Publishing and Advisory Group of JDC will work on a mission statement for our charity.
- JDC webinars, starting in February 2023, will bring good practice and experience to a wider audience. Details on p2 and on our website www.journalofdementiacare.co.uk

We plan to include a longer report on the issues, opinions and ideas discussed at Open Space meetings, in a forthcoming issue of JDC.

Sue Benson

United: Caring for our Loved Ones Living with Dementia

Author **Gina Awad** and cartoonist **Tony Husband** teamed up to produce a new book relating true stories about the challenges of dementia care faced by families. Gina tells how *United: Caring For Our Loved Ones Living With Dementia* came to be written

Over the past decade I have been raising dementia awareness. My vision of helping families affected by dementia feel more understood has always been at the core. It goes back over 40 years to when I visited care homes with my sister and grandmother who engaged with the residents in craft activities. It was the residents who weren't engaged that I was drawn to.

As an eight-year-old little girl I felt their sense of disconnectedness, vulnerability and what I believe to be loneliness. It felt uncomfortable, as if these wonderful people were striving for a meaningful connection. These feelings stayed with me for 30 years until I began my six-year part time health and social care degree in 2011 with the Open University.

I selected dementia care as my second module which was the catalyst in reigniting my feelings from many years earlier. At the time I had no idea how this would translate into making a difference for families affected by dementia. Little did I know...

I became a volunteer Dementia Friends Champion with Alzheimer's Society in 2013 until last summer and have delivered over 165 information sessions reaching 2600 people. It was through these sessions a pattern began to emerge from those who attended. Recurring themes included the complexities of navigating an extremely complex health and social care system, the lack of post diagnostic support and "overwhelm" – a sense of being overwhelmed often leading to despair.

Dementia is the biggest health and social care challenge of this century. Something had to change so, in 2014, I founded the Exeter Dementia Action Alliance which I have been leading ever since. Our vision revolves around raising awareness of dementia, partnership work and community engagement. We aspire to educate and equip local businesses and organisations with information to enable them to take practical action making their service provision more accessible.

My inspiration is heart-centred and I am truly grateful for the incredible human beings I have met over this past decade, not to mention Tony Husband. Tony's book *Take Care, Son: The Story of My Dad and his Dementia* was published in 2014 and it was through this we connected.

A renowned cartoonist with an edge, Tony's creativity goes beyond special and through our shared passion we have collaborated on a number of dementia-related projects with a view to helping people affected by dementia feel less alone. Our partnership led to a book published last June – *United: Caring For Our Loved Ones Living With Dementia* – which emerged from an idea I had in 2019 enabling families to share their caring stories in a

way that could help others and be universally relatable.

Time was spent reaching out through my networks and engaging with interested contributing families. Personal stories were shared through Zoom; many people contributed. Tony and I then worked together as I sensitively curated the stories and he illustrated them, conveying their emotions with eloquence and bringing the narrative alive. As *United* began to take shape, we shared each draft story with our contributors with some trepidation. It was imperative we told them with the sensitivity they deserved, but only small amendments were needed before we had our first draft.



But those dark feelings of failure, ineptitude and inadequacy often recur. I asked Fred once ...

'Can you imagine anything worse than me as your carer?'

'Yes, you not being my carer.'



A few months later our final manuscript was complete and it felt important for me to begin sharing it through my networks pre-publication. This generated more than 30 reviews from academics, health and social care professionals and families affected by dementia. The response was overwhelming and confirmed what Tony and I knew from the start: we had something very special.

United is an accessible, jargon-free short read, but not to be underestimated (we call it “the little big book”). It comprises several true stories covering an array of topics including accessibility in the home, navigating the care system, technology and its benefits, loss of friends and gaining new ones, person-centred care, the challenges with young onset dementia and the impact on a young working family, living in the public eye, issues surrounding their protection and privacy, employer support, and much more.

A comprehensively curated list of resources is included at the back to save people trawling through the vast quantities of information on the internet, which many have told me is one of the biggest challenges for them. Our

We felt it was our duty to raise awareness for Dad and other footballers who are literally putting their lives at risk heading a football.



book is proving popular with families and with health and social care professionals and academics, who use it as a resource for their training and CPD. We've even heard that it is to be translated into Chinese.

Tony and I have begun to reflect on developing a second book, so watch this space!

The Alzheimer's Dementia & Care Show

The Business Design Centre London 3-4 March 2023

The Alzheimer's Dementia & Care Show is the UK's leading event for care providers, healthcare professionals, families and carers. This is an unmissable CPD accredited event for those wanting to learn from leading experts, find practical advice and support, resources, develop a better understanding of dementia and further professional skills. The show features a full conference programme with talks from leading experts, carers and persons with dementia alongside professional advice clinics, dementia and care exhibitors and unique individual training opportunities you won't find at any other event.

Full Virtual Dementia Tour & Training Experience and Dementia Interpreters Course by Training2Care:

Free taster sessions and the only event where visitors can book the complete training as an individual.

Dementia and Care Matters Theatre: The main theatre hosts keynote speakers on range of topics as well as chaired daily Question Time panels.

Talks Hub: A range of practical talks covering dementia and care topics from professionals and exhibitors.

CPD Accreditation: Certificates available to professional attendees.

Admiral Nurses & Alzheimer's Society Advice Clinics: Free 25 minute 1-2-1 appointments.

Leading Dementia & Care Exhibitors: Practical ideas, new solutions and resources from dementia and care specialists.

For information and tickets visit alzheimersshow.co.uk. One-day tickets are from £18.00 online.

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ADVERTISEMENT FEATURE

The National Day of Arts in Care Homes 2022

Shining a spotlight on arts in care provision

Arts participation in care settings can bring immense benefits to the people who live and work in them. **Alison Teader** reports on the National Day of Arts in Care Homes

The National Day of Arts in Care Homes is an annual event that takes place on 24 September each year. Last September's National Day showcased a vast array of creative arts and demonstrated the immense value that the arts can have for the people who live and work in care homes.

Set up to champion, encourage and increase arts provision and participation in care settings, the National Day is a key part of the five-year Arts in Care Homes (AICH) programme, managed by NAPA (National Activity Providers Association). Care settings and partners were invited to organise an arts activity for the National Day and share related best practice stories. This time we also sent out an invitation to create floral artwork and images for a "Field of Flowers".

NAPA, a leading activity and engagement charity for care services, celebrated its 25th anniversary in 2022, and the arts have always been an important element of our work. The National Day of Arts in Care Homes was funded by the Baring Foundation and the Rayne Foundation.

In the run-up to the big day, NAPA developed an online programme of free events working with partners including Forget-me-not Chorus, Digital Voice for Communities, Vibrant Communities, the V&A, the Blair Academy and Jazanne Arts. Events included participatory dance and singing sessions, a digital masterclass, discussions with academics and artists, including an artist living in a care home, as well as related work around social inclusion.

We were delighted by the levels of involvement and the many amazing examples of creative work using a whole range of art forms such as visual arts, poetry, dance, drama and digital arts. We were also very pleased to hear about the brilliant partnership work being done in care settings with museums, art galleries, artists, arts organisations, volunteers, schools, colleges and local communities.

Last September's highlights

Events and arts activities for the National Day took place in care homes across the UK, often assisted by our arts and cultural partners to mark the day in a variety of ways.

For example, the FitzWilliam Museum in Cambridge shared a resource to encourage care homes to engage with their collection in creative ways; Gecko Arts in partnership with Magic

Me had screenings of their film STILL, created with care home residents and staff; and the artist Sharon Bailey presented her Home Alone mixed media installation of audio, films and drama sharing the loneliness experienced by some older people living on their own.

Anchor actively support the National Day every year and encourage all their care settings to get involved. The not-for-profit housing and care provider took up NAPA's theme and launched a Field of Flowers competition, for which it had over 60 submitted pieces of artwork. The 12 winning entries are featured in the Anchor calendar for 2023.

Some of Anchor's care homes in Manchester have been working on a partnership project with Manchester Museum, taking part in regular arts sessions based on the museum's collection. For the National Day, working with Karen Brackenbridge, the museum's culture, health and wellbeing assistant, participants created a plasticine floral image including a Forget Me Not in memory of the late Queen.

Asa Johnson, Anchor's service improvement manager, stressed the centrality of the arts. "Making sure that people have access to a range of different artforms is hugely important to our activity provision at Anchor," he said.

"We are always looking for new opportunities to develop our creative activity offering, and this year have embarked on exciting projects, including music therapy for people living with dementia, in partnership with Anglia Ruskin University and Cambridge Institute of Music Therapy."

Proud to Care North London, set up by the North London Sustainability and Transformation Partnership to aid recruitment and retention in health and care, invited care



Anchor Housing and Manchester Museum artwork for #FieldofFlowers



Alison Teader is programme director of NAPA Arts in Care Homes. www.artsincarehomes.org.uk



Clockwise from left above: Belong #FieldofFlowers canvas made up of fingerprints of customers, staff, families and friends; the art room at Appleby House; Milton Keynes University Hospital Field of Flowers session for AICH2022

settings locally to submit artwork based on the following suggestion: “Re-use what you have, make art that you love, and discover the joy of upcycling.”

Over 200 entries were received and the winners were decided by a vote of the residents in participating care homes. “The talent and creativity shown by the residents has been phenomenal and it has been such a joy to organise,” said Talia Lief, quality in care advisor at the London Borough of Barnet, one of the councils covered by Proud to Care North London.

Elsewhere, Belong Villages’ customers happily enjoy the arts as part of their everyday experiences in this dementia specialist’s care. They are part of an innovative four-year relationship with Bluecoat, Liverpool’s contemporary arts centre, which has seen a number of positive wellbeing outcomes recognised by academics as renowned artists work alongside Belong’s customers in their homes.

For this year’s Field of Flowers theme, those residing in the villages were supported to express their ideas in a number of different ways. While in one case they collaborated to make their locality’s biggest-ever floral display wall piece, others invited their families and communities to bring an ambitious display of thousands of floral fingerprints to fruition. Another took the opportunity to pay their last respects by creating collages in tribute to the Queen, local schoolchildren being welcomed for intergenerational partnerships for the occasion.

“It’s been wonderful participating in National Day of Arts in Care Homes,” said Belong chief operating officer Sue Goldsmith. “Though the arts are already well-embedded in our approach to care, we’ve enjoyed having the opportunity to share in this national event and our customers loved bringing this year’s theme to life.”

Overall, more than 100 care providers and partners registered events for the latest National Day of Arts in Care Homes on our website, and we know from experience that far more activities and events were organised for the day. Since our first event in 2019, the Arts in Care Homes programme has built a growing following on social media. Our hashtag #AICH2022 had a social media reach of 1.6 million and resulted in over 3,000 interactions.

During Covid-19 NAPA had to develop more opportunities for digital engagement and these have been taken up and continued by lots of care settings. Over 500 people booked on to our online events and watched recordings. However, digital exclusion is still a reality with many care settings and staff teams having limited access to computers and the internet, something that should be addressed if opportunities are to be equal for all.

It was wonderful for us to be able to attend two care home events in person this year, at Care UK’s Appleby House in Epsom and Forest Healthcare’s Bridgeside Lodge in Islington. This gave us the chance to see the benefits of arts in care provision first hand, by joining in art and singing sessions and enjoying musical entertainment by the Spitz, whose mission is to increase wellbeing through live music and whose approach includes performances by residents.

As we have seen over the course of the AICH programme, arts, creativity and cultural participation contribute a great deal to enhancing the health, happiness and wellbeing of people in care, staff teams, relatives and communities. Our long-term aim is to embed arts and cultural participation in care and we believe that partners in the arts sector have a significant part to play.

As we go into the final year of the five year AICH programme, NAPA will be looking at what is most needed to make arts in every care home a reality, in the light of extremely challenging times for the sector in terms of recruitment, energy costs and the effects of the pandemic.

Our AICH advisory group, consisting of representatives from the care and arts sectors, meets regularly. If you would like to be involved or have any thoughts or suggestions, please get in touch! Just email me at alison@artsincarehomes.org.uk.

Additional information

Read NAPA’s 2021 report – *Arts and Culture in every care home?* - based on a consultation with the care sector at <https://artsincarehomes.org.uk>. And you can read the Baring Foundation’s 2022 report *Every Care Home A Creative Home* at <https://cdn.baringfoundation.org.uk>. Some entries to Proud to Care North London’s competition can be viewed at <https://flic.kr/s/aHBqjA3ZzS>.

Improving access to dementia care in the Travelling community

Gypsy, Roma and Traveller communities frequently have poor health outcomes and little awareness of dementia. **Cheryl Scarrott** shares the implications for professional practice of supporting these families in the community.

Since 2019, I've been a dementia specialist nurse at Shropshire Community Health NHS Trust working with families affected by dementia to provide life-changing support and guidance. I'm also a member of the Romany Travelling community. For the Gypsy, Roma, and Travelling communities, periodically moving from place to place in search of a new home is a way of life (Traveller Movement, undated).



In England and Wales, it is estimated, there are 25,000 people currently living with dementia from black, Asian and minority ethnic groups, which includes the Travelling community (Alzheimer's Society 2020). This is expected to exceed 172,000 people by 2051, a seven-fold increase compared to a two-fold increase among the wider population (Friends, Families & Travellers 2020).

People in Gypsy, Roma, and Travelling communities have poorer health outcomes than any other minority (Houses of Parliament 2019), which is reflected in the experiences of families living with health conditions including dementia.

My own granny was diagnosed with Alzheimer's disease over a decade ago and I watched my grandad struggle with her care as there was no specialist dementia support available for families. My granny's passing was a turning point for me. I wanted to advocate for all families with dementia to improve access to care, especially those from under-served communities like mine.

At the age of 18, I left school to pursue a law degree but quickly realised this was not the career path for me. Following my granny's passing, I applied to study mental health nursing so I could become a specialist dementia nurse to honour her memory. When I qualified, I worked in several settings including a care home, memory clinic and the local community mental health team. This is what led me to become an Admiral Nurse at Shropshire Community Health NHS Trust, where I'm continually supported and developed by Dementia UK.

Health outcomes

People in the Gypsy, Roma, and Travelling communities have a lower life expectancy, one estimate putting it as between 10 and 25 years below the national average (Friends, Families & Travellers 2020). This is in part due

Cheryl Scarrott is an Admiral Nurse at Shropshire Community Health NHS Trust and a member of the Romany Travelling community.

Summary

People in the Gypsy, Roma and Travelling community have poorer health outcomes than any other minority. Why? It is partly due to a shortage of culturally appropriate health information, but also hesitancy in seeking professional support. Families typically go to accident and emergency services, as opposed to a more systematic approach involving primary and secondary care. This results in poorer health outcomes.

In addition to this, there is a stigma around illness in the Travelling community, and a lack of knowledge and awareness of dementia. It means that families do not typically seek help until a crisis point, especially as there is a tendency to "look out for their own", something of which there is little awareness among health and care professionals. End-of-life care is particularly important in this regard; families will care for their relatives at home up until they pass away.

I have utilised my experience of growing up in the community to advise health and social care professionals on supporting Traveller families. This has included delivering a series of lectures at the University of Staffordshire to third-year mental health nursing students, speaking at Dementia UK's Admiral Nurse Forum, and advising Shropshire Community Health NHS Trust's diabetes team on improving access to care for families.

I argue that, if we are to meet the individual needs of families from the Travelling community who are living with dementia, delivering personalised care is vital. Moreover, it's important to educate the health and social care workforce around health outcomes in these communities and cultural practices which may have an impact on their care.

to the limited awareness of good health choices; for men, in particular, drinking large amounts of alcohol is a part of the culture. It is also common to eat a diet that is high in saturated fat, but culturally appropriate health information for these communities is sparse.

Moreover, people in these communities have cited a reluctance to seek support from primary and secondary health and social services, on the grounds that they face discrimination from professionals and experience difficulties navigating the NHS (Lewis 2021). Consequently, they typically go to accident and emergency services, as opposed to a more systematic approach

involving primary and secondary care, as part of which they would visit the same GP. Worse than average health outcomes are the result.

In 2015, less than half of Joint Strategic Needs Assessments – an assessment of the current and future health and social care needs of the local community – included a chapter on Gypsy, Roma and Traveller needs. Where such a chapter was included, less than a third mentioned the needs of Roma people (Houses of Parliament 2019).

These communities were disproportionately affected by the pandemic, largely due to the conditions in which many families were living. For communities living in caravan sites, social distancing was not possible. They typically have poorer health, which put them at a higher risk of contracting Covid-19 and becoming seriously ill (Lewis 2021). Long-standing challenges around access to health care were exacerbated as more families were left isolated without the care and support they needed.

Barriers to care

Family and status are important in these communities. When a family member falls ill, there's an attitude of just getting on with it, otherwise it is deemed a weakness and reflects badly on the family. If someone shows signs of dementia, they might ignore the symptoms and refuse professional help.

Low literacy levels can also have an impact on the care received. The 2011 Census of England and Wales found that only 40 per cent of Gypsies and Travellers had formal qualifications, with many leaving school at a young age to support family and their business (Rattigan & Sweeney 2018). This means families do not receive vital information about dementia, including how to spot the signs and symptoms and guidance on diagnostic and post-diagnostic services.

Stigma, widespread stereotyping in society generally, and a lack of knowledge and awareness of dementia frequently combine to prevent families from seeking help until they reach a crisis point. It can then be extremely difficult to manage the progression of dementia or put appropriate care plans in place.

Professionals often have no knowledge of cultural traditions in the Traveller communities, particularly the “look out for your own” mentality. There is a deep sense of mistrust of outsiders, which is often the result of discrimination. Having a Traveller background as I do, in my Admiral Nurse role I've been able to build relationships with families through a shared identity.

Building relationships

I recently supported a Traveller family whose relative was at a late stage of dementia and receiving end-of-life care. The family wanted their relative to be cared for at home, in keeping with cultural traditions around death. I was able to draw on my experience in the community and advocate for them by working alongside the local hospice to ensure they received the best possible care, including pain management and emotional and practical support for the whole family.

Advising health and social care professionals on best practice, between 2016 and 2019, I delivered a series of

Key points for practice

- Remember that your word is your bond. If you say you're going to do something, you must do it. Your word is as if you'd signed a form
- Leave judgement at the door. We all make judgements but try not to let them affect your care
- Find out more about the culture of the community and share best practice with colleagues. There are lots of resources to help you improve your knowledge, such as the website Friends, Families & Travellers at www.gypsy-traveller.org
- End-of-life care is especially important — families will care for their relatives at home up until they pass away so it is vital to support and respect their decisions around care
- Ensure provision of care is accessible and culturally appropriate; whether that might be delivering an appointment over the phone or presenting key information in a digestible manner

lectures at the University of Staffordshire to third-year mental health nursing students as part of their “complex care: transient populations” module. Given my personal experience and my dissertation examining an episode of care with a Travelling family supported by mental health forensic services, the university was keen that I should share best practice on this topic.

To build awareness of key cultural factors, I utilised case study exercises encouraging students to explore how they would respond to specific scenarios involving the Travelling community. The lectures generated positive feedback from students, including one who remarked that this was the first time they'd ever been taught about Travellers in an educational context.

I also spoke at Dementia UK's Admiral Nurse Forum, an annual event at which we come together to share best practice. I gave a talk where I highlighted common misconceptions about the community as well as discussing historical context and cultural factors. Following my talk I received requests from services across our NHS Trust to advise on improving access to care for families in the community. As such, I advised the diabetes team on how to build relationships without taking non-engagement personally, practising a non-judgemental approach and unconditional positive regard to hold difficult conversations.

Bridging the gap

Dementia is a huge and growing health crisis; the estimated number of people living with the condition in the UK is 944,000 and it is expected to increase to 1.1 million by 2030. It is vital that more is done to bridge the gap in dementia care so that everyone, including the Travelling community, receives the best care possible.

For a long time now, people from the Gypsy, Roma and Travelling communities have been under-represented in dementia care services which can lead to a reluctance to come forward and seek support if culturally specific needs are not understood. One way to start bridging the gap is to make care careers accessible to all, while another is to take educating the current workforce more seriously so that they understand how pervasive attitudes can affect their care.

If we are to meet the individual needs of families with dementia, delivering personalised care is critical. This includes providing culturally appropriate dementia resources, offering different means of access to health care professionals (such as over the phone or face-to-face appointments), and ensuring memory tests consider literacy levels. We can also ensure that we are supporting families to stay in the accommodation of their choice as their condition progresses.

As dementia prevalence continues to rise, we face a steep challenge as health and care professionals in tackling the inequalities that leave families with dementia in under-served communities isolated and without the care and support they so urgently need. But we must start now.

More information

For information on Shropshire Community Health NHS Trust dementia services, go to shropcommunityhealth.nhs.uk/dementia.

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Reconsidering Dementia

A new book series

A new book series titled *Reconsidering Dementia* promises to be scholarly, engaging and attractive to a broad audience. **Dawn Brooker** and **Keith Oliver** set out their hopes and plans for the series, which encourages readers to think more deeply about the subject

Books are incredibly important to both of us. For different reasons and at different times we were both inspired by Tom Kitwood's *Dementia Reconsidered* (Kitwood 1997). Open University Press had invited one of us (Dawn) to undertake an update of this seminal text on the twentieth anniversary of its publication.

The resulting publication *Dementia Reconsidered, Revisited: The person still comes first* (Kitwood & Brooker 2019) reprinted the original text alongside contemporary commentaries, one of which was written on the experience of dementia by the other one of us (Keith, alongside Reinhard Guss). It has been very well received.

So Open University Press approached the two of us about being the editors of a whole book series on contemporary issues in the support of those affected by dementia, which we have called *Reconsidering Dementia*. In our discussions we agreed that there was a need for scholarly texts that challenge and engage readers to think deeply.

We wanted the books to draw on theoretical understandings, contemporary research and experience to critically reflect on their topic in depth. We wanted them to be read by those who are engaged in improving the care and support of people affected by dementia, just as Kitwood's original book had broad and enduring appeal for informed lay readers, students, professionals and academics.

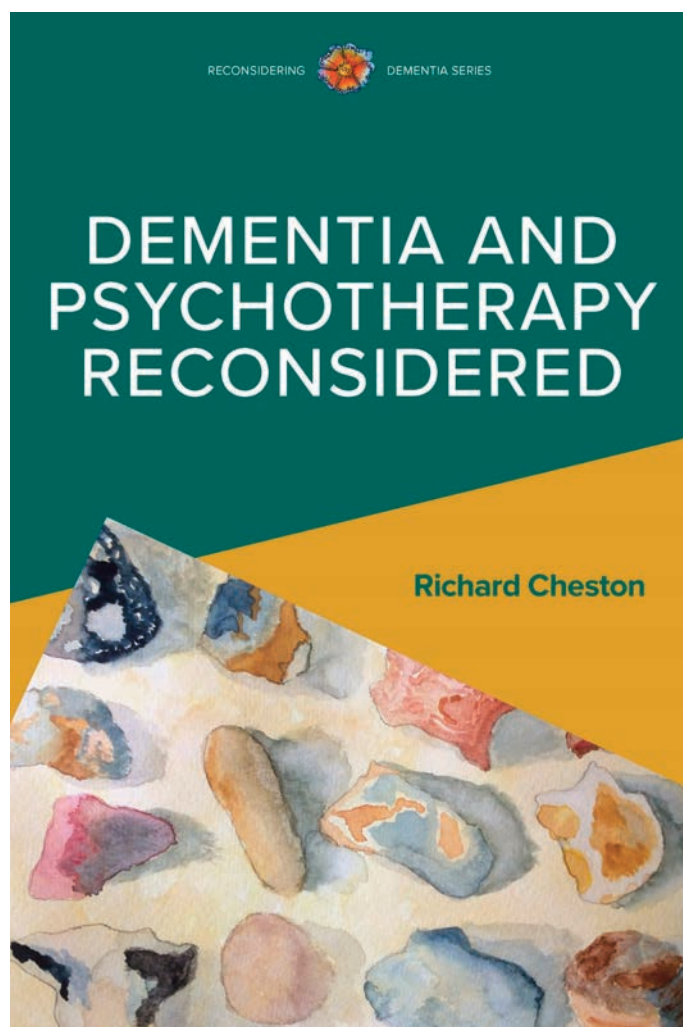
Many thousands of people are diagnosed worldwide with dementia, a number that will increase over time. The trend



The *Reconsidering Dementia* book series

is jointly commissioned and edited by Professor Dawn Brooker and Dr Keith Oliver. Professor Brooker has been active in the field of dementia since the 1980s as a clinician and an academic. She draws on her experience and international networks to bring together this series of books on the most pertinent issues in the field. Keith Oliver also brings an international perspective of his own and others' experience of what it means to live with dementia.

Dawn Brooker is professor emeritus at the Association for Dementia Studies, University of Worcester, and Keith Oliver is one of the foremost international advocates for those living with dementia.



is that people are being diagnosed at much earlier stages, while families and friends increasingly provide support to those affected over a prolonged period. Many people, both those diagnosed with dementia and those who support them, have an appetite to understand their condition at a deeper level than that which is provided by public health campaigns and dementia factsheets.

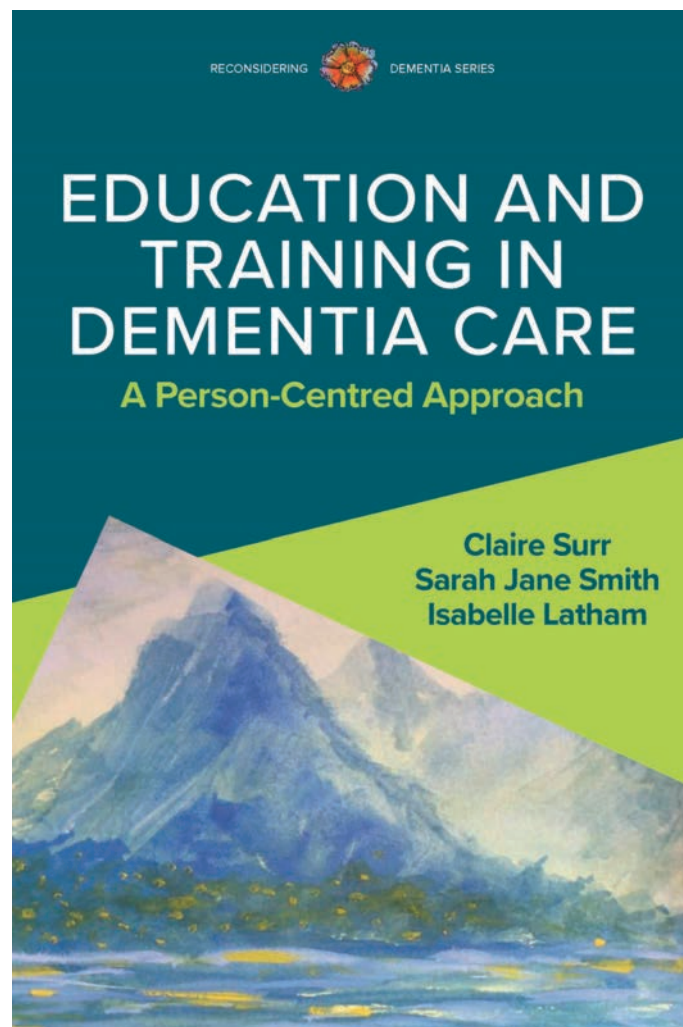
Over the past two years we have commissioned six books. These are currently at various stages of production and are due to be published throughout 2023 and into early 2024:

Dementia and Psychotherapy Reconsidered, by Professor Rik Cheston, due for publication in early January.

Education and Training in Dementia Care: A Person-centred Approach, by Professor Claire Surr, Dr Sarah Jane Smith and Dr Isabelle Latham, due for publication at the end of January.

Reconsidering Ethics in Dementia Care, by Professor Julian Hughes, expected in June.

Considering Leisure and Dementia, an edited text from Dr Chris Russell, Jane Twigg and Dr Karen Gray expected in August.



Neighbourhoods and the Lived Experience of Dementia: Spaces, Places and People, an edited text from Professor John Keady, expected in September.

Talking with Dementia, Reconsidered, edited by Dr Keith Oliver and Reinhard Guss, expected towards the end of 2023.

We also have two further titles - *Living Well with Dementia* and *Young Onset Dementia* - currently under review. We are keen to commission further books on family care, equality and diversity, diagnosis and physical health issues. We are open to suggestions for further titles and ideas for who might write them.

All will have the distinctive feature of bringing together the perspectives of professional practice, scholarship and the lived experience as they pertain to key topics in the field of dementia studies. We have loved editing this book series. All the texts so far have made us think more deeply about the topics they cover and have provided us with new insights.

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The IDEAL Living with Dementia Toolkit:

Living your life with hope

How to stay safe and well, stay connected, stay active, stay positive and keep a sense of purpose. **Allison Batchelor** and colleagues describe the development of a new Living with Dementia Toolkit, a freely available website for people with dementia and carers

During Covid-19 all our lives suddenly changed. Among the many challenges was the question of how best to support people with dementia through the pandemic and produce resources likely to be helpful to them. We want to focus on one such resource, the Living with Dementia Toolkit, which will continue to be relevant beyond the pandemic.

The IDEAL research programme (Clare *et al* 2014, Silarova *et al* 2018), which had been finding out what helps people to live well with dementia since 2014, continued to engage with people with dementia and carers when Covid struck.

Through a project called INCLUDE (2020-2022), 172 people with dementia and 288 carers described their experiences of the pandemic and the things they would find helpful to continue to live as well as possible with dementia. As part of INCLUDE there was funding to develop an online toolkit. Originally intended to be a resource to support people with dementia throughout the pandemic, the Living with Dementia Toolkit has proved that it will continue to have value now that it has passed.

The toolkit can be found at www.livingwithdementiatoolkit.org.uk and its content is also available for download in bitesize PDFs. The website is full of resources, films and links to:

- Give people with dementia and carers hope for the future
- Inspire through examples of real-life experiences
- Offer ideas to help people live their life as they choose.

This toolkit was born from the research findings of the INCLUDE and IDEAL research studies and shaped and enriched by a co-production group of people with dementia and carers. The authors of this article are members of the co-production group, supported by Cathy (University of Exeter) and Rachael (Innovations in Dementia).

We describe the process behind the development of the Living with Dementia Toolkit and how the collaboration between people with dementia, carers and researchers has created a website we wish had been available to us when

we as members of the co-production group were diagnosed with dementia.

We hope we can show you what has been special about the way we have co-produced this toolkit and that readers are inspired to try out these approaches in their own work with people with dementia. Quotes from some of us are included.

What is the toolkit?

The Living with Dementia Toolkit is a website full of stories, ideas, resources and tips around living with dementia. There are resources there for people with dementia, and resources for carers.

As co-author Chris says: "It's a box of ideas that you can adapt."

It suggests ways of getting on with life, and helps people know that they are not alone. In essence, we want it to give people hope to live the life they choose with dementia.

The toolkit came about in the first place because of Covid. We wanted to share the research findings from IDEAL and INCLUDE to support people with dementia and carers with practical solutions in response to the impact of the pandemic. As the restrictions during the pandemic began to relax, the content of the toolkit has re-focused on ideas for living your everyday life with dementia.

There are five themes to the toolkit, and these correspond to the key areas that influence wellbeing from the IDEAL research programme. The themes are:

- Stay safe and well: looking after your everyday needs in order to do the things you want to do
- Stay connected: creating, maintaining and enjoying relationships with other people
- Keep a sense of purpose: staying motivated and finding the things that give you purpose, so you can feel fulfilled
- Stay active: keeping active in body and mind – for your health, but also to feel good overall
- Stay positive: how you can remain positive and maintain a sense of hope amid what can sometimes be challenging times. ▷

Allison Batchelor, Jacqui Bingham, Chris Norris and Keith Oliver are living with dementia and are members of the ALWAYSs group. Jane Ward, David Scott, Julia Burton and Monica Cheeseman have all been carers and are members of the ALWAYSs group. Cathy Charlwood is research translation and impact manager for the IDEAL dementia research programme at the University of Exeter. Rachael Litherland is from Innovations in Dementia and supports the work of the ALWAYSs group. Claire Pentecost is a senior research fellow in the College of Medicine and Health, University of Exeter and the programme manager of the IDEAL programme.

▷ The toolkit is designed to be explored at leisure. Users can dip into the parts that are the most relevant. They may be interested in and need different types of content at different times. For those who don't know where to start, there is a useful tool on the home page:

How are you feeling today?

The “How are you feeling today” button takes you to a series of statements about how you might be feeling today. For example:

- I feel like looking forwards
- I feel like being inspired
- I'm struggling with my dementia today and finding things hard
- I've just been diagnosed, show me something that gives me hope
- I have been feeling down
- I want to know where I can find help.

Underneath these statements there are resources curated to match that particular feeling. We do not want the toolkit to be static. We hope people will make suggestions for resources that could be added to help people with dementia and carers live their lives with hope.

As Jacqui says, “It's not just about living. It's also about having fun, progressing and learning.”

Setting up for co-production

We began working on the toolkit in September 2021 and finished in March 2022. This was a short project and needed us to hit the ground running. Our co-production group was actually a (temporary) merger of two other groups: first, people with dementia who worked together to develop a self-help resource around goal setting called My Life, My Goals (available at www.alzheimers.org.uk); and, secondly, the longstanding ALWAYSs (Action on Living Well: Asking You) group, people with dementia and carers who have shaping and supporting the IDEAL research programme since the beginning. The co-production group is made up of four people with dementia (Allison, Chris, Jacqui and Keith) and four carers (David, Jane, Julia and Monica).

As Keith says: “This was a unique way of working. I've not encountered a project like this before - to construct something new but consistent with what was previously there. Normally it is just a project that is thrown together!”

“Therefore”, says Julia, “one of the advantages is a freshness of communication and ideas. I think that's made the group bounce! And somehow it has made us all think a bit differently and say things differently. We are all inspired again. To me, it's been like a rekindling”.

Jane agrees: “We've come together, reinvigorated, and the ideas have come from that. Sometimes if you're just looking at a report it's a bit dry. The Toolkit is fresh and energetic and full of other people. Whenever you look at it you find something new that you hadn't spotted last time. There's almost something for everyone, it's brilliant”.

The merger of two similar types of groups meant that we shared the same values and communication and involvement approaches, but we were full of rekindled energy, which surprised even us!

Working on the project

The ALWAYSs group has been an integral part of the IDEAL research programme. It is a PPIE group, which stands for patient and public involvement and engagement and which large research projects are usually expected to have. The group's role is to advise on different aspects of the project based on personal experiences, skills and expertise.

Involvement and engagement by the group is ongoing; they meet at least four times a year and have made huge contributions including shaping IDEAL project materials, providing feedback on questionnaires and interview processes, reviewing emerging theoretical themes and presenting project findings alongside the research team. Group members have reported previously about the positive impact of their role and how important it is that PPIE isn't seen as an add-on or delivered in a tokenistic way by researchers (Litherland *et al* 2018).

However, our PPIE role in the ALWAYSs group feels different to our work together to develop the Living with Dementia Toolkit.

“It's given us a sense of impact that the research is going to make a difference, and that we are directly involved in this” (Keith).

“It's been good to have an end date. It's kept us focused on getting the job done!” (Allison).

“I think it's very exciting to work with another group and getting an intertwined approach. The website is more than a report. It's a live space that people can easily access and find. A report can be buried” (Allison).

Responding to the needs of people emerging from a global pandemic was motivating as well. It made us want to work at speed.

“The toolkit came out of a crisis. It was very timely and that makes it different. We talked about what can be put in place now” (Julia).

“We wouldn't have had that impulse to throw ourselves into the job had times not been so strange” (Jane).

“It had a freshness. We had something to get on with. Research can take an awfully long time – and to then hear what the outcomes are. But this didn't. Every meeting had a life. This project lived” (Chris).

We met every fortnight between September 2021 and the end of March 2022. This kept the work fresh in our memory. The toolkit was put together meeting by meeting, with designs, templates and content being developed regularly (see box “Deciding on icons and pictures”). Consequently, we could see results taking shape based on all our ideas, feedback and amendments. ▷

Deciding on icons and pictures

Our responses to different designs to represent the five research themes were very interesting. For some we were in complete agreement. For others, we each saw things very differently. For example:



“Does it say Toolickety? It’s really hard to read”

“The bars of colour – what is all that about? It’s not meaningful unless you are in the know”.

“The different fonts make it difficult.”

“Don’t put TOOLKIT in capitals. It’s the Living with dementia that is important”.

“I don’t like it!”

By working on the design of the toolkit, we could see the changes that were happening because of our input. We heard and saw what happened and could see that we had a direct role of influence. We were part of the team – a tennis match backwards and forwards – to the final result!



▷ Importance of co-production

Co-production means different things to different people and is often misunderstood. It’s not just about participating in other people’s work or ideas but helping to shape new ideas from the beginning (Innovations in Dementia 2020).

Co-production is about:

- Getting involved as equals
- Being recognised for the experience you bring
- Making something happen together.

We think the values at the heart of this group made the three principles about co-production come to life. What is the point of a website for people with dementia and carers if no people with dementia or carers have been involved in its creation?

This was why we got involved, to be at the heart and start of the work. The voices of people with dementia and carers are woven throughout the toolkit, balanced by ideas from the research (rather than the other way around). That way, we get an end product that we want, and that we know is built on real experiences.

“Each member of this group is able to look from their own point of view and the point of view of others that we know. It enriches this work. We are not a group that

simply looks at their own situation - we want a toolkit that will work for other people” (Keith).

And this meant we shared the power in this group. We all knew the toolkit was going to be better if it was built by people with dementia and carers.

“We had freedom to be completely open. There wasn’t a set template. Things got fed in to make us bounce. We could pick up little things and add to the mix. And then we would bounce off again. We did a lot of bouncing!” (David).

“It was co-production and co-creation at its best. The word co is important as production and creation, without us you wouldn’t have a product. But without you we wouldn’t have a product. The best projects are those where the ‘co’ happens” (Keith).

Good facilitation is always helpful to move a piece of work like this along. According to the Cambridge Dictionary, facilitation means “*the act of helping other people deal with a process or reach an agreement or solution without getting directly involved yourself.*”

Facilitation by Cathy and Rachael meant that we put our energy into the job at hand.

▷

▷ “Because Cathy had been given this task to project manage the Toolkit, she has driven it, which has been very special. Particularly the personality she is – she kept it bouncing!” (David).

It was also important that we also had clear and consistent communication, both written and verbal.

“Communication is listening as well. We’ve all listened to each other” (Monica).

Finally, we think that co-production has to be enjoyable. You are volunteering your time and expertise and wanting to make a difference. But the work is so much easier if it’s fun. When we meet face to face, there is always tea and cakes to oil the wheels of co-production. In the virtual world we have had to rely on laughs!

“It was very good fun, this format worked well. When we were asked to look at signs and symbols to represent the different parts of the toolkit– we didn’t actually know what any of them meant! That was very funny actually, we laughed a lot!” (Julia).

Building consensus

We wanted the toolkit to reach as many people as possible and to be full of different experiences, stories and voices. We needed to reach broad agreements together to move the toolkit on.

“Because we were developing something step-by-step, we had to resolve any differences of ideas and opinions. This gave us a sense of purpose - to make life better for people with dementia – we didn’t have time to be contrary!” (Julia).

“It’s been useful to have people with dementia and carers mixed together in the group. We are sometimes coming from different angles, but we’ve had to resolve things. We’ve supported each other. If the group was people with dementia or only carers, we would have had a

completely different product at the end. We need to see the world from each other’s perspective” (Allison).

Sometimes we’ve had to balance issues and things that are experienced differently depending on whether you are a person with dementia or a carer. For example, we talked long and hard about the concept of risk. Carers are often focused on reducing risks, usually for good reasons. But this can result in people with dementia feeling disempowered. They may want to continue to take risks, even if there are negative consequences to an action. The issue of rights emerged here as well (see box “Let’s talk about risk” below).

We decided that there are no easy answers, but it can help to see the world from each other’s perspective. You can read more about these ideas by searching for “risk” in the Living with Dementia Toolkit.

We didn’t want the toolkit to be a place where anyone was judged for their actions. Therefore, we created a message for carers on the opening page, hoping just to nudge a different way of thinking about risk. This message was written from our hearts, and we have all signed it with a message that carers’ wellbeing matters also, and that opening up honest conversations can be helpful for both people with dementia and carers.

“The bottom line is that we are all worthy. If you recognise this from the outset, anything we build as a support system is driven by that. That you care, that you are respectful, we learn to live with all the difficulties. If you drop off the edge, then come back in at a different point” (David).

Respect is at the heart of our interactions together:

“Respect. We don’t lose sight of that. We have empathy and we trust each other. To do this work we have to trust each other.” (Keith) ▷

Let’s talk about risk

Allison: “Risk assessments are important – but mustn’t take over life. You need to have a balance.”

Chris: “Being wrapped in cottonwool can be as disabling as dementia.”

Keith: “Pre-planning is important to reduce risks. But it’s also important to keep some spontaneity and fun. They enrich life. Otherwise, it’s quite sterile.”

Jane: “My mum said, “there is no point in keeping us alive if we don’t have a life.””

Julia: “It’s important to think about risk in everyday life, not just out of doors or significant occasions. How can you support risk and not disempower people with dementia in those day-to-day things?”

Monica: “Life is a challenge. Let it remain so. Carers need to learn patience.”

Jacqui: “The impact of criticizing people with dementia can be huge. It knocks your confidence and makes you not want to try again.”

Jane: “You need to also think about the risk of not doing something.

Julia: “Don’t shut people down.”

▷ Please share toolkit

Do use the toolkit! Direct people to it. Support people to use it. Don't let it just sit there.

We hope that readers will also listen to our message around the importance of co-production, co-operation and inclusion, and that they will value the toolkit more because you understand where it came from.

Our recommendations for good co-production are:

- We enjoy getting involved in projects like this
- Don't be afraid to ask us to get involved. We often enjoy being stretched! We will say "no" if we need to
- But please don't be tokenistic. Talk to us, discover the way with us and support us to be part of your team
- Don't fill the space between meetings with loads of paperwork to replace the interaction of the group. It can be overwhelming and make you feel bombarded.

This is a living breathing resource for people with dementia and carers. It brought joy to our lives to be involved. We hope it brings hope to other people.

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Forget-me-Not garden project

Collaboration between a prison and a care services team

Evidence suggests that gardening can enhance the wellbeing of people with dementia. **Jilly Polson**, **Stuart Pomfret** and **Gillian Bowie** describe a unique collaboration between a prison and a care services team to promote learning, skill up staff and help care home residents experience the outdoors.

Gardening has been shown to have significant benefits for people living with dementia, so we were keen to collaborate with Dumfries prison on a gardening project designed, among other things, to build the knowledge and skills of both care and prison staff

There is a five-acre garden on the site of the prison – HMP Dumfries – in which the prison clientele work producing fruit and vegetables for the kitchens. It also serves as an exercise and events area.

Dumfries and Galloway's IDEAS team exists to help reduce and prevent stress and distress for people with dementia, while HMP Dumfries was keen to find out more about dementia to better support prisoners with the condition.

So both parties were delighted when we were approached by a therapeutic horticulture charity called Trellis, which was keen to enable community connections. As well as learning about dementia, the prison service was keen that community groups should use their garden as part of its community engagement.

Jilly Polson is an occupational therapist at NHS Dumfries and Galloway, Stuart Pomfret is head of offender outcomes at HMP Dumfries, and Dr Gillian Bowie is consultant psychologist for the IDEAS team, NHS Dumfries and Galloway.

The benefits of the outdoors for wellbeing include fresh air, exercise, maintenance of circadian rhythm, and improved mood (Pollock & Marshall 2012). For people living with dementia gardens are important for quality of life and social interactions (Clark *et al* 2013) and may have an effect on agitation (Whear *et al* 2014, Buck 2016). However, people with dementia sometimes lack opportunities to go outdoors (Lyons 2012). ▷

Summary

We report on a prison gardening project, which we believe is a good example of effective partnership in the community. It gave an opportunity for people with dementia to experience gardening and the outdoors. And it enabled the development of different knowledge and skills for care and prison staff.

The knowledge and skills acquired from this project can be used in the workplace and it demonstrated that perceptions can be changed about dementia as well as prison and prisoners.

What the project highlighted was the benefit of the outdoors and gardening in bringing people together, promoting learning, enabling achievement, fostering relationships, and, above all, having a lot of fun in the process!



The forget-me-not planter was constructed in the joinery workshop at the prison and planted up by prisoners

The IDEAS team

Dumfries and Galloway's IDEAS team provides specialist mental health support, working with people who have dementia and behaviours associated with stress and distress. The acronym stands for Interventions in Dementia, Education, Assessment and Support.

As part of the Dumfries and Galloway Health and Social Care partnership, the IDEAS team gives specialist advice, and carries out training and education, and specialist assessment and consultation.

▷ Project aims

While the gardening sessions that were the kernel of our project did not directly involve the prisoners, they were crucial in the planning and preparation as we will show. In the sessions themselves, people with dementia from a local care home, care staff, and prison staff all came together to learn from each other. The project aimed to:

- Increase the knowledge and experience of dementia for prison staff and gardening for care staff
- Raise awareness of the benefits of gardening within the wider community
- Enhance the wellbeing of those with dementia attending the group
- Contribute to the evidence base around gardening and the outdoors in people living with dementia.

No special funding was obtained for this project. All parties in the partnership contributed in different ways, eg, use of premises and equipment, staff time, materials, training, refreshments and transport.

Group sessions

Gardening sessions at the prison were organised in groups and planning and preparation were carried out over nine months. The first season of the group ran from July 2018 to December 2018. Group sessions were facilitated jointly by prison staff and the IDEAS team for two hours twice a month.

People with dementia from six local care homes (also known as “forget-me-not gardeners”) attended along with a care worker from each home, who was responsible for supporting their participation and ensuring their care needs were met throughout the session. Family members were also invited to participate and one did so. Numbers of forget-me-not gardeners attending varied from three to eight in each session, accompanied by three facilitators (two prison staff and one IDEAS team member).

A choice of activities was offered at each session with different activities for different individual preferences and levels of ability. Refreshments were served and enjoyed at each session. The garden is a tranquil spot but often the sound of raucous laughter, chatter and singing filled the air during the sessions.

While no prison clientele were present during the sessions, they were actively involved in the project, for



Image 4: Daffodils gifted to the forget-me-not gardeners by prison clientele to mark the first anniversary of the group.

example in preparing and setting up the environment, laying out the activities in the polytunnel, and proactively devising activities, eg, a popular flower collage frieze activity. These activities were laid out in a way that was helpful to the forget-me-not gardeners, for example by providing a completed example and minimising clutter.

Activities undertaken

Activities undertaken by the group included:

- A collage using natural materials
- Planting various vegetables from seed
- Harvesting vegetables and seeds
- Shelling peas
- Potting up flowers into planters or hanging baskets
- Nature mobiles (from Sensory Trust resources)
- Making seed mats (from Trellis resources)
- Making bird feeders
- Guided walks
- Sitting in the memorial garden admiring the plants
- Feeding the fish in the pond

Non-gardening activities were offered in addition, eg, bingo, crafts, and sing-a-longs, and the forget-me-not gardeners were also able to take away some of their work and some produce.

Evaluation and outcomes

Formal review meetings took place at three and six months, and a mixed methods evaluation was carried out at the end of the first season.

Word clouds were made from the written feedback from all participants (prison staff, care staff and people with dementia) at the end of each session.

Pre and post project questionnaires identified self-reported increases in the confidence of prison and care home staff. As one prison officer put it: “The garden group has been hugely beneficial for us; it has increased our confidence and understanding with regards to working with and supporting those living with dementia.”

Focus groups facilitated by the IDEAS team were carried out for those participating in the sessions. We will summarise the main themes here.

Apprehension

Both the prison staff and care staff felt apprehensive at the outset of the project. For the prison staff this was related to not having worked with anyone with dementia before and concerns around what they would be doing, whether they would be able to engage people with dementia, and whether their skills would be transferable.

“We were all apprehensive at the start about what we were going to be doing and dealing with,” a prison officer said. “I’ve certainly never worked with anyone with dementia.” For care home staff the apprehension was about going into a prison setting. “I was nervous about coming first time.....really really really nervous. I’d never been to a prison,” said one care worker.

Changing perceptions

Care and prison staff were keen to establish more community connections and potentially influence and improve public perceptions of both care homes and prisons. Care staff said their perceptions of prison had been totally changed, while prison staff shared how much they had learned about dementia and how this had changed their perceptions around the illness. They now saw dementia as the start of a new chapter and not the end, and they understood that everyone with dementia is different.

A prison officer expressed it in this way: “It’s the perception. There’s a label placed on them. That perception is ‘How will I work with them because...’ This is the label they’ve been given. But in fact, it’s just another chapter in their life, they’ve still got their own personalities.”

Another change of perception reported was about what constitutes an activity. The project seemed to help demystify what could be considered as gardening activities and give staff more ideas for activities to try.

“Everyone was involved in it (shelling peas) ... I used to do it when I was a kid and I used to love doing it ... so a simple activity like that and everyone loved it,” a prison officer commented.

Making a difference

There was a strong sense of everyone gaining from the group and all care and prison staff reported looking forward to the group and enjoying it more than they had anticipated. The forget-me-not gardeners also commented on the benefits of attending:

“It’s a very enjoyable time to come here. Everything feels so pleasant and happy and bright. It’s not doom and gloom,” said one, while another commented, “You feel welcome. You feel they’re making you welcome and they’re happy to see you.”

Staff from both care homes and prison also benefited from observing the difference the group was having on the forget-me-not gardeners:

“...we get reward from seeing our residents happy and being involved in things rather than sitting in chairs. That is priceless,” said one care home worker, while another

said, “It is great to see the clients open up and talk about past times in a garden environment, which in turn brings back memories of other times in their past.”

Knowledge and skills

Focus group participants regarded the knowledge and skills they acquired about gardening and dementia as another key benefit of the project. One of the prison officers put it like this:

“As we are an ageing population, so it’s inevitable we’re going to have prisoners with dementia soon. This (project) has helped us know how to deal with it a bit better.... We’re also going to be looking at our accommodation and see how this ties in with people living with dementia. Even the colours of the doors so that people know what door to go into.”

For care home workers, the benefit was finding out about gardening as a therapeutic activity: “My knowledge has increased as well,” said one. “Nobody taught me gardening. I knew nothing about gardening. But from coming here I’ve been able to pick up skills which then I can take back to others in the care home.”

In addition, many referred to a “ripple effect”, with word spreading about the project and benefits of gardening throughout the wider community, particularly as ideas were taken back to the care home.

Dementia Care Mapping

Dementia Care Mapping (DCM) was carried out by two IDEAS team members who had not been directly involved in the group sessions. DCM is an established approach to achieving and embedding person-centred care and was utilised by us to assess the quality of care being provided, determine how people with dementia experienced the group, and identify how sessions might be enhanced in future.

Three forget-me-not gardeners were present on the day of the map. Results showed that all three had high wellbeing scores as a result of the project, while it was also recognised that the commitment and enthusiasm of staff helped create a positive and productive session. There were many examples of interactions that enhanced people’s wellbeing, such as staff being welcoming and treating individuals with affection and care, bringing people into the conversation, emphasising achievements and skills, and encouraging participation with appropriate pacing of activities.

Anecdotal evidence of the impact of the project included a gift from one gardener of a wooden heart to the staff for display in the polytunnel and a spontaneous speech of thanks by another. One of the care staff reporting that a resident with poor appetite ate some of the produce from the garden that was brought back.

Since this first group ran in 2018, we have run a second season in 2019 and had hoped to run further seasons when the pandemic reared up and interrupted our plans. We are now reviewing the learning from the project and considering how it might inform future projects.

Implications for practice

- Partnership working can bring enormous benefit but takes careful planning and time
- Identify and utilise existing resources and relationships
- Ensure all parties are aware of their roles and responsibilities and those of others, particularly if new staff have joined
- Ongoing review and evaluation is crucial as well as ensuring risk assessments are regularly updated
- Consider how to disseminate and promote the benefits and learning from the project within the wider community
- Activities carried out were simple and easy to achieve and can easily be replicated elsewhere, eg, a care home, someone’s own home or a community centre.

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The importance of support for people living with dementia who are experiencing ‘sundowner syndrome’

“Sundowner syndrome” is common in people with dementia, resulting in agitation and anxiety, yet there are few therapeutic approaches or guidelines to help care professionals. **Lorna Chesterton, Matthew Ford and Anya Ahmed** (left to right below) explain the findings of their review of the literature

We will explore “sundowner syndrome” and the challenging symptoms which are experienced by people living with dementia, and the treatment options which could assist care



not uncommon, and it is estimated that they may affect up to 60% of people with Alzheimer’s disease and related dementias (Canevelli *et al* 2016) although Pyun *et al* (2019) argue for a lower prevalence of 20-27.8%.

professionals working in long-term care facilities to better meet their needs. First, we will define sundowner syndrome before looking at the results from our narrative review and the themes which have emerged.

Sundowner syndrome is characterised by changes in behaviours that become apparent in the late afternoon and early evening (Bedrosian & Nelson 2013). Typically this is experienced as agitation, anxiety, aggression, pacing, visual and auditory hallucinations, and walking with purpose (“wandering”) (Khachiyants *et al* 2011).

Symptoms of sundowner syndrome are observed to occur in those diagnosed with dementia as the sun sets and darkness gathers, accentuating shadows indoors and outdoors. In dementia, the circadian sleep-wake cycle rhythm, which is naturally controlled by light levels (internal body clock) becomes fragmented due to a loss of neuronal function in the suprachiasmatic nuclei.

Indeed, levels of the “sleep hormone” melatonin are controlled by the suprachiasmatic nuclei and released in response to darkness, with evidence showing people with Alzheimer’s disease have lower production of melatonin (Srinivasan *et al* 2006). This reduction in melatonin is also exacerbated by the normal ageing process whereby eyeballs thicken and become yellow with age, filtering out the blue light required to generate melatonin (Olson & Albeni 2021).

The manifestations of sundowner syndrome present huge challenges in terms of support for family carers in the community (Shih *et al* 2020) and care home staff (Gallagher-Thompson *et al* 1992) while also worsening cognitive decline for the person with dementia (Scarmeas *et al* 2007). Moreover, sundowner syndrome has adverse effects on the quality of life for both people with dementia and their family carers (Shankar *et al* 2014). However, these symptoms are

Methodology

Our narrative review searched all relevant databases as well as national and international policy documents related to dementia, and strategies for living as well as possible with dementia. A narrative review was selected to obtain a broad perspective on the topic, in an attempt to summarise the literature relating to sundowner syndrome. ▽

Summary

Extended hours of darkness during autumn and winter are particularly significant for people living with dementia, who can be affected by these changes in light, and may experience this as agitation, anxiety, aggression, and auditory hallucinations.

The term used to describe these changes in behaviour is “sundowner syndrome”, because symptoms occur in early evening, as the sun goes down, and shadows and darkness set in. This narrative review looks at sundowner syndrome, and its impact upon people living with dementia and professional carers.

Results demonstrate that, while “sundowning” symptoms are extremely common, little attention has been given to its treatment or the challenges that it presents for both community dwelling residents and care professionals in long-term care facilities.

Against the backdrop of these findings, this paper centres on the need to highlight the impact of sundowner syndrome and the treatment and support options that can reduce its effects.

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Key points

- We explore the impact of sundowner syndrome for people living with dementia and what treatment and support is available that can help reduce symptoms.
- A narrative review was conducted that focused on individual's experience of sundowner syndrome and the approaches taken to care and support.
- We consolidate findings from the review into three main themes: "Understanding sundowner syndrome", "Sleep/wakening patterns", and "therapeutic approaches to managing sundowning".
- This paper highlights that, despite the challenging nature of sundowner syndrome for professional carers and individuals, there are no guidelines around symptom management.
- Findings from this review suggest a need for more research in this area, using controlled trials that explore the improvement of sleep disturbances, as well as the role of innovative technology in alleviating symptoms.
- There is also a need for longitudinal studies, exploring the impact of interventions over time and through seasonal light changes.

▷ Searches explored studies which looked at individuals lived experience of sundowner syndrome, as well as approaches to managing it. Literature was screened by title and abstract, before full text format was retrieved on relevant articles. Following appraisal of papers, results were organised into themes, and gaps in the literature highlighted.

Results

Results explored the affects on those living with dementia of seasonal change in relation to the extended hours of darkness. We viewed this as important to the narrative review because managing the condition helps to reduce risk associated with night-time waking, and improves quality of life for the person with dementia and family and professional carers.

Care options were also explored for ameliorating behavioural changes associated with sundowner syndrome, which could improve the quality of life for those living with dementia and carers, and also reduce the burden on professional carers in residential and community settings.

Symptoms of sundowner syndrome often have severe impacts on the person living with dementia, and on the people caring for them, although there is a scarcity of literature pertaining to the lived experience of this condition. The following findings have been organised under the dominant themes explored in the literature.

Theme 1: Understanding sundowner syndrome

Sundowner syndrome, from a medical perspective, is thought to be related to the multifactorial impairment of circadian rhythmicity, caused by environmental and social factors, as well as degenerative changes in the retina and suprachiasmatic nucleus of the hypothalamus and reduced

melatonin production (Neikrug & Ancoli-Israel 2010; Gnanasekaran 2015). It can cause increased agitation, confusion or aggression in the late afternoon and evening as darkness falls, with people often feeling that they are in the wrong place (Dementia UK 2021).

Other clinical symptoms include mood swings, suspiciousness, and visual and auditory hallucinations (Volicer 2001). However, these behaviours are not specific only to sundowner syndrome and can be symptoms of delirium and Parkinson's disease (Khachiyants *et al* 2011). It is also thought that sundowning is caused and exacerbated by disturbances in routine, lack of sleep, medication, excess noise, and under/over exposure to light (Alzheimer's Society 2021) or to physical pain and poor nutrition (Dementia UK 2021).

A systematic review on sundowner syndrome by Boronat, Ferreira-Maia and Wang (2019) found that there were few comprehensive studies in this area, which made it difficult to make definitive judgements on whether the syndrome could be viewed as an early symptom, secondary symptom or precursor of worsening dementia. For family carers and care home staff, the symptoms and behavioural changes caused by sundowner syndrome present many challenges in care.

Theme 2: Sleep/wakening patterns

Research suggests that sleep disturbances and reduced quality of sleep increase with age, affecting 38% of over 65-year-olds (Klaffke & Staedt 2006) with around 50% of people with dementia experiencing sleep problems (Hess 1997). Sleep disturbances are known to have multiple impacts on health and wellbeing, increasing the risk of poor mental and physical health outcomes (Van Someren *et al* 2015).

Sleep patterns then are of vital interest in managing sundowner syndrome (Khachiyants *et al* 2011), with Dewing (2013) finding that people living with dementia spent 40% of their bedtime hours awake and 14% of the daytime hours asleep. Disturbed sleep patterns are also associated with agitation, anxiety and depression, negatively affecting quality of life (Peter-Derex *et al* 2015) and resulting in poor health outcomes for family carers (Gehrman *et al* 2018).

Night-time walking ("wandering") presents additional risk to people with dementia as they become disorientated in the darkness (Wu & Swaab 2007) resulting in falls, injury or elopement (Aud 2004), creating a situation that can lead to carer burnout (Gehrman *et al* 2018).

According to a Cochrane review there is no definitive intervention to improve sleep disorders, although emerging data suggest a combination of tailored light therapy with sleep hygiene initiatives may be beneficial (Livingston *et al* 2017). These could provide safer alternatives to pharmacological treatments if greater efficacy can be demonstrated (Gnanasekaran 2015).

Interventions to improve the sleep/wake pattern have often focussed on light therapy as a way of recalibrating the circadian rhythm (Gnanasekaran 2015). Bromundt *et al* (2019) explored the effects of a dawn-dusk light simulation intervention in 20 people with dementia in long-term care facilities. The study took place in the autumn and winter months and found that participants experienced

significantly better mood, in the morning hours after waking, when light simulation was used in the sleep-wake transition period.

A randomised clinical trial by Figueiro *et al* (2019) looked at the effects of a tailored lighting intervention on sleep quality, rest-activity, mood, and behaviour on 46 people living with dementia in long term care facilities. The study found participants experienced improvements in sleep, mood, and behaviour, and that tailored exposure to light therapy had positive effects.

The literature also explores how to address the risks of night-time walking with purpose, with a study by Ault *et al* (2019) looking at the use of smart home technologies to monitor movement and provide automated lighting and pre-recorded voice prompts to increase safety and reduce the risk of carer burnout and early institutionalisation.

Wider literature on ageing has also discussed how smart homes could be used as environments that optimise or support cognitive capacity (Choi *et al* 2019). Given the ever-growing presence of technological interventions to assist in dementia care, more research is required to investigate how light therapy and assistive technology can be used to alleviate sundowner symptoms.

Theme 3: Therapeutic approaches to sundowning

Responding effectively to sundowner syndrome is a challenge as there are no published guidelines in place (Goodman *et al* 2019). Pharmacological interventions include antipsychotic medication, antidepressant medication, anticholinergic medication, benzodiazepines, hypnotics, and melatonin (Boronat *et al* 2019; Yevchak *et al* 2012), although Gnanasekaran (2015) notes that these interventions have limited effectiveness and problematic interactions with other medications.

Therapeutic approaches have looked at music therapy light therapy and occupational therapy, yet have failed to produce conclusive findings and offered mostly anecdotal results (Boronat *et al* 2019). A study by Lineweaver *et al* (2021) considered the effects of individualised music listening on symptoms for 282 residents in long-term care facilities over a six-month period. By monitoring behaviour immediately before and immediately after listening to personalised music sessions, the study found that the most significant improvement was in relation to disengagement, confusion, and unresponsiveness, confirming that music therapy was an effective non-pharmacological approach.

In a small study by Rados *et al* (2021) a six-minute nature-based video accompanied by classical music assessed the tranquility levels of people with dementia when experiencing symptoms of sundowner syndrome. It showed that the intervention improved tranquillity levels and could offer an effective therapeutic approach. Although the study only involved 10 participants and analysed findings relating to one episode of sundowning, it does offer useful evidence and could be a catalyst for future research.

Physical activity is known to benefit the circadian pacemaker (Miyazaki *et al* 2001) with evidence indicating less agitation and behavioural change (Scherder *et al* 2010). A quasi-experimental designed study by Shih *et al* (2020) looked at the effects of walking for 120 minutes a week for six months on the symptoms of sundowner syndrome.

The study included 46 community-dwelling people living

with dementia and required them to walk either in the morning or in the afternoon, to see if the time of the day had an impact on symptoms. Results suggested that walking generally ameliorated the symptoms while afternoon walking appeared to have a quicker effect. Greater impact on symptomatic behaviour was shown by longer walking time.

Discussion

Sleep disturbances are known to compromise mental and physical health (Van Someren 2015), exacerbate sundowning symptoms and raise risk of disorientation (Wu & Swaab 2007), falls and elopement (Aud 2004), as well as produce physical and emotional burnout in carers (Gehrman *et al* 2018). But well-designed controlled trials examining how to address sleep disturbances are few and far between, although there are promising findings from some small scale studies.

For example, light therapy to recalibrate the circadian rhythm could, if sufficient efficacy could be established, offer a beneficial treatment option (Gnanasekaran 2015). Individualised music therapy (Lineweaver *et al* 2021) and music and video therapy (Rados *et al* 2021) also delivered interesting findings and added valuable insights to the body of literature, which could be built upon to provide generalisable results. Other studies highlighted the benefits of regular walking (Shih *et al* 2020) and the value of exercise (Miyazaki *et al* 2001).

Conclusion

Extended hours of darkness in the autumn and winter months can present challenges for people living with dementia and their family and professional carers.

Strategies should be considered for responding to sundowner syndrome, along with ways to mitigate the risk of falls, potential injury and elopement.

Approaches to address these behavioural and cognitive changes could also lie in technological advances and the implementation of therapeutic approaches. Indeed this review has explored contemporary research in light therapy and music therapy. Results are encouraging, but there is a need for further research in the following areas:

- Well-designed controlled trials exploring improvement to sleep disturbances, benefiting many people with dementia and carers, and potentially delaying long-term care admissions due to carer burnout
- How technology can assist in alleviating symptoms of sundowning
- Longitudinal studies into sundowner syndrome would be particularly useful, exploring the impact of interventions over a longer time period and through seasonal light changes
- International studies observing the impact of sundowner syndrome on people with dementia living in countries with extreme seasonal variations of darkness/sunlight.

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Voices from the frontline:

Turning research on care homes and Covid-19 into theatre

“Voices from the Frontline” is a theatrical performance originating in a research project to find out how care staff responded to the challenge of Covid-19.

Andrea Capstick and colleagues explain how care workers’ first-hand testimony was turned into “verbatim theatre”.

When the coronavirus pandemic first struck in March 2020, we realised almost immediately as dementia researchers that the impact on care homes would be immense. Although there was little media coverage of what was happening in long-term dementia care in the early weeks of the pandemic, it was clear that older people and those with co-morbidities were at particularly high risk.

These were the circumstances that led to our “Voices from the Frontline” performances, which dramatised the first person testimony of care staff who talked about their experiences of the pandemic. Our theatre piece had its origins in a research project to gain care staff’s perspective on what was happening.

Due to the lockdown conditions then in place, researchers could not go into care homes for this project, but we managed to get a small amount of internal funding from the University of Bradford’s Covid-19 Response and Recovery scheme to carry out online research. Many of the care home staff who took part were students or former students on our own MSc Advanced Dementia Studies programme.

The research was carried out in the summer and autumn of 2020, and the 20 care home workers participating told us their stories in a variety of ways, either through an online interview or discussion forum, or by submitting a written narrative. It quickly became apparent that this was a strikingly original body of first-person testimony about life on the frontline of the pandemic. Our first output was a booklet paying tribute to care home staff (Capstick *et al* 2021). The key findings, published in Capstick and Barbosa (2022) and Capstick *et al* (2022), concerned:

- Confusion and stress related to frequently changing guidance
- Impact of measures such as PPE, social distancing and cessation of family visits on people living with dementia
- Impact on mental health and wellbeing of care staff
- Creative coping strategies adopted by staff.

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It was only possible to include a small proportion of what participants told us in our journal articles and conference presentations, yet some of these messages were so powerful that we wanted to find a way of increasing their reach and of “amplifying” the voices, as Frank (2016) puts it, of the long-term dementia care workforce.

This is a workforce that is chronically neglected and under-represented in research and in the media, and during the pandemic social care staff received far less attention than those working in acute hospital care. Yet almost half (47 per cent) of all those who died in the first wave of the pandemic (the period from March to June 2020 covered by our study) were care home residents (Oliver 2022).

When the University of Bradford put out a call for events for its UNify community festival, one of us (Andrea Capstick) had the idea of turning the stories participants had told the research team into a piece of verbatim theatre called “Voices from the Frontline”. Verbatim theatre is a form of theatrical performance in which actors reproduce word-for-word what was said by the people who experienced an event in real life. Other terms used to

Script extract

Part 1: “In the beginning....”

As the actors enter stage right and take their seats, a radio news programme is playing Boris Johnson’s announcement of the first lockdown in March 2020.

Care Assistant 1: [Walks to centre spot with a placard with the words ‘In the beginning...’ handwritten on it, and speaks the words aloud.]
In the beginning...

Dementia champion: [from centre left] *In the beginning, I suppose, nothing really changed. We were becoming aware that there was a virus. At the time I don’t think it was called a pandemic. It had come into Europe, but it wasn’t big yet. I think when we all started taking it seriously was when the nursing homes in Spain happened. Nothing, and then suddenly it was just full tilt...*

CA1: [from centre right] *It all happened so fast. It was just, like, one minute we had visitors coming in and entertainers coming in and then the next day it stopped. There was no sort of like, you know, this is what’s going to happen kind of thing. It was very abrupt. No one had ever experienced anything like this...*



Above left: expert by experience Kevin Scanlan.

Above right: actor John Middleton.

describe this approach to disseminating research findings are ethnodrama or ethnotheatre.

According to Saldana (2011) three benefits of ethnotheatre are that it makes research findings accessible and engaging to non-academic audiences, it creates impact, and it stands in solidarity with research participants from socially-excluded groups. The university agreed to fund the 25-minute performance early in 2022, and we then had just six weeks before the festival in March to turn the data into a theatre piece.

Timing was very tight and the staging of the piece needed to be simple but effective. The draft script was composed by Andrea, who already had experience of using this approach. Initially, she searched the research transcripts for powerful material that had not been used in published papers and conference presentations, although there is a little duplication in places so that the story hangs together.

A narrative was then created with three short scenes representing different phases of the pandemic. “In the Beginning” covers the early weeks of lockdown. “Tough Times” relates to the period when care home outbreaks and deaths from coronavirus were at their height, and “The Legacy” draws out some key messages about what the workforce members learned in the process and what needs to be done in reparation.

The script was fine-tuned during rehearsals, with many creative ideas for staging added by the cast members and director. Different grades and roles of care home staff were represented in the drama: a manager, dementia champion, family support worker, two care assistants and one agency worker. Some of the characters were composites of more than one research participant, while others were based solely or largely on a single contributor.

We put out a call for volunteers to take on these roles and a variety of friends, university colleagues and experts by experience came forward. None of the actors had professional experience, although most have hobbies and interests related in some way to performance (one belongs to a speakers club, for example, one to an amateur improvisation group, and one is in a choir).

Impact on cast

Cast members working outside of social care were shocked to learn what the care home staff whose roles they were playing had endured during the pandemic. Giorgia Previdoli, co-author of this article who played the role of a family support worker, described taking part as “an extraordinary experience from the outset”. Tuiya Tembo, a lecturer in law who played an agency worker, described it

as “a real eye-opener...It was heart-breaking to learn of some of the experiences - the long hours, the loneliness, the confusion and also the loss of lives.”

Kathryn Loftus, a local government programme director who played the part of Care Assistant 1, said, “I had no idea of the trauma staff were put through during the pandemic. I realised that they are unsung heroes, and I was determined to bring one of those voices alive.” Rehanna Neky, a

freelance web consultant who played the part of Dementia Champion, said, “Reading this script for the first time illuminated the experiences of those on the front line of care in a way that was otherwise hard to imagine. It was a privilege to support their voices.”

Jackie Smart, who works at the University of Bradford as a senior educational developer and used to teach drama herself, played the role of the care home manager. She spoke of how much she had learned from working with the other cast members, the researchers, and particularly the director, Kathryn Carmichael, who is herself a senior care assistant in a local care home. In fact, Kathryn missed the second performance after catching coronavirus at work.

Developing the performance

We were lucky to be able to rehearse and perform at the university’s Theatre in the Mill, with dedicated support from senior producer Shabina Aslam, an expert in verbatim theatre. Creative details were added as we went along, including music tracks, audio extracts from news reports, and back-projected photography. The theatre’s arts technician, Ivan Mack, and film student Isaac Nash were a great help with the more technical aspects of the performance.

Over the six weeks of rehearsals relationships between the actors and the characters they were playing also changed and developed. Parts of the script that had originally been performed as monologues now turned into discussions between the characters, and the actors began to use touch and gesture more to acknowledge and respond to each other’s emotional reactions.

Despite attempts to recruit male performers, we ended up being an entirely female cast, but we used an empty chair on stage to pay tribute to Ricardo (Ricky) Bonsato, a care home worker, who was one of almost a thousand social care staff to lose their own lives to coronavirus.

In memory of Kevin Scanlan

Now performed twice, the play is dedicated to the memory of Kevin Scanlan who was, for many years a member of our experts by experience group at the Centre for Applied Dementia Studies. He died in a care home during the pandemic. Kevin’s wife, Karen, was part of the patient and public involvement (PPI) group for the research the play is based on, and was present with other family members at the first performance.

The play was introduced by John Middleton, the Bradford-born actor who played the part of Rev Ashley Thomas in the long-running TV soap *Emmerdale*. When John’s on-screen character was diagnosed with dementia in 2015, Kevin was one of the experts by experience who advised him on his role. John spoke of his debt to Kevin, and also



Despite attempts to recruit male performers, the cast ended up entirely female, but the empty chair on stage pays tribute to care home worker Ricardo (Ricky) Bonsato, one of almost a thousand social care staff to lose their own lives to coronavirus. From left above: Kathryn Loftus, care assistant; Tuiya Tembo, agency worker; Sue Bradbury, care assistant; Jackie Smart, manager; Giorgia Previdoli, family support worker; Rehanna Neky, dementia champion; Andrea Capstick, narrator.

of how coronavirus had exacerbated existing concerns about dementia. Voices from the Frontline was, he said, exposing something that is “often overlooked, often ignored, and should never be ignored”.

Audience reactions

Both performances were followed by Q&A sessions and had an enthusiastic reception. Michael Andrews, an audience member who lives with dementia, said, “I loved the way they had done the play, just straight to the point, no kid gloves, and put it across the way it actually happened. I tip my hat and applaud them”. Julie Hayden, who also lives with dementia and was a member of the Q&A panel, added, “It is so important that we are not just presenting statistics. Those affected were not and are not statistics. They are real people, and the traumatic impact upon them will last for many years.”

Professor Marcus Rattray, from the university’s Faculty of Life Sciences, who was among the second audience, described the play as “intensely moving in its account of the tragedy and humanity of the impact of Covid-19 in care homes”, while Professor Jan Oyeboode from the Centre for Applied Dementia Studies commented, “I found this a really powerful play. The simple way care staff’s words were re-conveyed to us was very effective in putting across the anguish they experienced as Covid unfolded. It was heart-wrenching, but it gave me a renewed respect for care home staff, who do a vital job with little recognition”.

Clare Mason, a co-author of this article and who led the PPI work for the research study, watched the actors perform the play many times, both in rehearsals and during the live performances. “I never failed to feel the emotion of the piece,” she said, “I think this play demonstrates the value of using theatre and the arts to disseminate research findings. It means researchers connect with a wider audience, especially those who perhaps wouldn’t usually engage with research, or even the arts.”

Justin Mazzotta, a graduate of the MSc Advanced Dementia Studies programme, reviewed the play as part of the Centre’s blog series (Mazzotta 2022). He wrote: “The play presents a collision of two worlds totally out of sync: on the one hand a government aiming to provide guidance which was virtually impossible to follow, on the other care

home staff afraid and unsure what was happening and how to do what was the best for their residents. The production provides a reflective space... where staff are able to think about and process the tragic events, many of them experienced in their daily roles during the pandemic.”

Team members are now hoping the play can be performed more widely in contexts that may help both to aid recovery for staff and to influence the forthcoming public inquiry into the government’s handling of the pandemic. Several of the cast have subsequently performed in another play Andrea has compiled using data from research, this time carried out with a group of women living with dementia in long-term care.

Entitled “The Other Side of the Wall” it was selected in a UK-wide competition as one of five experimental performances to be showcased at LIVE Bradford in November 2022. We hope Bradford’s recent success as UK City of Culture 2025 will provide more opportunities to use the arts to ensure the voices of people living with dementia and care staff are heard loud and clear.

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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 editor, Hazel Heath. We welcome suggestions of papers to be included: please contact sue@dementiapublishing.community

Delayed hospital discharge

People living with dementia often experience delayed discharge yet there is little research into their experiences. Using semi-structured interviews with people with dementia, family members and nurses, this study identified three main themes (1) Living and waiting (2) Distress and behaviours and (3) Looking beyond the designation. It identified labelling, a behaviour narrative and the passive nature of delayed discharge care. The authors emphasise the importance of fostering the abilities of people with dementia and recognising the significance of delayed discharge as a transition.

Sakamoto M, Phinney A, Thompson G (2022) Waiting for home: the experience of delayed discharge for people with dementia. *International Journal of Older People Nursing*. Published online Nov 17 2022. <https://doi.org/10.1111/opn.12516>.

Experiencing Spirituality

Although spirituality is recognised as an essential element in care, there is limited research into supporting the spirituality of older people with dementia. This study identified four elements to spirituality: religion, meaningful relationships, nature and art. It found that older people living with dementia and family members consider spiritual support to be important but emphasise that this needs to be based upon each person's personal understanding of spirituality. Additionally, to deliver optimal spiritual support, staff are required to offer understanding knowledge, competence, experience, time and presence. Further research and assessment tools are needed.

Toivonen K, Charalambous A, Suhonen R. Supporting the spirituality of older people living with dementia in nursing care: A hermeneutic phenomenological inquiry into older people's and their family members' experiences. *International Journal of Older People Nursing*. Published online Nov 15 2022. <https://doi.org/10.1111/opn.12514>. Open access.

Hope expressed through poetry

Hope has been identified as a positive psychological construct which can facilitate well-being. For this study, people with dementia submitted poems through an online platform about the meanings and their experiences of hope. Three main themes were: (1) "*Hope is light in the darkness*" (hope as a resource that spotlights what is still possible), (2) "*Poetry gives voice to experiences of hope*", and (3) "*Peers uphold hope and cast away the darkness*" (hope being blocked by the stigmatising views of others but facilitated through positive social interactions). The authors concluded that people are capable of having hope in the context of dementia, with hope being a functional strength that supports wellbeing. Amponsem S, Wolverson E, Clarke C. The meaning and experience of hope by people living with dementia as expressed through poetry. *Dementia*. Published online Nov 9 2022. <https://doi.org/10.1177/14713012221137469> Open access.

Family members' views on environments

In the context of limited research, this study used focus groups to explore the views of nursing home residents' family members on the environment. Themes were (1) "*A door ajar*" (potential opportunities for pleasurable everyday moments) (2) "*Why does it have to be so ugly?*" (institutional logic guiding design), (3) "*A place to care for?*" (the physical environment in care, carefully arranged and used with sensitivity), (4) "*Allegiance to the place*" (despite shortcomings, the environment provided a sense of a pleasant place). The findings highlight the physical environment, particularly common areas, as an integral aspect of care and move beyond ideas of 'homelike' and 'non-institutional'.

Palmgren M, Rosenberg L, Gaber SN, Johansson K. Family members' reasoning in relation to pleasant environments in nursing homes. *Dementia*. Published online Nov 25 2022. <https://doi.org/10.1177/14713012221144488>. Open access.

Staff experience of obtaining consent

Using focus groups, this study explored staff experiences of obtaining consent when caring for persons with dementia. Overall, staff found it difficult to know if they really had consent from the individual. Even if the person verbally gave consent, it was challenging to know if they really understood what they had consented to. The findings highlighted the significance of the relationship between the person with dementia and staff, getting to know the person and recognizing the person's response in terms of facial expressions and body language, as well as being able to explain and justify specific actions to the person.

Östlund L, Bravell ME, Johansson L. Working in a gray area – Healthcare staff experiences of receiving consent when caring for persons with dementia. *Dementia*. Published online Nov 15 2022. <https://doi.org/10.1177/14713012221137472>. Open access.

Online peer support in young onset dementia

This study explored the experiences of people with young onset dementia attending peer support meetings through online videoconferencing platforms. It identified that online platforms make peer support more accessible in that they overcome barriers of geography and for those who feel uncomfortable attending an in-person group. The authors suggest that researchers and policy makers should explore how to overcome barriers to online peer support, so that this becomes more widely accessible and clearly signposted to people with young onset dementia.

Gerritzen EV, Kohl G, Orrell M, McDermott O. Peer support through video meetings. Experiences of people with young onset dementia. *Dementia*. Published online Nov 18 2022. <https://doi.org/10.1177/14713012221140468>. Open access.

Online chair yoga (CY)

This is the first research to explore the use of telehealth-based online CY to improve physical activity and support socialisation for older adults with dementia who are socially isolated. It identified benefits, challenges and facilitators in participating in remotely supervised online CY from the perspective of older adults with dementia and their caregivers, including what would help them to participate in online interventions. Identified benefits included sleep and relaxation, emotional regulation, flexibility, muscle strength, convenience and caregiver-participant connection. Challenges included technological setup. Participants reported that they wanted to continue home-based online CY practice and the authors conclude that online CY should be prioritised to promote health and wellness in socially isolated adults with dementia.

Park J, Hung L, Randhawa P et al. 'Now I can bend and meet people virtually in my home': The experience of a remotely supervised online chair yoga intervention and visual socialisation among older adults with dementia. *International Journal of Older People Nursing*. Published online Nov 14 2022. <https://doi.org/10.1111/opn.12513>.

Effects of reminiscence music interventions

This study examined the effects of a reminiscence music therapy program on improving cognition and decreasing depressive and behavioural symptoms in older adults with dementia. Participants in the intervention group participated in 60-minute reminiscence music therapy twice a week over four weeks. The control group received usual care. Results showed that the intervention group exhibited a significant decrease in depressive symptoms

compared to the control group but effects on cognition and behavioural symptoms were insignificant.

Tz-Han L, Wan-Ru W, I-Hui C et al. Reminiscence music intervention on cognitive, depressive and behavioral symptoms in older adults with dementia. *Geriatric Nursing*. 49, Jan/Feb 2023.127-132. <https://doi.org/10.1016/j.gerinurse.2022.11.014>

Mealtime behaviours

This study examined characteristics of, and relationships between, person-centred and task-centred care and positive/neutral and challenging mealtime behaviours in persons with dementia. The findings emphasise the need to shift care approaches from task-centred to person-centred and recommend a focus on developing mealtime care training programmes to improve person-centred mealtime care practice.

Liu W, Perkhounkova Y, Hein M. Person-centred and task-centred care: Impact on mealtime behaviours in nursing home residents with dementia. *International Journal of Older People Nursing*. Published online Nov 14 2022. <https://doi.org/10.1111/opn.12512>. Open access.

Complexity in NHS Mental Health Inpatient services

Exploring the meaning of complexity within dementia assessment wards, this study conducted: (1) an online electronic survey of UK national dementia leaders, (2) individual interviews and a focus group with dementia practitioners in two dementia assessment wards and (3) case studies of four patients with dementia including their family carer and named clinician. The findings highlighted that complexity is constructed through a number of interconnected and interrelated domains that have been developed into the '3 Fs Model of Complexity' (Fixed, Flexible and Fluctuating). This model may facilitate a more holistic view of a person with dementia than when 'symptoms' are viewed in isolation. Subject to further refinement and testing, the '3 Fs Model of Complexity' could help guide the selection of tailored, personalised interventions for people with dementia.

Jones L, Cullum N, Watson R, Keady J. Introducing the '3 Fs model of complexity' for people with dementia accessing a NHS mental health inpatient dementia assessment ward: An interpretive study. *Dementia*. Published online Nov 8 2022. <https://doi.org/10.1177/14713012221136313>. Open access.

Characteristics of 'meaningful activity'

Through interviews and focus groups this study explored the key attributes of 'meaningful activities' from the perspectives of people living with dementia in residential care facilities, their family members and staff. Findings suggest that the meaning of 'an activity' is subjective; it varies over time and between individuals. Key characteristics of 'meaningful activity' include being enjoyable, social and engaging, aligning with the persons' interests, preferences, and abilities. To be considered meaningful, activities need to do more than occupy the person; they need to be linked to a personally relevant goal and an aspect of the individuals' identity. Participating in 'meaningful activities' was perceived as valuable to encourage participation and socialising, provide a sense of normality for residents and improve their wellbeing.

Tierney L, MacAndrew M, Beattie E et al. Characteristics and value of 'meaningful activity' for people living with dementia in residential aged care facilities: "You're still part of the world, not just existing". *Dementia*. Published online Dec 6 2022. <https://doi.org/10.1177/14713012221144488>

Blogs I'm watching—by Mark Ivory

Young onset dementia is not all doom and gloom, says Jane in her Memory for Two blog, where she reflects on the strangeness of grief. Her husband Ash was diagnosed with young onset dementia in 2017 and life since then has been an emotional rollercoaster. “Yesterday I was happy from beginning to end of the day. Today not so much which is why I’ve decided that grief is a very odd thing,” she says. On her visits to Ash in care he seems to be comfortably settled and she says she doesn’t miss him because he hasn’t been “my Ash” for so long. And yet... “And yet there are moments when thoughts of him come out of nowhere and knock me sideways. Mostly, I’ve realised, they’re not to do with memories but more that I know the old Ash would have loved the things I have planned... This morning I woke up and looked around my new bedroom realising with a jolt that he’ll never see it and I sobbed and sobbed. Not for long but with real heartache then, as usual, I put my chin up, my shoulders back and get ready for living again...”

www.memoryfortwo.com

In her blog just before Christmas, Alzheimer’s Research UK CEO Hilary Evans reflects on 2022 and acknowledges that pressures on care have made life “incredibly tough” for many people affected by dementia. But, by contrast, it was also an “amazing year of progress” in dementia research, particularly the release of promising results for the drug lecanemab as a potential way to slow cognitive decline. “I’ll never forget the moment I heard about the breakthrough so many of us had hoped for,” she writes. “It was the middle of the night on 28 September, and I was feeding my three-month-old baby, when a colleague in the US shared a link to a press release: a new drug, born from decades of rigorous scientific study of the diseases that cause dementia, that actually seemed to work. The following day was a rollercoaster of media interest and excitement. Our regular Trustees’ meeting became a moment of shared celebration and a chance to look to a new era. Emotions were high.” Lecanemab isn’t the be all and end all, she admits, and its benefits appear to be modest, but she hopes it will trigger an all-important debate. “Our health service is simply not yet ready to deliver drugs like lecanemab – it doesn’t have the staff, the equipment or the structures necessary,” she adds. “Lecanemab’s arrival should act as a catalyst to accelerate work on all these fronts, and we’ll be pressing hard for this to happen throughout 2023.”

www.alzheimersresearchuk.org/blog

Occupational therapists have an important role in dementia care in Edinburgh, from where Willy describes his experience of early stage Alzheimer’s disease on Alzheimer Scotland’s Let’s Talk About Dementia blog. His OT Jennifer does “occupational therapy home-based memory rehabilitation,” an intervention introducing cognitive strategies for maintaining skills and independence. Willy’s Alzheimer’s affects his eyesight more than his memory and at first he wasn’t convinced that “memory rehabilitation” could help him. “It’s not been easy realising I need help,” he admits. “Some areas where

I’ve struggled, I’ve been dimly aware of for some time. Then there are some problems that take me completely by surprise. An example would be when I discovered I have a problem seeing dark colours. My suitcase is dark and it turns out that when I went away I couldn’t see the zip on it, and I forgot how to actually open the case. It was an extraordinary situation. Since then, understanding the strategies I’ve been learning, my solution has now been to tie a bright ribbon to the zip and I can then see it.” It is one of the many adjustments his diagnosis has necessitated, but Jennifer’s professionalism has smoothed the way. “I’ve had to come to terms with the fact that some parts of me have changed,” Willy says. “I’m learning to be honest about these and the things I am having difficulties with.”

<https://letstalkaboutdementia.wordpress.com>

Resources

A new **Reconsidering Dementia** series of books being published by Open University Press aims to challenge and engage readers to take a fresh look at aspects of dementia care. Edited by Keith Oliver and Dawn Brooker, the series will cover a wide range of topics from psychotherapy, ethical issues, and the role of leisure to neighbourhoods and how people with dementia navigate and interact with them. The first book in the series, *Dementia and Psychotherapy Reconsidered*, by Richard Cheston, was published in November, and the second, *Education and Training in Dementia Care: A Person-Centred Approach*, by Claire Surr, Sarah Jane Smith and Isabelle Latham, is due in late January.

www.mheducation.co.uk

London and Yorkshire & Humber Clinical Networks have developed a **Guidance for appropriate prescribing of antipsychotic medication for patients with dementia toolkit**. Its aim is to promote good practice and to reduce variation in prescribing practice between the regions of England. The resource is intended to support primary care, care homes and memory assessment services, among others, to consider the uses, risks and alternatives to antipsychotic medication, risk reduction in antipsychotic prescribing, and delivering best practice in prescribing and de-prescribing as necessary. Go to the London Clinical Networks webpage.

www.england.nhs.uk/london/london-clinical-networks/our-networks/dementia

The **Living with Dementia Toolkit** is a freely available website that emerged as a resource during the pandemic but will continue to support people with dementia and carers well beyond it. Among the resources on the website are films and links to give people hope, inspire through real-life experiences, and offer ideas to help people live well. It was born from the IDEAL research programme, led by Exeter University, and is the result of a collaboration between people with dementia, carers and researchers.

www.livingwithdementiatoolkit.org.uk

The Young Dementia Network has announced details of its next webinar, **Young onset dementia: Changing perceptions of diagnosis**, taking place at 12.30pm on 8 February. Presenter will be Dr Susan Mitchell, head of policy at Alzheimer's Research UK, who will be accompanied by a panel of experts and will focus on the preferences of people living with dementia, the changing political landscape, and advances in research. www.youngdementianetwork.org.

Bespoke exercise programmes for care home residents have been launched by Royal Star & Garter using the physiotherapy app **Physiotec**. After each resident has been individually assessed, the home's physiotherapist then uses the app to create a tailored set of exercises for each one. Gursh Lotay, physio at Royal Star & Garter's home in Solihull, said: "Physiotec helps me to put together a set of exercises targeted at the individual. It empowers residents because the onus is on them to do the exercises. Their progress is in their own hands." www.physiotec.ca.

A toolkit from Dimensions aims to help health centres adapt to the needs of people with dementia, among other conditions. The **Designing for Everyone** kit forms part of Dimensions' #MyGPandMe health equality campaign and will help GP practices to improve the design and physical environment of their buildings. Commissioned by primary care building specialists Assura, the research-based toolkit was written by the University of Worcester Association for Dementia Studies. Among the research findings on which the toolkit is based are that only 22% of respondents felt independent in health centres and almost half felt worried, particularly in relation to décor, lighting, noise levels and waiting room layout. <https://dimensions-uk.org>.

A free **Alzheimer's Guide** is available from US health information resource Drugwatch. The guide includes information about diagnosis and the stages of Alzheimer's, causes and risk factors, signs and symptoms, treatment and prevention. www.drugwatch.com/health/alzheimers-disease.

Guidance has been published to help care homes support people with learning disabilities who have a diagnosis of dementia. The guidance, titled **My new home: Supporting people with an intellectual/learning disability and advanced dementia moving into a care home**, has been developed by a partnership between Healthcare Improvement Scotland, Alzheimer Scotland, University of Stirling and others to support people with a learning disability and advanced dementia to move to a care home should that be in their best interests. The partnership says that the transition to a care home often happens in a crisis and that the guidance was needed to improve outcomes. <https://ihub.scot/media/9648/supporting-people-with-a-learning-disability-and-advancing-dementia-guidance-for-staff-v20.pdf>

Expert training over two days on **reminiscence arts** in dementia care is to be held at the University of Greenwich. Scheduled for 19 and 20 January, the experiential course will be led by experienced practitioners and trainers with input from volunteers and former carers. It will be certificated by the European Reminiscence Network. A four-month apprenticeship scheme in reminiscence arts in dementia care is also available with up to 10 places for trainees to become accredited facilitators. Anyone interested should contact Pam Schweitzer. pam@pamschweitzer.com.

University of the Third Age (U3A) has set up a **forum for retired registered managers in the care sector**. It will meet monthly and will be an opportunity to share their wisdom and experience, although it is still to be decided how exactly the group will operate. <https://u3asites.org.uk/trustu3a/page/124819>

Dementia UK has compiled **advice for carers and people with dementia on the cost of living crisis**, available on the Admiral Nurse charity's website. It recognises that many families are struggling to pay their bills this winter and suggests some helpful strategies, such as simplifying finances, talking to utility providers' customer vulnerability teams, and accessing mental health support through the Admiral Nurse Dementia Helpline and local agencies. www.dementiauk.org

New for 2023: Journal of Dementia Care Webinars

Following the success of 2022's UK Dementia Congress, we are bringing some of the best sessions to you live online, with extra time for questions and discussion. More details on p2 of this issue; register via Eventbrite here or from our website www.journalofdementiacare.co.uk

Tues 28 February 2-3pm

Equality, Diversity and Inclusion: Actions not words

Trish Caverly and Roxanne Holton, Bristol Dementia Wellbeing Service. Chair: Lucy Whitman.

<https://www.eventbrite.co.uk/e/493704632847>

Mon 20 March 2-3pm

How 'Talking Mats' can improve care and communication with people with dementia in care homes

Isabelle Latham, Researcher-in-residence, Hallmark Care Homes. Chair: Suzanne Mumford, Care UK.

<https://www.eventbrite.co.uk/e/503233644377>

Mon 24 April 2-3pm

Responding to people with dementia in distress

Helping staff to be more confident and competent in communication skills: use of the CAIT online program

Ian James, Clinical Psychologist CNTW NHS Trust,

<https://www.eventbrite.co.uk/e/503270213757>

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Many thanks for showing interest in investing in Dementia Publishing Ltd, the newly formed, not-for-profit Community Benefit Society which has just bought the UK's most extensive source of dementia-focussed information for professionals working with people living with dementia. Successfully launched by Hawker Publications almost thirty years ago, the Journal of Dementia Care (JDC) is now the leading publication for professionals. As the new owners (and original founders of JDC) we are committed to providing you with all that is so loved and valued at JDC, plus a lot more: the journal itself of course, now in an electronic format (still ably edited by Mark Ivory), a much more extensive website, www.journalofdementiacare.co.uk, and dementia-focused newsletters and events including the UK's largest annual event in our dementia care world, UK Dementia Congress.

JDC's ultimate purpose has always been to improve the care of people living with dementia and we have, over many years, built up a community of practitioners, researchers, family carers and people with dementia themselves

– everyone who cares passionately about dementia care and the vital importance of supporting all who work in the field. This support is needed now more than ever, in the current climate of intense pressure on services and staff. In that spirit we believe a not-for-profit Community Benefit Society, whose purpose is to support a 'community of interest', funded by social investment makes it the ideal model for JDC and the UK Dementia Congress.

We hope that our friends old and new will join us in supporting this venture, so that our work can continue with the journal and we can resume, as we hope, the important meeting of minds, refreshment and renewal that was and is JDC and the UK Dementia Congress. Whether you are individual or an organisation please find the appropriate forms for investment below and overleaf and we very much look forward to working with you as a much valued member of Dementia Publishing Community Benefit Society.

Sue Benson, Dr Richard Hawkins, Barbara Stephens, directors of Dementia Publishing

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2	How much do you want to invest?	£	INVESTMENT
	(min £1,000, max £10,000)		
<ul style="list-style-type: none"> If the share offer is oversubscribed and/or we are unable to offer you any or all the shares you have applied for, we will refund the difference by the same means you have made payment. In the event of the offer failing to reach its minimum target your payment will be returned to you. 			

3	How will you be paying?	PAYMENT
	<input type="checkbox"/> A cheque payable to Dementia Publishing Ltd is enclosed with this application and sent to Dementia Publishing Ltd, 7 Southlands Mews, Park Road, Ryde PO33 2FQ <input type="checkbox"/> Bank transfer to Dementia Publishing Ltd, sort code 08 92 99 , account number 67226649 using your organisation's name as a reference	

4	<input type="checkbox"/> We confirm that: (<i>this consent is required for the Society to accept the investment</i>)	CONSENT TO INVEST
	<ul style="list-style-type: none"> The person signing this application has the authority to make the application in our name. We have read the share offer document and understand and accept the terms of the share offer and the Society's Rules. We understand that it our responsibility to notify the Society of any changes to the identity or details of our nominee. We understand that the Board of Directors may reject this application, and not be obliged to tell us why it has been rejected, and that the Board may conduct such checks as necessary to comply with money laundering regulations. 	
	<input type="checkbox"/> We also consent to receiving formal notices by the nominee's email address on this Form and links to formal documents on the Society website (optional)	
Signed		Date / /
Position		