

The Journal of DementiaCare

For all who work with people with dementia

Vol 31 No 4 July/August 2023



Music in the air

**Also inside
this issue:**

- Good dementia education and training
- Talking Mats
- Dementia-friendly audit of a care home
- Housing and home

For all who work with people living with dementia

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The Journal of DementiaCare

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Cover photos: Sincere thanks to all involved in The Spitz participatory music sessions at Bridgeside Lodge Care Home (Forest HealthCare), Islington for the National Day of Arts in Care Homes 24 Sept 2022. Photographer: Hannah Lovell. See Perspectives p8 and <https://www.spitz.org.uk/>

This was a "next generation" project, when children of the "grown up" musicians were invited in to perform as well. Pictured are, L-R in main photo: John Chamen (resident, with guitar), Ben (Spitz musician), Arthur Lea (piano), Alice (Spitz musician). Lower photo (L-R): Arthur Lea (piano), John Chamen, Ben, Alice, Isabella (daughter of Marcus Bonfanti), Joseph Ryan (resident), Marcus Bonfanti (guitar).



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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

Still waiting for change

By Mark Ivory,
Editor, *Journal of Dementia Care*



As we went to press we were still expecting the interim report on the Major Conditions Strategy, originally slated for early summer, that health secretary Steve Barclay heralded to most people's surprise at the start of the year. It will contain the government's new strategy for dementia in England, alongside its strategies for five other medical conditions. But, if the focus is medical, how much attention will it pay to social care?

This journal is fully committed to the quest for new treatments, more and earlier diagnoses, and investment in the necessary medical technology, but the shiny Rolls Royce of our imagination won't look so impressive beside social care's clapped out Morris Minor. Nor will it be remotely practical. According to the spring survey from social services directors (see News p6), most councils lack confidence that they can even meet basic legal requirements for social care. While waiting lists have fallen since Covid, well over 400,000 people languish on them as their situations worsen and their hopes of remaining independent diminish.

The government in Westminster has just published an NHS workforce plan putting booster rockets under training and jobs. Where is the equivalent for social care? Social services directors say that the recruitment and retention of care staff remains a challenge and continues to undermine progress. For example, more than 500,000 hours of home care that should have been delivered wasn't delivered because of staff shortages. We agree with the National Care Forum (NCF) that a long-term workforce plan for social care that develops career structures and qualifications would go a long way to solving the problem.

A further finding from the spring survey is that unpaid carers are bearing the brunt of an under-resourced and overstretched system. Carer burnout is the number one reason why care arrangements that support independent living are collapsing. Nine in 10 directors say that unpaid carers are coming forward with increased levels of need. "Already a bleak outlook, things will only get worse without a fully funded, long-term plan to transform social care in England," comments Carers UK CEO Helen Walker.

While it may be doubted whether a medically focused Major Conditions Strategy for England will place the emphasis where it's needed, the new Scottish 10 year strategy which is entirely focused on dementia at least promises to address the broad range of problems specific to dementia: long waits for a diagnosis, access to post-diagnostic support, and communities with the kinds of resources people with dementia and their carers need and want. But even here there are concerns about funding and about how it will tackle a dementia care system widely perceived to be in crisis.

When the social care white paper for England was published in 2021, we were promised more support for people to live in their own homes for longer and Alzheimer's Society responded that it had the potential to transform hundreds of thousands of lives. Two years on, we are still waiting and wondering when change will begin. ■

News round-up

Rising tide of social care needs

Most local authorities are not confident that they can meet minimum social care support requirements set in law, the Association of Directors of Adult Social Services (ADASS) has said. In its annual Spring Survey, released on 21 June, ADASS said that waiting lists for social care remained far too high and could rise again next winter without more staff.

Although waiting lists had fallen in the aftermath of Covid-19 – standing at 430,000 at the end of March – directors said that many thousands of people continued to deteriorate while waiting for assessments, care or direct payments.

ADASS president Beverley Tarka said: “Our findings show that a short-term funding boost from the government and the hard work social care teams have done to rebuild services after the pandemic is making a difference to thousand of people needing support and care, but we’re not out of the woods yet. Leaders tell us they are paddling hard to keep up against a tide of increasing and complex needs.”

The National Care Forum (NCF) said that the survey undermined the government’s claim to be investing enough money in social care and highlighted the urgent need for a fully funded social care workforce plan.

NCF chief executive Vic Rayner said the report painted “a worrying picture of high levels of unmet need, increasing acuity of that need and the closure and scaling back of services.”

Scotland’s dementia strategy

A 10-year dementia strategy setting out a long-term vision for change has been published by the Scottish Government. The strategy, titled “Everyone’s Story”, promises to address thorny issues like long waits for a diagnosis, consistent access to good quality post-diagnostic support, well coordinated care and support, and access to palliative care. A series of two year “delivery plans” for different aspects of the strategy will, the Scottish Government believes, “hold us to account on the long-term transformation we want to see and that people living with dementia and their care partners are entitled to expect.” The first plan is due to be agreed by the end of 2023.

A pledge is made in the strategy to “strive to promote and uphold Human Rights Principles” and take a human rights approach through the dementia journey. It is admitted that “less than half of those who are entitled to post-diagnostic support receive it”, but the strategy adds that peer support networks, Meeting Centres and dementia-friendly communities can all help to ensure that everyone receives it in future. Charity Age Scotland welcomed the new strategy and commended the involvement of people with lived experience in drawing it up. “The commitments outlined today represent an extremely positive step towards ensuring every person living with dementia receives the care and support they deserve, as well as recognising the needs of unpaid carers in their own right,” said Age Scotland head of dementia Dr Kainde Manji.



Youth and age: An intergenerational space is being opened as part of a Nottinghamshire care home to bring together residents and children from a neighbouring nursery. The initiative by Wren Hall, a dementia specialist nursing home, will see the opening of a “new collaborative building” with Little Wrens nursery, which is attached to the care home. Children from the nursery are pictured with a Wren Hall resident.

Right to a diagnosis

A timely dementia diagnosis should be a fundamental right, argues a new “Consensus Statement” signed by a group of 27 dementia experts.

In the statement, the experts call for better funded and evidence-based dementia care pathways to make timely diagnosis a reality and say that health services must commit to returning diagnosis rates to pre-pandemic levels.

Launched on the eve of Dementia Action Week in May, it was closely followed by Alzheimer’s Society’s “It’s not called getting old, it’s called getting ill” campaign to stress the benefits of a diagnosis. A survey by the Society found that nearly two-thirds (64%) of people stayed silent about their dementia symptoms because they confuse them with normal ageing.

MPs at a parliamentary event, fronted by Alzheimer’s Society ambassador Dame Arlene Philips, were urged not to let dementia fall down the political agenda. “Earlier, more accurate diagnosis is essential for people to be potentially eligible for the exciting new treatments coming down the line for early stage Alzheimer’s, and for everyone affected to get the vital help and support they need,” said Dame Arlene.

Among other findings from the survey of more than 1,100 people are that 23% of respondents waited over six months before they spoke to a medical professional and only 15% brought up the issue straightaway. Respondents cited not wanting to worry family members and fear of stigma as among the reasons for failing to act quickly. A third of respondents said they did not want to concern loved ones, while 16% were afraid that their relationships might change.

Diagnosis rates fell back from 67% to 63% during the

pandemic and the experts behind the Consensus Statement for England, Wales and Northern Ireland, who include Alzheimer's Society, the Three Nations Working Group on Dementia, Alzheimer's Research UK, and leading academics, aim to put them back on a firm footing.

Arts in care homes

A week-long celebration of the arts in care will culminate in the National Day of Arts in Care Homes (#AICH2023) on September 24. This annual event, launched by the National Activity Providers Association (NAPA), focuses on creativity in care settings and the ways in which this supports health and wellbeing.

Care providers and partners such as arts and cultural organisations have been invited to join in by organising events to celebrate the day. "We are very proud of what has been achieved so far during the NAPA Arts in Care Homes programme and we are looking forward to the fifth annual National Day of Arts in Care Homes on 24 September," said NAPA executive director Hilary Woodhead. "It has been wonderful to watch the support for this event growing each year and to highlight the wealth of good work... This year we also hope to identify what is most needed to develop this work going forward, in order to make arts in every care home a reality."

For further information, go to <https://artsincarehomes.org.uk>.

Grief counselling

Family carers of people with dementia have a much greater need of formal grief counselling than other groups deemed eligible for bereavement care. Findings from a UCL study of pre-death grief, published in the *Journal of Geriatric Psychiatry*, show that the need for formal counselling for dementia carers was around 300% higher than current predictions suggest.

The study found that 30% of dementia carers needed professional support rather than the 10-12% indicated by existing public health framework, which assumes most people will adapt to loss through their social networks.

Pre-death grief is described in the paper as the carer's response to "perceived losses in a valued care recipient." Lead researcher Kirsten Moore said: "Our research showed that 78% of those caring for someone with dementia reported experiencing pre-death grief. The participants cited that finding the right person to talk to wasn't always easy and that some feel they can't access bereavement services as the person is still alive."

In brief

NAPA Leadership award

JDC's owner Dementia Publishing Community Benefit Society is sponsoring the Leadership category at the NAPA Member Awards in October. This award recognises an individual who is a role model to others, demonstrates a high level of commitment, and is dedicated to excellence in activity provision. The purpose of the awards is to promote best practice in activity and engagement, and pay tribute to those individuals and teams who have demonstrated outstanding excellence in the last 12 months. The award ceremony will take place in central London on



Winning ways: Artist Willy Gilder's Self Portrait with Alzheimer's has won a prize in an art competition run by the Edinburgh Practice together with Alzheimer Scotland. Willy says: "It was painted shortly after

diagnosis and represents an amount of confusion". Diagnosed with Alzheimer's in 2021, he lives in Edinburgh and devotes his time to painting, drawing and campaigning on issues he is passionate about.

6 October. Finalists and friends will be invited to the event, where there will be some surprise entertainment and an auction. Finalists will be announced on 26 July.

Dementia Carers Count

Frances Lawrence has been appointed CEO of Dementia Carers Count (DCC) a national charity for family carers looking after someone with dementia. She has worked for charities since 2007 and has a background in fundraising. Among her employers have been the Prince's Trust, the NSPCC, and most recently the Young Women's Trust. Lawrence said that in her new role she wants to increase DCC's impact "and reach more carers than ever before." She added: "I lost my mum to dementia two years ago so I know how lonely and challenging it can be to care for someone with dementia. I am determined to make sure that people looking after someone with dementia get the information, recognition and support that they need to be able to cope."

Air pollution risk

Researchers have been awarded £500,000 to investigate the link between air pollution and dementia as they seek to understand how air pollution particles enter the brain. There is increasing evidence that exposure to air pollution increases Alzheimer's risk but the mechanisms underlying the link are unknown. The funding from Alzheimer's Research UK and Race Against Dementia was announced on Clean Air Day (15 June), and it will allow Warwick University's Dr Jake Brooks to study the properties of the particles and how they interact with Alzheimer's hallmark proteins.

Dementia friendly football

Wembley Stadium has become the first UK football stadium to be declared dementia friendly, the result of a partnership between the Football Association and Alzheimer's Society. Public-facing staff such as matchday stewards have received special training, accessibility has been improved, and the website gives clearer information about services useful to people with dementia. The FA is also backing the Society's new "Dementia Friendly Sports Clubs and Venues" guide.

Call for more Admiral Nurses

Numbers of Admiral Nurses should be more than doubled if families affected by dementia are to receive the support they need. That is the view of Admiral Nurse charity

Dementia UK, which launched the call for more specialist nursing capacity on International Nurses Day (May 12). “We hear time and time again from families who receive little or no support,” said Hilda Hayo, CEO and chief Admiral Nurse at Dementia UK. There are currently 434 Admiral Nurses working across the UK, but the charity said that at least 1,000 were required to support families when they need it most.

Benefits of arts in care

All the benefits of the arts in care are charted in a new report researched and written by Dr Hannah Zeilig and Millie van der Byl Williams. It looks in particular at the health and social impacts of “Our Day Out”, a programme of creative workshops run for older people in Norfolk over the past seven years. The authors say that the programme, designed and run by professional music and movement artists, is statistically proven to improve the wellbeing of participants. For the report, go to www.creativeartseast.co.uk/wp-content/uploads/2023/05/2016-22-External-Report.pdf.

Tech-based innovations

Projects for developing technology-based tools in collaboration with people with dementia have been awarded £1.9 million by the Longitude Prize on Dementia. Grants of £80,000 each have been awarded to 24 projects, funding innovations such as an augmented reality map to prevent people getting lost or confused, high tech specs for facial recognition, and a virtual speech assistant to fill in missing words. The prize is funded by Alzheimer’s Society and Innovate UK to help people with dementia lead independent, more fulfilled lives. It is an international competition and teams have entered from across the world including the UK.

Growth in new drugs

Novel therapies for the “treatment of agitation” and disease-modifying therapies will help drive up the annual growth rate in Alzheimer’s disease drugs to 20% over a period of 10 years from 2020, according to an analysis by GlobalData. The market in eight of the world’s major economies, including the US and UK, was worth \$2.2 billion in 2020 but is expected to be worth \$13.7 billion in 2030.

New chair for Alzheimer’s Society

Dame Suzi Leather has been made chair of Alzheimer’s Society and takes over the role from Stephen Hill in September. Dame Suzi has previously chaired the Charity Commission and held several other leadership positions in the health and charity sectors. CEO Kate Lee welcomed the announcement by the Society’s board of trustees and said Dame Suzi’s skills and experience would be “integral in supporting us to achieve our ambitious strategy and ending the devastation caused by dementia.”

Call for research participants

Worcester University researcher Rosemary Davies, who is a qualified counsellor, is looking for research participants with mild to moderate dementia to assist her

Perspectives

by Alison Teader



Shining a spotlight on arts in care provision

The National Day of Arts in Care Homes takes place on 24 September and is managed by the National Activity Providers Association (NAPA). The aim of this annual event is to highlight good work and promote discussion. It provides an opportunity for care and arts partners to promote the beneficial outcomes for care recipients, staff teams, relatives, friends, and local communities, and celebrate together the amazing work being done across the UK in this field.

Now in the fifth and final year of the Arts in Care Homes programme, which is funded by the Baring Foundation and the Rayne Foundation, we hope to continue and develop this important work in the future. To mark the end of the first five years, we’re holding Arts in Care Week, which starts on Monday 18 September and culminates in the National Day itself. It is open to anyone using arts in any type of care setting, so you can get involved by organising an arts event, sharing stories, and connecting with us and other care providers and arts organisations in free online events.

This year we’ll be giving five Arts in Care Homes prizes to events registered on the Arts in Care Homes website, so don’t forget to share your details! Just go to <https://artsincarehomes.org.uk> and look for the “Get Involved” pack on the National Day 2023 webpage. We believe that access to the arts is a human right and would like to see a person-centred arts offer in every care home.

The theme this time is “Reflections.” Care settings are invited to plan arts activities, involving all their communities and can respond to the Reflections theme in many ways. Artwork using any art form, including visual arts, dance, drama, creative writing, ceramics and digital arts to name a few, could be developed around reflections found in nature. Or artwork could be based on reflections on life and ageing, sharing words of wisdom or self-portraits. Most importantly, enjoy being creative together!

Participants may also want to take up the NAPA creative challenge for 2023, developed in partnership with Drawing Life. “Drawing On Memories” is an invitation to develop artwork based on happy memories.

As the National Day of Arts in Care Homes falls on a Sunday this year, we will also be focussing on more reflective, one-to-one arts engagement and arts role in palliative and end of life care. We have been told that this event provides care settings with lots of motivation and enjoyment - the planning and creative activities often take place over many months in the lead-up to the big day.

Please get in touch if you have any queries or want to discuss your plans. We cannot wait to see what you all come up with!

*Alison Teader is programme director,
NAPA Arts in Care Homes
alison@artsincarehomes.org.uk*

with her project at the Association for Dementia Studies. She hopes volunteers will contribute to the aims of her research, which are to improve counselling for those with a recent diagnosis by providing a better understanding of the lived experience. It will involve one interview at a time and place to suit each participant. Contact Rosemary at DAV3_21@uni.worc.ac.uk for further information.

Top employer

Alzheimer's Society has been named as one of the UK's top employers in the Sunday Times Best Places to Work 2023 survey. The charity scored highly for employee engagement and workplace happiness based on anonymised employee feedback. Overall engagement score was 86%, 13% above the industry average; 89% expressed confidence in management; job satisfaction and wellbeing scores were 86% and 85% respectively.

Dementia Diaries

Every week we hold a Dementia Diarists Zoom meeting.

We've been doing this since the start of lockdown, and have spent more than 200 hours together over that time.

It's a very relaxed group, and have become very close during the last three years. We share news, discuss topics of the moment, and sometimes we even talk about dementia. Increasingly, we have started recording diaries live as thoughts arise during our conversations.

We'd often hit upon a subject that people really wanted to talk about in more depth, but time had a habit of running away with us.

It was for this reason that we decided to hold a series of longer meetings, focused on specific subjects that people wanted to discuss. We called these meetings DEEPER Conversations, and I'd like to use the Diaries columns in this edition to tell you some more about these, and give you an idea of the kind of issues we've been covering. Here are a few of the podcasts we've created from our conversations. You can find them on Spotify here:

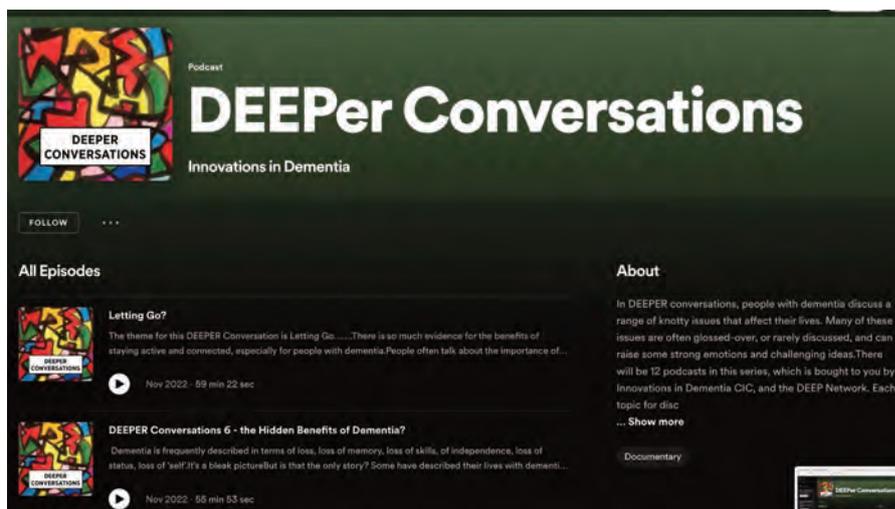
<https://open.spotify.com/show/3kYoVDIHgThHzEoZ0cJ7Y3?si=ec42e370d39847dc>

You'll also find them on Apple Podcasts here:

<https://podcasts.apple.com/gb/podcast/deeper-conversations/id1607362151>

In "What Next?", people with dementia share their thoughts about the future. Many in the group have often talked about how different their world is compared to how they *thought* it would be when they got their diagnosis. People talk about what has meaning for them, what they value most in their lives at this point, and what they want to hold onto in the years ahead. There's a raw honesty on display here, and some deep fears being expressed, along with a strong sense of hope for continuing to live well in the future.

<https://open.spotify.com/episode/52WInyq03Lz14YtnCaRqXg?si=436b39d4c6714883>



In "Once you've met one person with dementia..... you've met one person with dementia" the group explores the tension between individuality and the idea of a collective voice. People describe how their 'label' of dementia often seems to overshadow their individuality in the eyes of others. Is it any surprise that people sometimes feel themselves that the things that make them unique are being lost? Everyone experiences dementia differently, as the title suggests, but what is the implication of this for the idea of a common experience that binds people together, let alone the notion of a collective voice?

<https://open.spotify.com/episode/6InRa7Sxg9iyM7jIyUAv4E?si=2d39529ed6674007>

In "Letting Go?" we discuss the benefits of staying active and connected, especially for people with dementia. People share their thoughts and experiences of learning new things, keeping up interests, and the importance of stretching oneself. But people also talk about the importance of knowing their limits, and not putting too much pressure on themselves. How do we know when is the right time to let go, and how does letting go make us feel? The conversation also encompasses the kind of support people feel they need to keep on keeping on.

You'll find more of our DEEPER conversations at the links given above – and we'll feature one in each of our forthcoming Dementia Diaries columns.

Steve Milton is a director of Innovations in Dementia

JDC asks:

Outdoor activities can have enormous benefits for physical and mental wellbeing among people living with dementia. What outdoor activities do you recommend for this summer, now Covid restrictions have been lifted?



Left to right: Wendy Mitchell, Sean Moore, George Rook, Angela Luckett, Keith Oliver, Claire Windsor

Wendy Mitchell, Dementia Diarist and author of the acclaimed memoir *Somebody I Used to Know*:

Many people saw Covid as a negative experience and I did too to begin with; my routine of travelling around the country coming to an abrupt end. However, something very special then happened.

One day, I saw my camera, idly staring at me from the bedroom floor. From then on, each day I'd go out with my camera snapping at the wonderful world around me. Sunrise being my first walk, then another before lunch, then one after...this was my new routine. I'd post my photos each day on the village Facebook page – I didn't even know we had one pre-Covid - as I realised many had been forced into isolation and weren't able for health reasons to step out of their door.

I began to get comments saying how happy it made them, to be able to see the seasons change through my photos. Then one day, I met a villager while out on one of my walks and he addressed me as the camera lady..."Morning camera lady" he smiled.

At that point, not many people in the village realised I had dementia, so instead of sowing seeds by travelling, I realised I was sowing seeds right in my own back garden, my village. People saw my talent first, then discovered I had dementia. I also realised, how being outside, gave the impression of diluting my dementia.

Simply being out in the wide open space, instead of feeling chained to dementia in the house made me feel so much better. I'd go out exploring and was overjoyed by a single moment of a bird singing, click.... People began to say that I saw what they missed, another click.

The only certainty any of us have in this life is this very moment, no one knows what's around the corner. Dementia taught me to appreciate the moment, my camera helps me capture those special moments.. and I still post my photos each day on the village Facebook page. We all had talents before a diagnosis of dementia, we don't suddenly lose all those talents overnight when we receive a diagnosis.

Sean Moore is head of wellbeing at Summerhill care home in Kendal

Our garden-specific activities are things like bird watching and nature sounds. This is a great way of calming residents who may be having a bad morning. We have a regular gardening group made up of all our gardening enthusiasts, which plants into wellington boots and displays them around the garden. We have also done this in partnership with the local primary school.

Outdoor games are another great way of getting a group of residents together, like outdoor exercise classes using beach balls and beanbags, along with giant Jenga and connect 4. We also have paper boat making competitions, which involves making simple boats and then testing them in our paddling pool.

Flower arranging is another activity which is always very popular. These can be flowers picked from the garden itself or you could contact a local supermarket or florist to ask for any flowers they have left over.

A garden scavenger hunt is another great idea. We have an A-Z list of things to spot while out in the garden printed at the entrance, so staff and visitors can do this while walking round the garden. Any chance we have to get family and friends involved is always very beneficial for both the resident and their loved ones.

A smoothie station is also a good addition in the summer, but rather than just serving residents the smoothies, it's a good idea to get them to choose fruit by playing a game - maybe by throwing beanbags into hoops which have fruit designated to them.

George Rook, a Dementia Diarist who lives in north Shropshire:

Trees. Research has shown that just having trees in view improves wellbeing. So go find trees to look at. Sit under a handsome tree. Get to know it. The bark, the leaves, the branch shapes. Rustling, booming, whispering, buzzing.

Sit in an open space...could be a park, or wasteland, or by a river, or in a field...anywhere, and listen. Hear birds, or distant vehicles, airplanes or thunder.

Smell. Dip your nose into flowers. Pinch a leaf and sniff

it. Waft the aromas into your nose.

Look. See what is going on around you. People walking by. Bees and insects floating along. Shapes of leaves and flowers. Grass beneath your legs.

And touch everything you can. Is it smooth or rough, slippery or abrasive?

And when you have time and interest, find out the names of what is around you. Books or apps. Apps can identify from a photograph, or from a birdsong.

Just take time to stop and take it all in.

You will be rewarded.

Angela Luckett, experience & cultural co-ordinator at Belong Morris Feinmann care home in Manchester:

Since Covid restrictions have been lifted, we all understand the benefits of any outdoor pursuits. From sitting in the sunshine, to soaking up nature and going from there into a sensory session, a reminiscence session or simply a cup of tea or coffee with friends. The socialisation, the physical wellbeing and the mental health benefits are huge, as we have seen.

All our residents are encouraged to walk and take exercise, joining in during the summer months. As soon as we can, our doors are flung open and anything from quizzes, art, bowls, gardening, storytelling to music sessions is put on, hosted either in our main garden or our roof garden.

As the weather improves and we approach the height of summer, shady places are imperative in our outdoor space. Music acts as a healer, a reminder, an emotion and a journey that all our residents, from our most vulnerable to our most able enjoy all the more in our garden.

Invitations are sent out to local music schools, to local orchestras and opera singers in our area. We shout from our rooftops Dementia UK's ethos, that "music is our medicine"!

Our Amazon Alexas are one of our most valuable assets on a quiet day. Create a music playlist, taking our residents choices on board, and off we go! A burst of sunshine is exactly what we prescribe.

Keith Oliver is an Alzheimer's Society Ambassador and member of the 3 Nations Dementia Working Group Steering Group.

As spring moves into summer hopefully time outdoors becomes increasingly appealing. For me walking and talking is a central part of my care plan as it engages me with the environment I am walking through, alongside a stimulating conversation with a family member, friend or student supporter.

The physical exercise derived from walking is beneficial but also stopping to pause, relax and absorb what I am seeing and listening to is good for the body and soul, and

to share this with someone is both enjoyable and enables the memory to stay longer through the conversations we have.

Often I will keep to the same route but occasionally deviate from this to provide a little extra challenge. Covid and lockdowns made this a very solitary and unrewarding pursuit, so I am pleased and relieved that it is once again a part of the "new normal" for me. Activity such as walking is energising, and keeps me grounded, appreciating the area where I live as travelling far and wide is now very difficult for me.

Irrespective of the weather or Covid, our garden magnetically draws my wife and I into its magical, colourful world. The activity will differ according to the weather and time of year. This ranges from physical heavy lifting, mowing and digging, through to planning and planting, and then making sure to enjoy the garden sitting with a cuppa.

Keith would like to acknowledge Ashley Main, an undergraduate on placement who supported him in writing this piece.

Claire Windsor is activity co-ordinator at Amy Woodgate House in Chessington, Surrey.

We encourage our residents to be outside to enjoy our beautiful gardens and summer house. We believe that having activities outside benefits our residents' wellbeing greatly.

Activities we do inside can also be carried out outside, such as reading a book or magazine, immersing oneself in creative arts and crafts, memory jogging quizzes, and reminiscence to boost mental health.

Going outside and getting some much-needed vitamin D and fresh air, especially on a bright, sunny morning can help people with dementia improve their functioning, make them more alert, lower their risk of falls and reset their body's internal clocks, not to mention relieving stress, providing a more positive psychological functioning.

Our memories are often linked to certain locations, objects, activities or even smells. The outdoors can provide excellent memory triggers which can take people back in time when they were younger, visiting local events, church services, or even just a trip to a café shops can bring back some great memories.

Sensory activities, such as bird watching, gardening, eating outside, having a farm and animal therapy day or just listening to music can improve mood, encourage relaxation and trigger many positive memories.

Gentle exercises, gardening, walks, playing ball games can improve wellbeing and cognitive health in many ways, and boost self-esteem, as well as aid sleep. Three cheers for summer!

Effective ways to engage with people living with dementia

A dementia diagnosis is not evidence of an inability to communicate and the principles of the Mental Capacity Act should always be respected.

Liz Leach-Murphy and **Jayna Patel** (L to R below) discuss effective ways to engage with people

Imagine the case of “Angela”, who is living with dementia. She takes a while to think about what she wants to say and to find the right words when replying to people. Her support worker notices that people in Angela’s life are answering questions for her when there are long gaps



between someone asking her a question and her response.

Her support worker believes that people are answering on Angela’s behalf to help her; some feel uncomfortable with the long silences and other people are answering as they think Angela can no longer answer questions.

Concerned that Angela is losing her opportunity to express herself and that people around her are losing their chance to fully understand her and her preferences, the support worker discusses the matter with her family. They also encourage everyone to give Angela time to answer. By doing this, the group begin to appreciate that some answers given on Angela’s behalf aren’t quite what she wants.

Communication and capacity

Assuming that people living with dementia like Angela can’t answer questions, is to assume they can’t make decisions themselves. This couldn’t be more untrue. Many people with dementia are more than capable of self-directing their support and care, and making decisions about their lives, particularly in the early and mid-stages of their condition.

The assumption of this decision-making ability is enshrined in law, namely the Mental Capacity Act 2005. Two of the Act’s five core principles are:

- A person is assumed to have mental capacity until it’s proven otherwise
- All practical steps must be taken to help the person understand the decision they’re making and the options available to them.

A dementia diagnosis is not evidence that capacity has been lost. So, how do we ensure we hold ourselves in check when supporting someone with dementia and avoid assuming they’ve lost capacity?

Liz Leach-Murphy is founder and managing director of Imagineer Development UK and the National Brokerage Network. She has over 25 years’ experience working in health and social care. Jayna Patel is an editor and content writer for health and wellbeing app Evergreen Life



The answer is communication. It’s paramount we take the time to understand how a person processes information and expresses their wishes. Only then do their preferences stand a chance of being honoured.

Methods of communication

Over the last few decades, huge advances have been made in communication methods that can be adopted when supporting people with dementia.

For example, symbols can represent everyday objects, feelings, and people to aid decision-making and conversation. If someone with dementia thrives communicating with symbols, these should be available during the conversation so that they can be shared to represent what’s being discussed. They can also be visible in the environment, on wall charts or in clear plastic wallets so the person can refer to them to express what they need or want.

Talking Mats use symbols to create a story or question (**see article in this issue**). The symbols are positioned on a mat in an order that represents the conversation or question. For instance, if someone with dementia who prefers to communicate this way had been swimming, the story about going swimming would be organised on the mat to aid the conversation about the experience and establish information such as: Was it enjoyable? Would they like to go again? Does anything about the experience need to change for it to work better for them?

Pictures that are relevant to the person can facilitate

Key points

- Answering questions on behalf of someone living with dementia is to assume they can no longer make decisions for themselves
- A dementia diagnosis is not evidence that mental capacity has been lost
- Only when we take the time to understand how a person processes information and expresses their wishes can the core principles of the Mental Capacity Act be honoured
- Over the last few decades, huge advances have been made in communication methods that can be adopted when supporting people with dementia

effective communication. Choosing images carefully is important to ensure that person responds to them positively. To select the right images, a deep understanding is needed of the person's interests and passions, and of the people and times that are important to them.

Through their work with people with dementia, a community interest company called Pictures to Share have found that it is effective to utilise images offering:

- Beautiful and vivid colours or subjects
- Strong photographic or painting style
- Human or animal subjects looking directly at the viewer
- A strong sense of narrative that encourages storytelling
- A strong line or sense of texture that will encourage tactile exploration
- A depiction of positive emotions, like happiness
- Humour that doesn't require sophisticated interpretation.

Images to be avoided as possibly triggering feelings of anxiety or distress that someone with dementia may be unable to rationalise are:

- People in an aggressive or distressed state
- Vulnerable people or animals at risk.

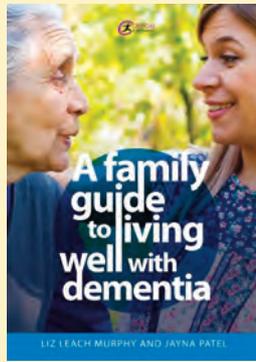
iPad and touchscreen technology can aid communication and decision-making, and open new avenues to record people's lives and achievements. Technology can support recall, increase interpersonal interaction and intergenerational communication, improve relationships and quality of life and be easy for people with dementia to use. It's not uncommon for speech and language therapy departments to lend equipment to people with dementia to try before they and their carers decide whether the purchase is worthwhile.

People with dementia can also develop their own approaches to communication. Familiarising themselves with this preferred method of communication can help carers fulfil the second principle of the Mental Capacity Act, namely fully informing the person they support about all the options available in a manner they understand.

Beyond words

It can be beneficial to consider the idea that building an understanding of a person and what they value doesn't always require talking; spending time together, watching and learning can work just as well. This was the case for "Philip", who struggled to respond to direct questions and would easily become distracted by things happening around him. The inability to convey his preferences naturally led to feelings of frustration for him.

When it was thought all communication methods had been exhausted, his person-centred planning facilitator suggested Philip and his family carers meet in the local town where he had spent most of his adult life.



Our new book *A Family Guide to Living Well with Dementia* is an easy-to-follow and accessible guide to help people gain knowledge and insight to be able to support a person with dementia live the life they wish. It stresses the role of person-centred approaches to dementia care and includes chapters on the shape of care and support, support during the later stages of dementia, and understanding behaviour and communication. It is published by Critical Publishing.

They went to a local café that Philip used to frequent. On the way, the person accompanying him noticed how much Philip was looking around and gazing into shop windows, and how he seemed to enjoy being back in the town.

Philip's enjoyment was discussed with him in the meeting, and he decided that, rather than spend time in the café, it would be good to revisit some of the places he used to regularly go into, such as the post office, greengrocers, and local shops. So much was learnt on this visit about the friendships Philip had in the area, the shops he loved, the items that captured his attention, all things that could help personalise his future support.

Behaviour as communication

Attention to the smaller details being communicated through a person's actions can often be overlooked. Honouring simple everyday preferences makes a difference to how a person feels: their wellbeing, self-esteem, and sense of security.

Take the case of "William", who was on a general medical ward. Staff caring for William, who had advanced dementia, described him as confused and "wandersome". He seemed anxious and touched his face constantly. Frequently, he was found walking towards the bathroom in his dressing gown, so staff would help him back to bed.

But a student nurse working with William recalled her university training along with her "dementia friends champion" role, which led her to believe that William wasn't "wandering" without cause, and that there was something that interested him in the bathroom.

After talking to him, it became apparent that all he wanted was a shave. He was accustomed to shave every Sunday but hadn't done so for weeks. He had been wearing his dressing gown to go to the bathroom, which had a shaving brush and a safety razor in the pocket. The student nurse found some shaving foam and accompanied him to the bathroom, helping him to foam his face. She then left him to shave, checking on him regularly.

Although William had dementia, he wasn't at risk of falling or a danger to himself with the razor. He knew what his needs were, and simply needed help to meet them. For the rest of the day, he was calm and chatty, and there was no "wandering" or anxiety.

Regardless of the communication methods chosen by the person, it is only when those around them are open to listening, observing and exploring that the Mental Capacity Act can be implemented in practice.

Talking mats: The power of simply being heard

Talking Mats can support conversations on a wide variety of topics. **Paula Douglas** explains how this tool helps people with communication difficulties express their views and have more control.

Talking Mats is a social enterprise with a clear vision and has been trading for over 20 years. It has found a significant role as social care services increasingly strive to make the delivery of services reflect the opinions of those who use them.



Developed in the University of Stirling from research by a team of speech and language therapists and people with communication difficulties, Talking Mats is a research driven, person centred, innovative, visual approach to communication. Margo MacKay, Talking Mats' managing director, describes it as "simple but not simplistic".



Listener

Thinker

Completing a mat involves a listener (usually a practitioner) and a thinker (the person expressing their views). A topic is agreed and a structured conversation carried out using symbols to represent options within that topic. Symbols are placed by the thinker along a scale, from positive to negative, and a picture of their views is created.

Talking Mats symbols can support these structured conversations on a wide variety of topics and cover all age groups, but those most relevant to people with dementia include health and wellbeing, social care, eating and drinking, advance care planning and foot health.

UK legislation emphasises the need for individuals to be included at all levels when decisions about their lives are being made. Talking Mats can help to make this happen.

Paula Douglas is communications and marketing lead at Talking Mats.

Key points

What is a Talking Mat?

A communication tool in physical and digital formats

Why is it needed?

Talking Mats put the person at the heart of care planning, helping to support shared decision-making

How can the symbols help people with dementia?

Symbols based on the WHO International Classification of Functioning help a person express their views about everyday life as well as their care. Within service evaluation, it allows everyone to have a voice

What difference can Talking Mats make?

Research shows Talking Mats help people to say more and the quality of what they say is improved.

For example, Hallmark Care Homes used Talking Mats in their annual survey and used the findings to implement changes across their services. Inspectors from the Care Quality Commission (CQC) recently trained in Talking Mats and are using this approach as part of their audits of care services across England and Wales.

The theme that recurs in projects looking at Talking Mats and people with dementia is that adopting this approach helps people to say more and the quality of what is said is improved. It does this by:

- giving control to the thinker
- breaking topics down and allowing the thinker time to process
- developing self-identity by expressing opinions
- supporting memory by referring to the symbols.

Caring for someone does not solely involve asking questions about aspect of their care; creating a relationship is as important and can help reduce isolation felt by both the person with dementia and their families. John Locke (1998) stated that "small talk" is crucial for the construction and enjoyment of relationships. The ability to verbally express thoughts and opinions is often lost quickly in the progression of dementia. Sharing opinions is a way of maintaining that crucial human bond and highlighting

that having dementia is only one thing about a person, not the whole thing.

The most powerful way to understand the impact Talking Mats can have is to hear what people say about it. One person told researchers: "It was nice to talk about things. We never seem to do that any more but the pictures really helped us do it." Another said: "That is what I think, right in front of me; I don't have to rack my brain to remember" (Murphy *et al* 2007).

A Hallmark dementia care practitioner involved in the annual survey initiative put it like this:

I really believe this gives a way to hear everybody's voice you know We all sit here with our preconceptions but actually this isn't about us. This is about us hearing the voice of our residents that wouldn't have been heard if we hadn't of used TM as part of the survey.

Or as James McKillop, who lives with dementia, remarked: "I think it's an amazing thing; something so simple could be so useful to people."

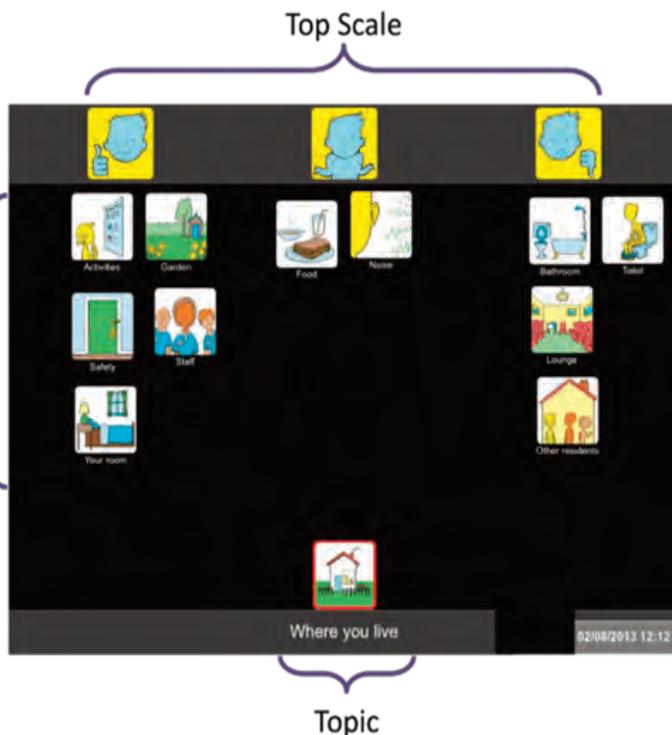
More information about Talking Mats, our resources and training can be found on our website www.talkingmats.com.

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Options



Talking Mats in action



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Dementia friendly care homes

An audit by people with lived experience

Dementia friendly audits have become more common in various settings, but less so in care homes. **Toby Williamson** describes a ground-breaking care home audit, while lived experience auditor **Chris Maddocks** and KYN head of dementia **Emma Hewat** (L to R below) give their perspectives.

KYN is a new care home organisation and has just opened its first care home in Bickley, south London, with space for 85 residents. It aims to combine the quality of service and customer care associated with the upper end of the hospitality industry with professional, person-centred residential care for older people, including people living with dementia. Further KYN homes are due to open in Fulham and Kensington in London over the next couple of years.

Features of the Bickley home include a spa treatment facility, a bar serving alcohol, and using unobtrusive technology to enable care and support to be provided in an individualised way when it is required. Hospitality and domestic staff being able to put into practice person-centred care is considered just as important as care staff being able to do the same.

Good practice in making a care home dementia friendly needs the active involvement of people with lived experience of the condition. So KYN asked me to coordinate a dementia friendly audit of the home before it



opened, by people with lived experience. Staff, especially head of dementia Emma Hewat, were closely involved in the audit (see box).

Preparing for the audit

Through various networks I invited three couples to undertake the audit.

Each couple included one person diagnosed with dementia. One of the couples included Chris Maddocks and her partner (see box).

None of the couples needed residential care so it was important to try and ensure that those individuals with a diagnosis would be comfortable doing the audit, given that being in a care home could raise thoughts about how their dementia might progress.

No previous dementia friendly audit experience was required; they were all capable of giving feedback, with support, and their views about the type of environment and assistance they would want if they had to move into a care home would be potentially invaluable to KYN.

Audit tools

Although I had occasionally heard of local initiatives involving quality checks on care homes by people with lived experience, I couldn't find any published reports or research about audits exactly like this. I found audit tools for professionals to assess the dementia friendliness of care homes (Kings Fund 2014) and tools for people with dementia to assess the dementia friendliness of generic indoor spaces (Innovations in Dementia *et al* 2017), but there appeared to be nothing focused on care homes that could be used by people living with dementia.

In conjunction with KYN I therefore devised a list of plain English questions for the three couples (the "auditors") to guide their feedback during the audit, which they could use with other ways of recording their views as they preferred. This was discussed with the auditors before the audit took place, as well as collecting essential information (eg, dietary requirements and relevant support issues regarding their dementia) and providing them with clear and comprehensive information about their role and what to expect during the visit.

Feedback was welcomed from both the person living with dementia and their partner, but the emphasis was on the former, so the aim was that they would act as "critical

Summary

Over the last 10 years there has been growing involvement of people with lived experience of dementia in helping ensure that services and organisations are dementia friendly and accessible. This has been a welcome development, yet actively involving people with dementia in making care homes dementia friendly and inclusive has proved more challenging.

Factors such as the severity of dementia experienced by most care home residents, pressure on resources, and a focus on meeting Care Quality Commission (CQC) requirements are not conducive to lived experience involvement initiatives and it is difficult to find any examples.

However, a new care home organisation, KYN, invited people with lived experience to undertake a dementia friendly audit of its first care home just before it opened. Here, I describe how the audit was done, some of its findings, and give a perspective from one of the people with lived experience, as well as from a senior manager at KYN.

Toby Williamson is an independent consultant
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friends” with their partners. A programme of activities was prepared in advance for their stay and the auditors had different ways they could give their feedback (on paper, orally, etc), both during the audit and after it took place, including anonymous feedback via myself.

Audit visit

The audit involved the three couples and myself arriving at lunchtime and staying overnight until lunchtime the next day, with all meals and drinks provided, and took place in January 2023. The stay was complimentary, courtesy of KYN, and the auditors were also paid a small fee to acknowledge their contribution.

As the auditors didn’t need the level of care provided by the home and this hadn’t started at the time of the audit in any case, the auditors were asked to focus on the physical environment, hospitality services, activity taster sessions and the general conduct of staff. Before the audit took place, they were also asked to complete KYN’s draft life story document, “My Memoirs,” so that their stay could be individually customised, but also in order to receive feedback on the document.

Several KYN staff talked about their roles with the auditors. There was a tour of the building and garden, and the home’s use of technology including in residents’ rooms was explained. A film was shown in the cinema room in the evening, and a “taster” art session was put on for the auditors in the home’s activity room.

Auditors’ feedback

The audit was very successful on a number of levels. The auditors’ stay in the home passed off smoothly and all of them expressed their thanks and appreciation to KYN for making them feel safe and comfortable. Some of the

Key points

- While dementia friendly audits of buildings and services by people with lived experience have become quite commonplace, they have seldom been attempted in care homes
- We conducted such an audit: six people with lived experience did a 24-hour, overnight stay in KYN’s new care home. They gave meaningful feedback and comments about how dementia friendly they found the home and suggestions for improvement, and enjoyed doing the audit
- KYN were very pleased with the feedback which covered the home’s physical environment and design, assistive technology, interactions with staff, hospitality services and activities
- Lived experience audits like this require careful preparation, appropriate support before, during and after the audit for participants, and dementia friendly audit tools and methods to enable people to feed back their views.

auditors commented on how progressive it was of KYN to support an audit of this nature; they also appreciated how well organised it was and how they felt well supported in doing the audit, including pre-audit preparation and debriefing afterwards.

For various reasons there were some changes to the planned timetable which meant that there was less down time for the auditors to look round the home at their leisure



A bedroom at KYN Bickley

Comment: Chris Maddocks, lived experience auditor

As someone living with dementia I believe that audits by people with lived experience are a really good way of making services better for people with dementia. So when Toby asked me to audit KYN's care home, initially I was happy to say yes.

But then I thought "do I really want to go and spend a night in a care home," because I was worried about what it might be like and how it would make me feel. And then I thought, "yes you do, go and check it out," and I'm pleased I did because I feel much better about care homes now.

It was a really good experience and I think the feedback we gave was positive and fair. I hope they didn't take it as criticism because the place was outstanding. The food was amazing, the staff were so kind and so helpful, and nothing seemed to be too much trouble. Having an Admiral Nurse based at the home was excellent, as was My Memoirs to get to know people before they moved in, and KYN seemed to be very person-centred.

We had different opinions but we all agreed it would be good to include additional space for physical exercise in the home. The audit was quite tiring and it would have been good to have had more time, but the support and reassurance we were given was needed, and it was spot on. I would definitely be willing to do another audit like this.

and give their feedback. This was an important reminder for me about being careful with the amount of information and activity for auditors to consider, or alternatively (as some of the auditors suggested), starting the audit earlier on the first day or finishing it later on the second.

Overall, the auditors were very impressed with the quality of the care home environment and hospitality services, and the friendliness, support, and professionalism of the KYN staff they met. KYN's attention to detail, including a customised welcome present for the auditors based on information they had given in My Memoirs, the choice and quality of food, and the arts activity session were all greatly appreciated, as was for some, the bar! As one auditor put it: "Overall it was a lovely, lovely place, absolutely gorgeous, and the staff were really, really good."

The auditors made a number of observations and comments about the home where making changes could enhance its dementia friendliness, or could be built into the planning of future homes. They also suggested improvements to My Memoirs. All understood that part of KYN's ethos was to create a homely and comfortable environment and to maximise the use of unobtrusive technology for the purposes of care, but they made a number of suggestions to ensure greater accessibility and inclusivity for people with dementia.

One issue that the auditors agreed on was the need for additional space for physical exercise, as well as the existing studio space, recognising the beneficial effects on dementia and falls prevention of maintaining good physical health.

The final report made several recommendations to KYN and the comments here from Emma Hewat indicate how these have been acted on since the audit was done.

Comment: Emma Hewat, KYN head of dementia

KYN is new to the care home sector and KYN Bickley, its first home, is led by a highly experienced team. Much time has been spent during the last four years creating an impressive and beautifully appointed home.

However, in line with the KYN value, "Think Harder", we realise there is always an opportunity to learn more and that everything can be made a bit better by thinking a bit harder. The lived experience audit forms part of this open culture of learning and reviewing.

My expectations when commissioning the audit were that we would hear honest, meaningful feedback from people living with dementia about any suggestions for improvement. I believed this would have more impact than just reading the latest best practice guidance, and that the team would embrace these ideas and learn for future builds.

Naturally, I had some concerns before the audit took place, particularly about potential criticisms, and ensuring the safety and comfort of the auditors. Thankfully, partly through good planning and preparation, none of these concerns were realised. The report and experiences of the auditors were well received by colleagues, who were all keen to support ways of implementing the recommendations both at Bickley and future homes.

KYN takes a holistic approach to our work, paying particular attention to resident wellbeing, including their physical health, and since the audit we have identified additional space within the home for physical exercise to take place.

I really valued the feedback from the auditors which has contributed to KYN's value of thinking harder. I was pleased with how the audit went and we will be conducting further audits on future builds.

Conclusion

Undertaking a dementia friendly care home audit involving people with lived experience is fairly groundbreaking and comes with some risks for everyone involved, regarding both process and outcomes. This audit demonstrated that, through careful planning and preparation and good communication and support, people with lived experience of dementia can provide important and meaningful feedback and advice on how to make a care home more dementia friendly.

KYN had already put a lot of thought into this before the audit but are to be commended on commissioning the audit and responding positively to the recommendations. And all the auditors are to be thanked for their participation and excellent feedback that made the audit so worthwhile.

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Dementia: Post Diagnostic Support, early evaluation

Patchy post-diagnostic support can lead to feelings of abandonment among people newly diagnosed with dementia. **Ruth Cook** reports on a new multi-agency post-diagnostic support service designed to help people adjust to their diagnosis.

In recent years the need for support following a diagnosis of dementia has been widely recognised. “People diagnosed with mild to moderate dementia [should] receive information and psychosocial interventions to improve their ability to ‘live well’” (Van Horik *et al* 2022)



In Northumberland, an efficient and long-standing memory assessment service facilitates the assessment and diagnosis of dementia. Following any diagnosis, pharmacological treatments can be initiated as appropriate before the individual's care is handed over to primary care. However, only one post-diagnostic appointment is offered, where patients are signposted to non-statutory services and provided with verbal advice and written information packs before discharge.

Feedback from people with dementia and carers using this service is that they have feeling of abandonment, a sense of being dropped off a cliff and being left to get on with it. In addition to this feedback, we know that psychosocial interventions can be helpful at this time. There is evidence that “people living with dementia who obtain access to dementia-specific services early in their dementia journey can improve their ability to live independently” (Department of Health 2009).

Moniz-Cook observed that dementia has a major impact on the lives of people and their families, but that people often postpone asking for help (Manthorpe & Moniz Cook 2020). We know that, although there are some support services available, “fragmentation of care services further hampers the scope for people and families to find support” (Manthorpe & Moniz-Cook 2020).

In answer to these problems, our new post diagnostic support service – launched in early 2022 in Northumberland - is facilitated in partnership with Alzheimer's Society and with Carers Northumberland. We hope that this joint approach will go some way to “de-fragmenting” care services and ensuring that people are linked up with services before they really need to ask for help. Cumbria, Northumberland, Tyne and Wear NHS Trust (CNTW) is the lead organisation.

We recognise that the diagnosis of dementia should be followed by some sensitive education around the diagnosis and adapting to the impact that the progression of dementia

Summary

At present there is only one commissioned post-diagnostic offer to support people recently diagnosed with dementia in the north of England. This service began in early 2022 with Cumbria, Northumberland, Tyne and Wear NHS Trust (CNTW) as the lead organisation working with partners.

The aims of the support include improving patients' and family carers' experience, reducing the fragmentation between statutory and non-statutory services, improving social inclusion and reducing referrals into specialist secondary care mental health services.

Support offered includes memory groups as well as domiciliary support depending upon individual need. The interventions should be evidence-based and the efficacy of the support needs to be measured to inform continuing service improvement.

This initial service evaluation looks at the first year of the service, what we have learned from it and what our next steps are. As is often the case we recognise that although we have positive outcomes so far, there is a need for more long-term evaluation and research into the efficacy of this psychosocial intervention.

will have on both the patient and their family and caregivers. It includes support in understanding the emotional effects as well as practical and social implications.

A range of non-statutory organisations exist but our experience tells us that simply signposting people to these services is ineffective and, as people report feelings of abandonment, potentially damaging. In Northumberland, the commissioners agreed some funding for a post-diagnostic pathway in early 2020, based on a joint proposal from CNTW as the lead provider and its third sector providers.

A stepped model was agreed:

Step 1 Generic older adult roadshow (multi-agency)

Step 2: Dementia specific roadshow (multi-agency)

Step 3: Memory support group provided by CNTW

Step 4: Community Treatment Team (CTT) intervention in secondary care to manage risk and complexity in relation to mood and behavioural disturbance.

Ruth Cook is an advanced clinical nurse practitioner at Cumbria, Northumberland, Tyne and Wear NHS Trust.

Step 3 of the model

We will focus here on Step 3 of our new post-diagnostic model, a memory support group provided by CNTW. We already had local evidence in relation to running memory groups through a series of pilots run by North Northumberland Older Adult Community Treatment Team (CTT) staff. There had been several pilot programmes, through which the model had been gradually amended based on feedback.

The final programme included seven weekly sessions for the person with dementia and their caregiver in a group format and content covered practical and emotional topics following diagnosis. The intervention was evaluated internally with positive service user feedback, giving us a good platform from which to launch and develop our own post-diagnostic support offer.

This is “step 3”, known simply as “post-diagnostic support” and aiming to go wherever the need is in Northumberland. We acknowledge that this is a limited intervention, in terms of time and number of sessions, and in its focus just on the person living with dementia who has a carer to support them.

Step 3’s target group is those people who need some additional support to adjust to a diagnosis, but are who are not so complex that they require CTT interventions (step 4). So far about two in every three referrals have come from the Northumberland Memory Service (NMS) and the remainder from CTTs across the localities.

Three experienced mental health community practitioners were recruited for step 3. At an initial home visit the intervention options will be discussed and a care plan agreed, the intervention being a blend of educational, emotional, peer and social support. Agreement is also sought on goals, which include gaining an understanding of dementia and the available local support networks, getting connected with Alzheimer’s Society and Carers Northumberland, and meeting other people with a similar diagnosis.

A further facet is developing an individual “living well plan” that should contain pertinent information and advice, as well as more general information and contact details for local support services. The literature suggests that a diagnosis of dementia should be followed by a management plan for the short and long term, to maintain optimal function and quality of life for as long as possible (Reynolds 2022).

Memory groups or home visits

Attendance at a course of seven memory groups, facilitated by the registered mental health practitioners, is the preferred step 3 approach. As far as possible local venues are booked – church halls, community hubs, and the like. Groups are informal, with tea and biscuits an essential element, and each session tackles a different topic.

Among the benefits of joining the memory groups is that participants have the opportunity to question a consultant psychiatrist about dementia, discuss emotional responses with a clinical psychologist, find out about medications and delirium from an advanced pharmacist, and learn from a specialist mental health occupational therapist, who attends to discuss practical tips, aids and staying safe.

Taken together these topics form the basis of

Key points

- A new post-diagnostic support service for people newly diagnosed with dementia in Northumberland
- Service helps people to engage with non-statutory community support
- A multi-agency stepped care model promotes understanding of the diagnosis and the range of services that can provide support
- Memory groups enable peer support and discussion
- Service evaluation is ongoing to inform how the service needs to evolve to provide best outcomes.

understanding and managing dementia, widely seen as good practice (eg, Bamford 2021). The professionals mentioned so far are all employed by CNTW, but our partners Alzheimer’s Society and Carers Northumberland also each lead a session to explain the nature of the support that they can offer. The final session is an opportunity to reflect on the sessions, look at living well plans and exchange contact details should the participants wish to. If available, Alzheimer’s Society can support with these final sessions to assist the transition from statutory to non-statutory services.

Attendance at the memory groups is also a social opportunity to challenge the stigma associated with dementia. It is a chance to meet other people in similar circumstances and share experiences and ways of coping, and participants are also encouraged to attend local dementia cafes and community-based social facilities. We know that initiatives focusing on the social needs of people with dementia are highly appreciated (Manthorpe & Moniz-Cook 2020) and that social disengagement may set up the path to more rapid decline (Reynolds 2022).

If for whatever reason people do not wish or are unable to attend a group, then the second option is that the mental health practitioner will facilitate a domiciliary intervention to replicate the content of the groups. This includes a final domiciliary visit before discharge from CNTW, in which any loose ends are tied up and the living well plan is completed to the specification of both patient and carers.

It must be admitted that domiciliary visits cannot reproduce the richness of the groups and the peer support, but it is also evident that we simply don’t have the resource for everyone to attend the groups anyway. Too many participants would risk losing the supportive element of the groups.

Feedback

We are aware that research on the outcomes of interventions like ours is sparse, so we have sought feedback both from the memory groups and the domiciliary visits. This has been largely positive. Comments include:” [Facilitators were] interested in us as a couple”; “Information helps, I am in a better position”; and “[We have] a better understanding of the condition.” Some comments have made us think about how best to ensure our support is tailored to individuals, eg, “[I] would

have preferred more separate carer time,” and, “Not enough detail about the journey.”

Across the county we have received referrals for people with young onset dementia and we are working with them to provide a more bespoke experience. It is another area requiring research and careful evaluation.

Overall, we have gone some way to improving the experience of post-diagnostic support for people with dementia and their carers, but we need further evidence to clarify exactly how far we have come. Importantly, we need to be prepared to evaluate the support against service user and carer feedback and against current literature so that we can understand how to develop the service further.

And we want to find out more about the longer-term impact of this kind of intervention. A formal service evaluation is to be carried out over the next 12 months in an attempt to gain some initial qualitative information about the extent to which it supports people to live well and how it can be improved. A proposal has also been submitted to gather feedback from younger people living with dementia and their caregivers to identify areas of service development required to better meet their needs.

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Chess as a form of cognitive stimulation: A reflective piece

Cognitive stimulation can be an effective way to reduce cognitive decline and improve wellbeing. In this reflection on her case study of “BW”, **Natalie Peake** considers the potential of chess as a form of cognitive stimulation in older adults

Current clinical practice in the North Cumbria Memory and Later Life Service at Cumbria, Northumberland, Tyne and Wear NHS Trust relies on pharmacological interventions to treat cognitive decline. This has significant implications for the post diagnostic support the service is able to provide, as pharmacological treatments for cognitive decline are diagnosis-specific. Cholinesterase inhibitors and memantine are only routinely prescribed for a diagnosis that contains elements of Alzheimer’s disease (AD) or Lewy body dementia, and work to slow the rate of cognitive deterioration in the face of progressive decline.

For some patients these medications can help stabilise cognitive decline for a time, but they do not stop the progression of the disease completely. I have supported a considerable number of people who have experienced significant side effects when trialling memory medications or have been unable to tolerate the therapeutic doses needed to slow the rate of deterioration. Consequently, they have not received the cognitive protection these medications might have provided.

In other cases, physical health problems or lack of social support has prevented patients under my care from trialling these medications in the first place. And for those diagnosed with a vascular dementia, where medications are ineffective, educational support is provided in the form of a post-diagnostic feedback session, but no formal preventative treatment is available other than medications to control vascular risk factors.

Similarly, for those with a diagnosis of Mild Cognitive Impairment (MCI), follow-up reviews are completed at six and twelve months to monitor any cognitive deterioration, but no preventative treatment is available despite the well evidenced fact that individuals with this diagnosis are at higher risk of developing a dementia (Knopman & Petersen 2014).

Cognitive Stimulation Therapy

The only currently accepted and evidence-based non-pharmacological intervention that targets the rate of cognitive decline is cognitive stimulation therapy (CST), which has protocols developed and designed to treat those with a mild to moderate dementia.

Since its introduction, CST has been shown to reduce the rate of cognitive decline while improving wellbeing and life quality for those with a dementia diagnosis

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Summary

Cognitive stimulation is the act of exercising the brain to strengthen cognitive functioning with the aim of building cognitive resilience to reduce the risk of further cognitive decline. The very limited research that has examined the effectiveness of chess as a form of cognitive stimulation has shown some evidence to suggest its efficacy in improving cognitive functioning and preventing further deterioration for older adults diagnosed with cognitive difficulties.

Here, I will consider a case study of “BW”, a 78-year-old retired university lecturer, who was diagnosed with a mild cognitive impairment (MCI) with a vascular aetiology. BW expressed the view that if his cognition or intellect worsened, life would no longer be worth living.

BW was therefore engaged in a series of six chess cognitive stimulation sessions to assess the game’s efficacy in building cognitive resilience. Cognitive and wellbeing assessments were taken at baseline and upon intervention completion where results suggested improvements in both cognition and wellbeing.

Tailored cognitively stimulating interventions may help to prevent and slow down the rate of cognitive decline in older adults experiencing cognitive difficulties. Further research is needed to understand the effectiveness of such interventions in order to draw more conclusive findings.

(Lobbia *et al* 2018), especially when coupled with pharmacological treatment (Devita *et al* 2021). However, no current evidence based treatment has been developed for those with a diagnosis of MCI to target the early stages of symptom expression.

A recent trial was conducted by Xue *et al* (2021), who used game training for older adults with MCI and depression. Sessions lasted for 50 minutes and were conducted three times a week for eight weeks. Game training tasks included memory games, solitaire, group and partner games, poker, puzzles, and board games. Significant improvements were observed in cognition, as measured by the Montreal Cognitive Assessment (MoCA), notably in relation to naming, attention, language, and delayed recall, and depressive symptomatology as measured by the Geriatric Depression Scale.

In spite of these positive findings, the evidence basis for non-pharmacological interventions that target the rate of cognitive deterioration is still a work in progress. Given

the lack of cognitively stimulating treatment options provided by our Memory and Later Life Service, I conducted an initial person-centred exploration that used the game of chess for the case of BW and here I reflect on the results from that intervention. I hope that it will lead to further research with a view to advancing current clinical practice in the service.

Playing chess activates high level thought processes such as forward and critical thinking (Dania *et al* 2021), while also stimulating visual memory (Smith *et al* 2021), calculation (Mel 2021), problem-solving (Atherton *et al* 2003), shifting attention and processing speed (Pfortner & Hristova 2021).

Case study: BW

While working for the service, I was presented with the case of BW*. BW, a 78-year-old retired university lecturer, was diagnosed with a mild cognitive impairment with a vascular aetiology, and at a six-monthly review he presented with short term memory difficulties, was repetitive in conversation and reliant upon practical aids to assist his memory.

Given his high premorbid functioning and insight into his emerging cognitive difficulties, he expressed the view that, if his intellect or cognition worsened, life would not be worth living. Maintenance of BW's cognition was clearly important for his wellbeing, so we discussed the idea of trialling a form of non-pharmacological intervention to exercise his thinking abilities and to try to build some cognitive resilience and prevent further decline. Fully informed consent was obtained and, as chess was an activity he used to enjoy, this was selected as the form of cognitive stimulation to be used.

Despite the potential benefits of chess as a form of cognitive stimulation, very little research has actually explored its use in the prevention of cognitive decline for individuals who have already been diagnosed with a cognitive impairment in later life. Lillo-Crespo *et al* (2019) stated in their meta-analysis that little is understood about the protective factors for this group, as there has been a tendency to focus on neurotypical individuals to see whether cognitive stimulation can prevent cognitive decline from starting in the first place.

A prime example of the use of chess as a form of cognitive stimulation for neurotypicals is found in the work of Cibeira *et al* (2021), who conducted a pilot for older adults where participants were engaged in hourly chess sessions, twice weekly, for 12 weeks. They documented significant improvements in cognition, specifically attention, processing speed, and executive functions, as well as an improved quality of life.

This research demonstrated the effectiveness of chess as a form of cognitive stimulation for neurotypicals, but when it comes to investigating the impact of playing chess on those who already have cognitive difficulties, research is sparse. One study, however, did provide chess sessions to older adults living with cognitive difficulties (Wahyu Laksono *et al* 2019), concluding that the game did hold potential for preventing further deterioration.

The study documented how participants displayed more active thinking as sessions progressed, and researchers observed improvements in long-term memory span upon

Key points for practice

- Research has started to acknowledge the effectiveness of non-pharmacological interventions in the treatment of cognitive difficulties in later life
- In North Cumbria's Memory and Later Life Service, there is no current preventative treatment for individuals diagnosed with a mild cognitive impairment (MCI), despite the well evidenced fact that older adults diagnosed with a MCI are at greater risk of developing a dementia
- Playing chess exercises an array of cognitive domains and functioning, as the case study discussed indicates.
- In conjunction with the limited existing literature, the case study suggests the potential efficacy of chess as a form of cognitive stimulation for older adults experiencing cognitive difficulties in later life
- Further research is needed into cognitively stimulating non-pharmacological interventions to determine their effectiveness as a form of treatment for emerging cognitive difficulties in later life to slow down further deterioration and strengthen remaining cognitive capabilities
- Such work should look to advance current clinical practice in the Memory and Later Life Service and enhance post diagnostic support more widely.

intervention completion. In this context, I engaged BW in a series of six chess sessions, once a week for six weeks, to exercise his remaining cognitive capabilities and stimulate his thinking abilities.

I used the Addenbrookes Cognitive Assessment Version III (ACE III) to assess BW's cognition and assessed his wellbeing using the short version of the Geriatric Depression Scale (GDS). Both measures were taken at baseline and upon intervention completion.

A worthy opponent

Having already reviewed BW's presentation prior to the intervention, in the first session I knew I had to present a challenge to BW when playing chess so that he would view me as a worthy opponent, and to engage his attention. Although I took no formal measures of chess playing abilities during the intervention itself, I did note down clinical observations during the six sessions.

I saw BW's processing speed improve, without compromising the quality of his play. BW's navigation of the chess board got better and he became more able to predict and visualise future moves, not only of his own pieces but mine as well, which he often verbalised during a game. Decision-making also improved, and BW was progressively more able to equate the value of pieces to the value of his position of the board. For example, he would sacrifice a high value piece to gain an advantageous

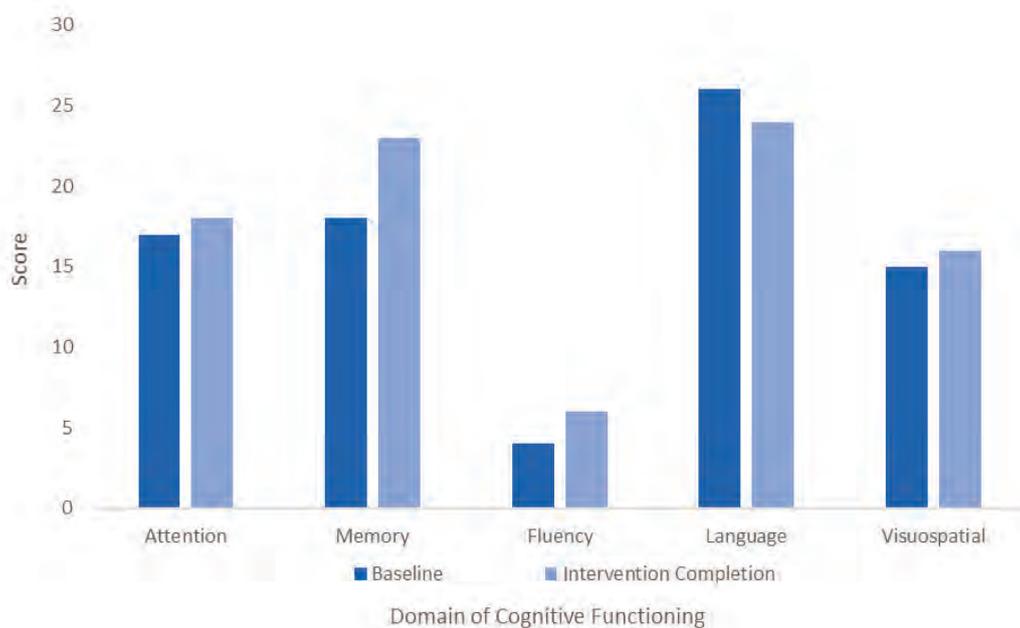


Figure 1: ACE III domain scores at baseline and on intervention completion

position, reflecting development in higher level strategic thinking and idea formulation.

BW scored 7/15 on the GDS at baseline and 3/15 on the GDS upon intervention completion, suggesting an improvement in wellbeing. He scored 80/100 on the ACE III version A at baseline and 87/100 on the ACE III version B upon intervention completion, suggesting a measurable improvement in thinking abilities.

The scores from each domain of cognitive functioning on the ACE III at baseline and upon intervention completion are shown in Figure 1 above. The greatest improvements were observed in the memory domain, while subtle improvements were observed in attention, visuospatial domains, and fluency, but a small reduction was observed in the language domain.

During games I always considered BW's mental fatigue and frustration levels so as to protect him from harm. BW did not respond negatively to failure, but often did struggle to use pieces cohesively to pin my king in the endgame.

The potential benefits of chess

Although this is only one case study and the findings are no more than suggestive, it does indicate that chess may hold potential as a form of cognitive stimulation, and strengthens the argument for it as a non-pharmacological treatment and means of cognitive stimulation in the already diagnosed population. It provides supporting evidence for the work of Wahyu Laksono *et al* (2019).

While I acknowledge that recent research has highlighted the interrater variability when scoring ACE III assessments (Say & O'Driscoll 2022), in this case, assessments within this intervention were administered and scored only by myself. It is appreciated that many secondary factors can influence the building of cognitive resilience and the simple interaction with a health professional may have influenced the suggested protection against cognitive decline that was built during the intervention for BW.

There is a tendency in research to try and discover generalisable treatments for people experiencing similar difficulties, but this approach fails to account for individual differences or the realities of professional practice that

strives for person-centred care. Future investigation would help to advance the post-diagnostic support provided by memory services by examining the effectiveness of non-pharmacological cognitively stimulating interventions to develop the range of preventative post-diagnostic treatments accessible for people in the early stages of cognitive decline.

** BW consented to this intervention being submitted for publication in a research journal and, to safeguard his anonymity, some details have been altered.*

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Good dementia education and training

Good dementia education and training depends not just on content but on the context in which it is delivered. **Claire Surr, Sarah Smith and Isabelle Latham** (L to R below) present two models for helping to ensure that education and training is implemented in practice.



Good dementia education and training is more than just a well-designed and delivered course. Impactful programmes of training also need to consider the wider context and how training will be implemented within this and put into day-to-day practice.

Here, we will introduce models that can help us to think about different aspects of implementation as well as how we can evaluate whether training programmes are leading to their desired outcomes. These are covered in more detail in our book on education and training in dementia care (Surr et al 2023).

The last 10-15 years have seen successive UK governments prioritise dementia workforce education and training, which has quite rightly seen a focus on ensuring those entering and currently working in health and social care receive dementia training that is appropriate to their role. We led a programme of research that developed “gold standards” of design and delivery.*

But our research also showed that good design and engaging and effective delivery methods are not enough. There are several models that can help us to consider different aspects of the implementation of training programmes, which includes the rollout of the training itself and then the ability of staff to put their learning into practice.

These models come from a field called “implementation science”. Implementation science is a field of research about the uptake of evidence into routine practice (Bauer et al 2015). It involves how we move from what we know to how we do things. We present two models; one looks at organisational level factors (i-PARIHS) and the other at individual behaviour change (COM-B).

Claire Surr is professor of dementia studies at Leeds Beckett University, Sarah Smith is reader in dementia research at Leeds Beckett University, and Isabelle Latham is researcher-in-residence for Hallmark Care Homes.

Summary

What does the implementation and evaluation of good dementia education and training look like? In this brief overview, which parallels publication of our new book from Open University Press**, we argue that successful implementation requires careful planning and consideration of a range of issues.

These issues include context and the resources in place to support learners at local and system-wide levels, as well as the needs of the learners themselves. We also present the importance of the evaluation of training to complete the implementation cycle – and why choosing the right evaluation methods is essential.

i-PARIHS model

i-PARIHS stands for Integrated Promoting Action on Research Implementation in Health Sciences. The i-PARIHS Framework (Harvey & Kitson 2016) is an evidence-based model of the components required to successfully implement training or other interventions into practice in health and social care settings. It has four elements (see figure 1 below): Innovation, Recipients, Context, Facilitation.

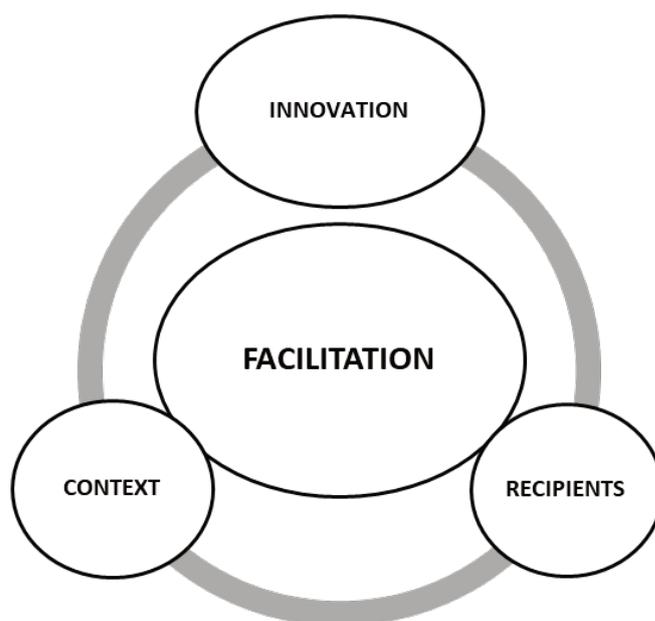


Figure 1: The i-PARIHS framework (based on Harvey & Kitson 2016)

Facilitation

Facilitation is the central ingredient of training implementation, since it is the facilitators who lead implementation. They do this by assessing implementation readiness, barriers, and facilitators across the other components of the model and then put an implementation plan into action. They are the ones who drive forward the implementation. Facilitators do not necessarily need to be those delivering the training itself but can be tasked with broader implementation.

It is therefore essential that the training implementation facilitators:

- Know about the innovation that is being implemented
- Understand how people are going to respond to the innovation
- Can assess the contextual factors that will influence the implementation.

Innovation

The innovation element asks us to think about the characteristics of the training itself as being central to the success or failure of the implementation. These include:

- Is the training underpinned by a strong evidence-based approach?
- Is this evidence aligned with local priorities and practices? That is, is it compatible with current practice? Can you show or make a case for how it could be implemented within the ways people already work? If people feel it's unfeasible, they probably won't even try to put it into practice.
- Is the information presented about the training and its implementation accessible and useable?
- Does implementing the training offer benefits over the current practices?
- Is it something novel, new or different, rather than staff feeling this is something they do already or have tried before?
- Can it be tested on a small scale to show that it makes a difference?

Recipients

The recipients are the individuals who are involved in implementing the training. This might be training teams and managers who need to ensure staff are able to attend the training. It also needs to be managers and staff attending the training, and people living with or supporting someone with dementia who will be impacted by the training. They need to consider how they can put what is learned into practice.

So, we need to consider individual and collective views, beliefs and existing ways of working, as well as the wider organisational culture. These all have an impact on how easy or challenging implementation is. For example:

Key points for practice

- The success or failure of dementia education and training depends on more than the content and design of the training
- The context in which education and training is delivered should be considered *before* delivering the training and influence *how* the training is delivered
- Models from what is known as implementation science can help
- Think about the features of the context that are important for the successful delivery of training
- Evaluating training using appropriate methods will help to reflect on the success of the training and improve it in the future.

- Are people motivated to change practice?
- Do they see the training as valuable towards achieving this?
- Does it fit with their or the organisation's values and beliefs?
- Do a number of staff share the same view?
- Do people have the knowledge, skills, resources and support needed to implement the training?
- Is there local leadership to help put the training into practice?

Context

Context needs to be understood as operating at three levels: 1) micro or local/team, 2) meso or organisational, and 3) macro or external including the wider health and social care system. Influences at each of these levels will affect implementation of change.

Therefore, before implementing a programme of training we need to consider what contextual factors will support implementation and what might act as a barrier. It is important to use the facilitators to our best advantage and to plan for ways to tackle the potential barriers.

For example, at the macro level, recent government policy across the UK has strongly supported or mandated dementia training for all NHS and social care staff and it has consequently been prioritised. However, at a meso/organisational level there may be a range of competing priorities for staff time and resources. These might be mitigated by micro/individual level factors, such as staff saying they need dementia training and report what is on offer as being valuable to their day-to-day practice.

COM-B model

COM-B stands for the Capability, Motivation and Opportunity Behaviour System. This system (Michie et al 2011) looks specifically at individual behaviour change and what supports or impedes this (see figure 2).

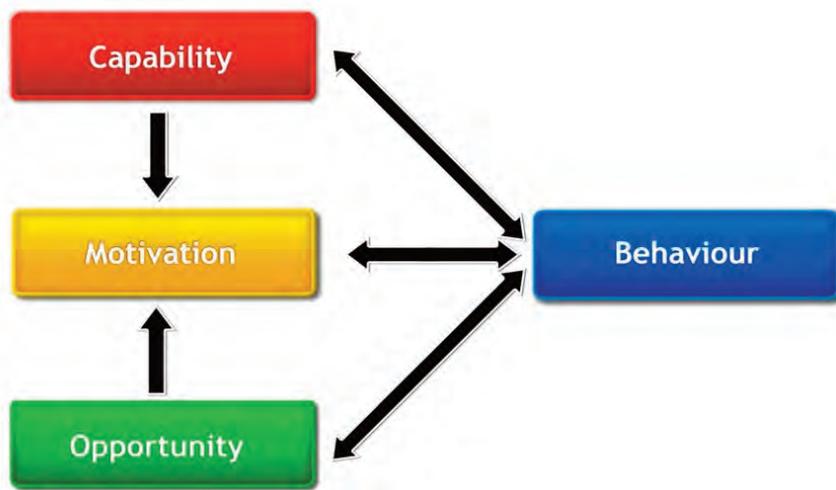


Figure 2: The COM-B system (Michie et al 2011)

Capability consists of an individual’s physical and psychological capacity to engage in the intervention and behaviour change activity.

Motivation includes people’s goals, decision-making, habits, emotions and analysis that motivate their behaviours.

Opportunity is the external factors that facilitate or prompt a behaviour. These might be support for time to implement training (or not), organisational readiness for change and its culture. These are the sorts of things that the i-PARIHS framework considers.

The COM-B model emphasises the complexity of implementing training. For interventions to have any effect on individual behaviour, the right conditionals are essential. Without considering individual factors, any intervention is unlikely to have the desired effects and is unlikely to result in the training being implemented well or having the outcomes that are desired. This leads to the final part of our paper; the need to evaluate training to check it is delivering its intended outcomes.

Evaluating training

A framework we find particularly helpful for thinking about how to evaluate training is the Kirkpatrick Framework (Kirkpatrick 1984). This has four levels at which training can be evaluated. No level is more important than any other. However, different approaches to evaluation are needed at each level:

- 1. Reaction** – how do those attending the training react? Did they enjoy attending? Did they feel it was useful and applicable to their practice. People are unlikely to try to put training into practice that they do not feel was enjoyable or useful.
- 2. Knowledge** – has the training improved the knowledge, attitudes and/or confidence of those attending? This should relate to the learning objectives of the training.
- 3. Behaviour** – do those who have attended training do things differently in practice? This relates to the implementation aspects we discussed earlier. Are they able and willing to implement learning?
- 4. Outcomes** – does the training make a difference to outcomes for people with dementia, their carers, or staff?

This is often much more difficult to evaluate since it is not always easy to be able to attribute any particular differences in outcomes to a programme of training. Likewise, there may be other barriers to or things preventing desired outcomes being achieved, which are beyond the scope of training to address.

There are different methods that can be used to evaluate training. These include questionnaires, observations, interviews, routinely collected data and documentary analysis (see Table 1 on next page). Each of these methods come with their own advantages and disadvantages and can be

better suited to the recipients of training or to people with dementia, their carers/supporters. It is likely that in most cases a comprehensive evaluation will need to use a variety of data collection methods.

Conclusion

This brief article has provided an overview of the implementation and evaluation of dementia education and training. Successful implementation requires careful planning and consideration of issues such as context, the resources in place to support the learners at local and system wide levels, as well as the needs of the learners themselves. Failure to consider the facilitators and barriers that sit outside/alongside the training programme itself can mean that the training you deliver can fail to have impact – even if the content is excellent.

As part of the implementation and evaluation cycle, it is essential to know if training has managed to achieve what it set out to do. To do this robust evaluation methods are important. If your training has not had impact you will need to understand why and at what point the training fell short. For example, did the learners enjoy the training itself, but fail to carry this forward into the way that they are delivering care?

In most cases, a good evaluation should use more than one method to capture the impact on a range of recipients (staff and people living with dementia) and across the different levels of the Kirkpatrick model (reaction, knowledge, behaviour, outcomes). This approach will offer a more comprehensive understanding of the impact of the education or training. The evaluation you undertake should be based on the expertise and resources you have available.

In summary, investment of time and resources in the implementation and evaluation of education and training is a key component of the success of the training. As much consideration should be given to the preparation for and evaluation of dementia training as is given to the training itself.

*For more information on “‘What Works’ in Dementia Education and Training,” go to www.leedsbeckett.ac.uk/research/centre-for-dementia-research/what-works/.

***Education and Training in Dementia Care: A Person-Centred Approach*, by Claire Surr, Isabelle Latham and Sarah Smith, was published earlier this year by Open University Press.

| Method | Advantages | Disadvantages |
|--|--|---|
| <p>Questionnaires - one of the most frequently used methods for evaluation. Can take the form of standardised measures or tailored to specific outcomes. Can include numerical and fixed response questions.</p> <p>Useful for assessing levels 1 & 2 of the Kirkpatrick Framework (reaction and knowledge).</p> | <p>Flexible method of data collection</p> <p>Relatively easy to administer in terms of time and resources</p> <p>Allows comparison across individuals/groups/time</p> <p>Straightforward and quick to complete</p> <p>Can be completed anonymously</p> <p>Useful for gathering views of many staff who have completed training</p> | <p>Self-report is not always accurate</p> <p>Response bias (respondents may give the response they feel is more socially acceptable)</p> <p>Questionnaire items can be interpreted in different ways</p> <p>Fixed response questions (for example yes/no or Likert scales) tell you what people think but not why they think it</p> <p>Not always easy for people with dementia or cognitive impairment to complete</p> |
| <p>Interviews - allow you to explore in more detail with individuals, about their experiences and thoughts. Can be conducted individually, in small groups (two-three people) or as focus groups (usually four-eight people).</p> <p>Useful for assessing levels 1, 2 & 3 of the Kirkpatrick Framework (reaction, knowledge and behaviour).</p> | <p>Allowing the evaluation of in-depth experiences and views of a single person or group.</p> <p>If inclusive methods are used helpful for obtaining the views of people with cognitive or communication difficulties</p> <p>Offer the opportunity to give breadth of opinion on a particular topic.</p> | <p>Participants may not feel comfortable or able to share their true thoughts, or beliefs.</p> <p>Can be time consuming to do well</p> <p>Interviews need transcribing and analysing appropriately</p> <p>Resource intensive</p> |
| <p>Observation - commonly used evaluation approach which can give an insight into the experiences of a person who is unable to give a detailed account of their experiences (eg, Dementia Care Mapping).</p> <p>Useful for assessing levels 3 & 4 of the Kirkpatrick Framework (outcomes and behaviour).</p> | <p>Allows an evaluator to see things they would be unlikely to capture using interviews or other data collection methods</p> <p>Gives a voice to the perspective of people who might be unable to communicate this for themselves</p> | <p>Time consuming</p> <p>Requires skills and experience to do well (observing, recording notes, etc)</p> <p>People may act differently while an observer is present or may seek to engage with an observer if there are no staff present</p> |
| <p>Routine Data - refers to data that is routinely collected by health and care services. For example, e.g. number prescribed medications, healthcare appointments</p> <p>Useful for assessing level 4 of the Kirkpatrick Framework (outcomes).</p> | <p>Can provide a consistent source of information to evaluate training outcomes</p> <p>Data available from before and after training programmes</p> <p>If obtained and analysed anonymously poses fewer ethical issues around consent and permission</p> | <p>Quality of the data may be variable, particularly if it is recorded by different individuals and/or if there is not a standardised recording method</p> <p>Routine data might not be collected on the specific outcomes you are interested in</p> |
| <p>Documentary Analysis - can range from care plans/records and assessment documents, to details of complaints, incidents or satisfaction with services.</p> <p>Useful for assessing level 4 of the Kirkpatrick Framework (outcomes)</p> | <p>Documents have the benefit of being an ongoing record, so it is possible to examine if and how any changes occur over time.</p> | <p>Standardised formats for and ways of completing documents, especially those that may be subject to more formal or external audit, can mean that there is limited opportunity or openness to changing how these are written for evaluation</p> |

Table 1: Evaluation methods

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Housing, home and dementia: what's the story?

What does “home” mean to people with dementia and how can the sense of identity associated with home be preserved through life’s transitions? In the second in a series of articles, **Ruth Eley**, **Penny Redwood** and **Marney Walker** (L to R below) argue that attachments to people and objects should be respected when planning a move from one setting to another



One of the most influential factors in all our lives is the environment in which we live. Home is a significant part of that and it is as important to people with dementia as it is to everyone else. The big question is, what are the implications when someone who has dementia moves to a new home?

In the first article of our housing and care series (Eley & Redwood 2023), we focussed on the current housing situation in the UK and the importance of the housing sector being able to deliver inclusive, age and dementia-friendly housing and communities. In this second article we consider what “home” means to people with dementia (and to all of us) and how we can support people to remain at home or through transitions by acknowledging those individual attachments to home.

Our starting point is this quote from Professor John Bond, an expert on ageing, who said: “As people age they become more orientated towards home; it is seen as a refuge and becomes increasingly important as other social roles in later life are relinquished” (1993).

Home and identity

“Beyond the Front Door”, our original project with Life Story Network (LSN 2018), gave us opportunities to talk with people with dementia about what home meant to them. From these conversations, themes emerged around connectedness with people, places, memories; the creativity embedded in home making; the importance of location and familiarity; the significance of cultural expectations and roots; and how home can offer privacy, comfort, feelings of safety and security. Other significant

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Summary

Home is a place of investment – a place that people have creatively fashioned to meet practical, emotional and spiritual needs. It is a place full of attachments which in turn feed that sense of the uniqueness of who we are. One’s home contains everyday objects which provide familiarity, memories, orientation and quality of life.

Recognising the significance of home to people with dementia who are facing or potentially facing transitions from one setting to another is key to being able to provide meaningful and person-centred support in managing what is likely to be a challenging and stressful move.

Discussions about what is important about home and attachments, as well as housing options, enable people with dementia to make choices and decisions about what is important to sustaining their wellbeing after a move.

contributory factors were identified, both positive and negative, such as age, abusive relationships, whether people had raised their families there, immigration and types of housing.

These all confirm the understanding of home is unique to each of us. It is only when we have acquired a sense of the deep significance of home to individuals that we can negotiate how best to support them in a person-centred way at times of significant change. “There’s no place like home” is a familiar adage; if we stop to think about what home is, we realise that it provides us with far more than shelter.

Our premise is that the idea of home is inseparable from our sense of self and our sense of identity. We invest in creating our homes as we want them, both financially and emotionally. Our homes are places that we fashion; they become assets, places of collective and personal memories, and as the architecture and design writer Edwin Heathcote put it, “containers of meaning and symbol, as theatrical sets against which dramas of our lives are enacted.” (2012)

It is well known that the sense of identity for people with dementia can easily be eroded. “Place attachment” is important as it keeps the past alive, remains constant during times of change and maintains a sense of continued

competence (Peace et al 2006). In the words of Steven Sabat: “It is increasingly clear that the environment in which the person with AD (Alzheimer’s disease) dwells can exert a potent effect upon his or her cognitive and behavioural abilities” (2002).

We know that people with memory loss function best in a familiar environment where they are most orientated, although there will be exceptions, for example, people who have experienced abuse or significant trauma at home. One woman who contributed to our study had experienced devastating ill-health after the death of her husband and consequently felt unsafe in her home environment. Moving to extra care housing gave her a new lease of life and a freedom that she had lost in her old home.

Moving home

People with dementia move home for a variety of reasons such as bereavement, deterioration in health, increased frailty and dependence, a change in personal circumstances, to be nearer to family or to free up finances. Changes in the neighbourhood and the need for greater security and companionship had led some in our Beyond the Front Door study to consider a move. Often it is a move that is triggered by distressing events such as a fall and consequent hospitalisation.

Decision making in the face of cognitive decline has its own particularities when it comes to moving. Having to face a move because of your diagnosis of dementia concentrates the mind on difficult and negative issues such as memory loss and loss of independence, mortality, choice and control. These feelings can be exacerbated when other people are making decisions for you; we all know that moving house is considered the most stressful life event.

Transitions from one setting to another for older people are often influenced by concerns about the ability to



Marney Walker's research is exploring how design can support the expression of everyday aesthetic preferences in dementia

Key points

- The idea of “home” is inseparable from our sense of self
- People invest in creating a home emotionally as well as financially
- Identity can be bolstered through the symbolic use of everyday objects
- Transitions from one setting to another for people with dementia are often undertaken without the involvement of the person themselves
- Planning for potential moves should be part of post-diagnostic support

manage safely in one’s own home environment. As a consequence, decisions are primarily made or influenced on the basis of a risk assessment (formal or informal) undertaken by worried relatives or carers. It is important therefore that positive risk management is collaborative and able to balance strengths and values against risk of harm, with a focus on quality of life for the person.

Calouste Gulbenkian (Robertson 2014) makes three key points about transitions:

- they generally involve grieving for the loss of the old and readjusting to the new
- they often work best when they are predictable and approached intentionally
- they often work best when there is an understanding of the personal challenges that they represent and when there are societal or personal supports in place to help the individual cope with and overcome these challenges.

Post-diagnostic support

While there is general acknowledgement that early diagnosis is beneficial to planning and adjustments, there is a tendency for information about housing to be scant and limited. Where someone is to live is as essential as information about support, care and psychosocial intentions for wellbeing.

Beyond the Front Door identified a general uncertainty about what housing options were available, and who could offer advice. Good quality information, staff awareness of options and opportunities, and knowledge of where advice can be sought are crucial, especially post-diagnosis, so that people can begin to identify their goals and priorities for quality living, care and support. Training, multi-agency working, collaboration, and shared decision-making all play their part.

Support to settle after a move is also critical and housing support workers have a key role here. Some people in our study described situations where established tenants had been unwelcoming and this had made their transition difficult. Others told us of problems with neighbours and that feeling unsafe in neighbourhoods with changing demographics and developments became the impetus for

their relocation.

In considering possible transitions or moves, risk assessments undertaken by professionals and families or other concerned carers need to be enabling rather than disabling, recognising the significance and importance of those factors that contribute to maintaining esteem, identity, love and belonging as well as those physiological and safety needs.

My Home Matters

My Home Matters is a booklet developed by tide that enables people to engage with future planning by considering what their attachments are in terms of location, people and objects. The extent to which we have control over our personal space expands and contracts throughout life; in later life, this may be due to changes in occupation or physical capacity. Following retirement and in later life, we may spend more time at home so that daily routines become associated with everyday objects.

“Clinging to one’s habits implies an attachment to one’s possessions: the things that belong to us are as it were solidified habits ... this armchair waiting for me to sit in it every evening” (De Beauvoir 1977).

For people living with dementia, where a detailed narrative and biographical memory may fade, it is suggested that embodied emotional memory is retained (Brown 2017) and that identity can be experienced and expressed through “the symbolic use of material objects” (Buse & Twigg 2014).

As dementia progresses there is often an increasing reliance on assistance with reduced choice and control over immediate surroundings, whether at home or in residential care. Personal space shrinks (Førsund *et al* 2018), which can lead to alienation. In care home environments that can feel more like hotels, with all the associated dependency that is implied, a new approach described as “material citizenship” (Lee 2019) advocates active engagement with utilitarian objects by residents, to reinforce a sense of familiarity and competence rather than passive receipt of care.

In terms of personalisation, the relevance and specificity of environmental stimulation can have positive impacts on motivation (Jao *et al* 2016). Attention to accommodating individual differences is advocated (Bowes & Dawson 2019). A doctoral research project titled “I know what I like” by Marney Walker, co-author of this article, is exploring how design can support the expression of everyday aesthetic preferences in dementia.

This approach means focusing on the sensory sensibilities retained in dementia and the meaning conveyed through physical contact, using everyday objects and colour preferences as visual ways to support expression of personal preferences. It involves asking about a favourite mug, colour and spaces in the home.

The intention behind this doctoral research is to explore whether these everyday choices can help to reflect a sense of identity, and support person-centred engagement and interaction where verbal expression becomes more challenging. Part of this process has involved capturing images and quotes from recorded interviews with

participants that are compiled into personalised booklets that provide a record of everyday aesthetic preferences (Walker 2022). Workshops with practitioners have considered how this approach might be transferable to different contexts and how people’s preferences might become clear through opportunities for conversations or simply providing choice, eg, from a variety of mugs that might help maintain hydration.

In our final article, we will explore the My Home Matters tool and invite readers to think about what home means to you and how you might use it in your work.

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New guidance to support people with a learning disability and advancing dementia to move into a care home setting

As people with a learning disability live longer lives, they find themselves at a higher than average risk of dementia which may result in a move to a care home.

Lynn Flannigan and colleagues discuss new guidance on making this transition a more positive experience.

As more people with a learning disability live to an older age, they become increasingly likely to develop dementia, and sometimes this results in a move to a care home, planned or unplanned. But how can we ensure that this is a more positive experience than is often reported?

Our answer was to create guidance for all professionals involved in supporting people with a learning disability and advancing dementia.

The guidance, titled *My new home*, focuses on people with both conditions who are moving to a care home, usually because their needs have increased and can no longer be met in their current home.

Intended for health and social care staff, the guidance aims to enhance the appropriate care and support of people living with a learning disability and advancing dementia before, during and after a move to a care home, should this be the most appropriate option for meeting their needs.

People with a learning disability are at increased risk of dementia as they age when compared to the population generally (Glover 2018). For people living with Down's syndrome, the risk is higher (Moran 2017):

- around 30% of people living with Down's syndrome who are in their 50s experience dementia (Moran 2017)
- about 50% of people living with Down's syndrome in their 60s experience dementia (Moran 2017)
- age-related dementia of all types is more common at an earlier age in people living with a learning disability than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population) (UK Health Security Agency 2018), and
- for those aged over 60 years the prevalence is estimated to be at two to three times greater in people with a learning disability (UK Health Security Agency 2018).

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Summary

People with a learning disability are now enjoying increased life expectancy and therefore are more likely to develop illnesses associated with ageing. This population is at increased risk of dementia compared with the population generally, and individuals with Down's syndrome are at particular risk of early-onset dementia.

While recognising that individuals should be supported to remain in their current home as dementia advances, if this is their preference, there are occasions when this is no longer practical, safe or indeed desired by the person. However, in reality when a move is made, it is often unplanned and in a crisis situation with appropriate alternative placement difficult to access.

It is in this context of advancing dementia that an increasing number of moves are made by people with a learning disability to a care home for older people. In recognition of this, a multi-agency group was established in Scotland to explore what was needed to create a more positive experience if a move to a care home was unavoidable or desired.

The group has developed guidance – entitled *My new home* – for all professionals involved in supporting people with a learning disability and advancing dementia. It aims to ensure that, should a transition to a care home be made, a person-centred approach seeks the best outcomes for the person, and that support is in place for care home staff as required.

Key themes informing the guidance were multi-agency collaboration for person-centred, timely transitions; staff knowledge and skills with support and training to implement good practice; and physical and social environments reflecting the needs and wishes of the person living with a learning disability and advancing dementia.

By the time a person is living with the advancing stages of dementia, the illness has affected all areas of ability. Memory, communication, understanding, thinking, judgement, planning, learning and physical functioning are all severely compromised, although people can live with

advancing dementia for many years (Alzheimer's Society 2021).

While our guidance did not focus on palliative care specifically, we recognised that a palliative care approach may already be appropriate, and have been implemented, prior to a move or deterioration in health. Advancing dementia (progression and changes experienced on an individual basis) was distinguished from advanced dementia (later stages). "Advanced dementia" often carries an assumption of end of life which does not reflect the extended period of time that an individual may live not only with dementia, but also with co-morbidities.

Although, in the first instance, individuals should be supported to remain in their current home as their dementia advances if this is their preference, there are occasions where this is no longer practical, safe or indeed desired by the person and their family (Sturge et al. 2021). This transition is often as a result of crisis with appropriate care home placements difficult to access at short notice, leading to reports of less positive outcomes and experiences for the person, their family and friends.

The rationale for a move to a care home should be carefully reviewed and decisions should not be made based solely on cost or other service-driven reasons. For example, if someone is unable to navigate stairs, an upstairs room in a care home will be equally inappropriate and may restrict outdoor access. Similarly, if waking night staff were previously required, a care home should provide the same therapeutic environment at night.

The decision to move into a care home should only be made after all other options to enable the person to remain at home have been explored, and the person with a learning disability has been supported to engage in this process, using accessible and person-centred communication methods where appropriate.

Developing guidance

Focus on Dementia is a quality improvement team in the improvement hub (ihub) of Healthcare Improvement Scotland. Its role is to support the delivery of Scotland's national dementia strategies through quality improvement methodology. A commissioned programme of work on dementia care co-ordination identified lack of support for staff and people with a learning disability as an issue during a move to a care home.

The Focus on Dementia team contacted colleagues in the Care Inspectorate, who confirmed this was a widespread challenge. The Care Inspectorate is the national regulator for care services in Scotland who inspect social care and social work services provided by local authorities and carry out joint inspections with partner organisations. They play a part in improving services for adults and children across Scotland, act as a catalyst for change and innovation, and promote good practice.



Key points

- People with a learning disability are living longer and are more likely to develop dementia than people without a learning disability
- Discussions about future care and support should be anticipatory, person-centred and involve the person with a learning disability as early as possible in the course of dementia
- People should be supported to live in their preferred home where possible for as long as desired
- If transition to a care home is the preferred option, this requires multi-agency collaboration
- Staff require specific knowledge, skills and training to support people with a learning disability and advancing dementia in any care setting
- Physical and social environments should be appropriate to meet the individual's needs

A multi-agency group was established to explore the issues that prevented a positive experience during care home moves, and try to identify some of the potential solutions. The group included partners and topic experts from the Care Inspectorate, Alzheimer Scotland, Inverclyde Health and Social Care Partnership, NHS Lothian, Quarriers (a local social care organisation which provides care and support for people with a physical or learning disability), the Scottish Government, Thorntoun Estate Care Home, and the University of Stirling.

Findings and next steps

It became apparent that care homes for older people were often reluctant to admit people living with a learning disability and dementia. Concerns included:

- staff not having the confidence, knowledge and skills to support someone with a learning disability
- questions around whether the individual would "fit in" to the care home, and their integration and communication with other people living there, and
- a belief that the individual's specific needs would not comply with the conditions of the care home's registration, with changes and adaptations potentially required.

An initial session with the group was facilitated to examine these issues and develop themes for further discussions. The group felt that guidance for staff would support them to implement good practice when caring for people living with a learning disability and advancing dementia. Group members had subsequent discussions with people with lived experience in community settings and research groups that included people with a learning disability and dementia. Case studies were produced to ensure that the voices of people with a learning disability and their carers were heard and informed the guidance.

Further exploration of these issues was the key driver for development of the guidance, which covers:

- ensuring a person-centred approach
- knowledge, skills and training
- Specialist support and multi-agency collaboration
- environment
- physical health needs
- meaningful and purposeful engagement
- commissioning, resources and registration.

Recommended best practice advice and signposts to other resources are also part of the guidance. In order to reflect the voice of the person with a learning disability and dementia, each section begins with a statement such as “My care home will (for example) ensure a person-centred approach is taken to decision making and care planning.”

Implications for practice

This guidance has implications for health and social care staff across sectors before, during and after an individual’s move to a care home. It provides guidance to support the transition. A person-centred approach is advocated throughout to seek the best outcomes for the person and their family and friends, while emphasising the necessity for appropriate and ongoing support and training to be in place for care home staff.

It is also essential that conversations about future care and support are timely for people with a learning disability and advancing dementia and do not take place in a time of crisis. Everyone who has a new diagnosis of dementia in Scotland, including individuals with a learning disability, is entitled to a minimum of one year of support from a named link worker, and to the development of a person-centred plan (Public Health Scotland 2020). This support is most often delivered using Alzheimer Scotland’s Five Pillars model, two pillars of which explicitly support planning for future decision making and planning for future care.

Entitlement to a minimum of one year’s support should result in timely conversations between the link worker and the person they are supporting, but take-up of this service among people with a learning disability remains very low with many families and organisations in Scotland unaware of its availability.

Ideally, decisions about the future should be anticipatory where the person with a learning disability and their carers can talk about what matters most when making plans for care. This information should be documented in an anticipatory care plan (ACP). The use of appropriate communication support should ensure the person’s rights and preferences are heard and respected, and that the person is at the centre of any decision making.

Lessons learned

To facilitate the transition and achieve positive experiences for the person concerned, the following were found to be important:

- Multi-agency collaboration to support person-centred and timely transitions before and after a move. This includes knowing about the person before they had dementia, their likes and dislikes, and ensuring preferences are shared and updated as

needed. Life story work or similar activities may assist, if the person with a learning disability has agreed to this.

- Ensuring staff have the knowledge, skills, and training they need to support people living with a learning disability and advancing dementia. This includes knowledge of what it means to have a learning disability and (separately) what it means to have advancing dementia.
- Ensuring the social environment reflects the needs and wishes of the person, such as appropriate communication methods and awareness that these may change.
- Ensuring the physical environment is safe and understandable. It may help the transition if the person’s bedroom can be recreated as far as possible in the care home.

Future plans

Now that the guidance has been published, the multi-agency group will continue to support its implementation and will work with colleagues in the Care Inspectorate to evaluate and capture examples of how it has improved experiences and outcomes.

The *My new home* guidance is free to download and can be found at

<https://ihub.scot/media/9648/supporting-people-with-a-learning-disability-and-advancing-dementia-guidance-for-staff-v20.pdf>.

Further information about Focus on Dementia’s care co-ordination work can be accessed at <https://ihub.scot/improvement-programmes/focus-on-dementia/care-co-ordination/>

Useful resource: *Jenny’s Diary*, a downloadable illustrated booklet to support conversations about dementia with people who have a learning disability. <https://www.learningdisabilityanddementia.org/jennys-diary.html>

If you would like to get in touch, please contact the Focus on Dementia team at his.focusondementia@nhs.scot

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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

Clock Drawing Test (CDT) in screening

This is the first study to examine the additional value of the CDT to the MMSE (Mini Mental State Examination) in a large older memory clinic population with mild cognitive impairment (MCI), Alzheimer's disease (AD) and subjective cognitive impairment (SCI). It concluded that the CDT contributes significantly to the MMSE in discriminating SCI from both MCI and AD patients. The authors highlight that an abnormal CDT with a normal MMSE is an indicator for cognitive impairment while an abnormal CDT in combination with an abnormal MMSE can be considered as an indicator of disease progression.

Claus CC, Staekenborg SS, Verweij KHW *et al.* The clock drawing test is an important contribution to the Mini Mental State Examination in screening for cognitive impairment. *International Journal of Geriatric Psychiatry*. Published April 21 2023. <https://doi.org/10.1002/gps.5914> (restricted access).

Experiences in acute care settings

This review sought to describe the data collection processes from peer-reviewed evidence sources that include direct consultation with, and elicit feedback from, patients with dementia about their care experience in the hospital setting. It concluded that valuable information on lived experiences can be meaningfully collected from people with dementia and that, generally, a qualitative, flexible, conversational approach to data collection will provide the highest quality data. It highlights that careful attention should be given to the sensitive and complex ethical issues during the recruitment, consent-giving, and data collection stages of any

research activities involving people with dementia in the transitory hospital setting. Principles of person-centred care should guide practitioners' and researchers' processes.

Adams A, Lone L, Oorloff A, Duffy C. Collecting data on the experiences and perspectives of people with dementia in the acute care hospital setting: A systematic scoping review. *International Journal of Older People Nursing*. Early View. Published April 10 2023. <https://doi.org/10.1111/opn.12535>. Open access.

Post-diagnosis support

This international survey, including UK, examined the experiences of people living with dementia and informal caregivers of the support they received following diagnosis (satisfaction with information, access to care, health literacy, and confidence in ability to live well with dementia). While the perceptions of carers and people with dementia differed, the study highlighted the need to improve support. The authors recommend that provision should be tailored, accessible and evidence-based and it should include a range of strategies from which individuals can choose in order to assist them to live positively with dementia.

Hevink M, Wolfs C, Ponds R *et al.* Experiences of people with dementia and informal caregivers with post-diagnostic support: Data from the international COGNISANCE study. *International Journal of Geriatric Psychiatry*. Published May 3 2023. <https://doi.org/10.1002/gps.5916>. Open access.

Cognitive impairment support in acute care

This study evaluated the impact of implementing the Cognitive Impairment Support Program on patient hospital acquired complications, patient

reported quality of life and staff satisfaction in an Australian hospital. It provides evidence that a multicomponent Cognitive Impairment Support Program had a positive impact on staff confidence and satisfaction and on patient quality of life.

Fox A, Dulhunty J, Ballard E *et al.* The impact of a cognitive impairment support programme on patients in an acute care setting: a pre-test post-test intervention study. *BMC Geriatrics* 23, 260. Published May 1 2023. <https://doi.org/10.1186/s12877-023-03930-1>. Open access

People with intellectual disability: dementia risk screening

Dementia risk is elevated in people with an intellectual disability, particularly for those with Down syndrome. This review draws on research evidence to highlight that lifestyle interventions (such as increasing physical activity, reducing social isolation, minimising alcohol and cigarette consumption and treating/managing diabetes, depression, hypertension and obesity) can be targeted to enhance cognitive reserve and reduce dementia risk for people with intellectual disability. It recommends cognitive and functional performance screening from the age of 35 upwards and highlights an example of good practice in this area. (<https://www.tcd.ie/tcaid/research/NIDMS.php>).

Allen AP, McGlinchey E, Fallon M *et al.* Cognitive reserve and dementia risk management in people with an intellectual disability. *International Journal of Geriatric Psychiatry*. Published March 16 2023. <https://doi.org/10.1002/gps.5906>. Open access

Online singing groups

For this study, people with dementia and their care partners took part in ten weeks of online singing sessions. It found that, while online singing cannot recreate the experience of group singing face-to-face, and it requires some technical knowledge, it provides a worthwhile alternative in a time of need for some people with dementia and their carers. Furthermore, for some people online singing may be preferable due to its accessibility. Given the potential for online singing to include people who cannot go out for any reason and its relatively low cost, providers may wish to consider hybrid online/in-person singing groups in future.

Dowson B, Schneider J, McDermott O, Orrell M. Online Singing Groups for People With Dementia: Adaptation and Resilience in the Face of the COVID-19 Pandemic. *Dementia*. 2023;0(0). Published June 9 2023. doi:[10.1177/14713012231179262](https://doi.org/10.1177/14713012231179262). Open access.

Nursing student communication

This pilot study explored nursing students' perceptions and experiences of communicating

with people with dementia incorporating the VERA communication skills framework. The findings reveal students' initial reservations about communicating with people living with dementia. They employed strategies including nonverbal techniques, distraction, reminiscence and life story work. However, students who received the VERA communication training felt more prepared to engage in these strategies because of the VERA training. The authors conclude that the VERA training may be a useful framework for increasing undergraduate nursing students' knowledge and confidence in advance of clinical placements in older person's services.

Smyth S, Dempsey L, Jordan F *et al.* Perceptions and experiences of nursing students communicating with people living with dementia: The validation, emotion, reassure activity (VERA) communication skills framework. *International Journal of Older People Nursing*. Published online April 5 2023. <https://doi.org/10.1111/opr.12537>. Open access

Montessori-based programmes in residential care

This systematic review examined the effectiveness of Montessori-based programmes for individuals with dementia living in residential aged care. It found that Montessori-based programmes significantly improved engagement, mental health outcomes and feeding difficulty. However, there were mixed results in nutritional status, and the synergistic effect of integrating Spaced Retrieval with Montessori-based activities in improving eating ability and nutritional status of individuals with dementia was also emphasised. There were no significant changes in activities of daily living and quality of life. Future Montessori-based programme designers would highly recommend tailoring personalised Montessori-based activities to individual care needs, cognitive ability and personal preference.

Yan Z, Traynor V, Alananzeh I *et al.* The impact of Montessori-based programmes on individuals with dementia living in residential aged care: A systematic review. *Dementia*. 2023;0(0). Published May 13 2023. doi:[10.1177/14713012231173817](https://doi.org/10.1177/14713012231173817). Open access.

Remote visiting to care homes

The purpose of this study was to assess the feasibility and acceptability of 'Connecting Today', a remote visiting program designed for use with care home residents living with dementia. It concluded that facilitated, remote visits are feasible and highly acceptable to residents and their family and friend contacts. The authors suggest that Connecting Today shows promise to address social

isolation and loneliness for people living with moderate to severe dementia because it can promote positive engagement in meaningful interactions with their family and friends while they are living in a care home.

O'Rourke HM, Swindle J, Chacinski D, *et al.* Connecting Today: Feasibility and acceptability of a remote visiting program for people living with dementia in long-term care homes. *Dementia*. 2023;0(0). Published June 21 2023. doi:[10.1177/14713012231176858](https://doi.org/10.1177/14713012231176858). Open access

Specialist palliative care

This mixed-methods study explored the perspectives of specialist palliative care (SPC) teams in Ireland. In the survey, staff ranked timely access to community agency/ specialist support and managing the needs of people with dementia as most challenging. Their learning needs were ranked highest in differentiation of dementia subtypes along with pharmacological and non-pharmacological management of noncognitive and cognitive symptoms. These findings can inform the design and delivery of tailored education programs for SPC staff. There is also a need for closer working between dementia services and SPC services to provide integrated, holistic care for

people with dementia. One aspect of achieving this is greater awareness of local dementia-care services among SPC staff, and vice versa.

Currie SJ, Curtin C, Timmons S. Specialist Palliative Care and Dementia: Staff Challenges and Learning Needs. *Journal of Palliative Care*. 2023;0(0). Published June 21 2023. doi:[10.1177/08258597231180966](https://doi.org/10.1177/08258597231180966). Open access.

Predicting mortality in advanced dementia

Challenges in formulating prognoses for people diagnosed with advanced dementia (AD) hinders timely referrals to palliative care. These authors set out to develop and validate a prognostic model (the PRO-MADE) to predict one-year all-cause mortality (ACM) in patients with AD presenting at an acute care hospital. It concluded that the PRO-MADE attained good discrimination and calibration properties. The authors conclude that, used synergistically with a clinician's judgement, this model can identify AD patients who are at high-risk of one-year ACM to facilitate timely referrals to palliative care.

Kaur P, Kannapiran P, Ng SHX *et al.* Predicting mortality in patients diagnosed with advanced dementia presenting at an acute care hospital: the PROgnostic Model for Advanced Dementia (PRO-MADE). *BMC Geriatrics*. 23, 255, Published April 28 2023. <https://doi.org/10.1186/s12877-023-03945-8>.

Book review:

Dementia and Psychotherapy Reconsidered

By Richard Cheston, Open University Press, ISBN 9780335250981, £25.99

Richard Cheston's book aims to provide an in depth and nuanced understanding of how to support people living with dementia to remain in their communities over the long term, through the provision of psychotherapy. The author has been a pioneer over 30 years in the development of psychotherapy for all impacted by dementia.

Inspired by Tom Kitwood, he argues that "it doesn't matter what sort of psychotherapy we practice, just so long as we don't think that dementia, by definition, means someone is 'out of psychotherapeutic reach'". His book is a passionate and thorough overview of the opportunities for psychotherapy of all kinds in this field (excluding art, reminiscence and music therapy).

Well organised into three parts, it has helpful summaries at the end of each section accompanied by a commentary on the implications for people living with dementia, family carers, therapists and dementia care workers. Part one is focused on themes of loss, threat and change; part two explores how individual therapy, couples therapy and group therapy can be used for this client group.

The third section, "Becoming the same, but different," is perhaps the most thought provoking in that the author challenges us to think about how we talk about dementia with people who are living with a dementia. "In my work I

have come to see a capacity to talk about dementia as synonymous with adjustment - both in the sense of people finding the words to describe their dementia to themselves and within therapy but also in their being able to tell other people."

Cheston makes the case for using a framework derived from Bill Stiles' "Assimilation of Problematic Experiences" model. The outcome of this is that the person becomes less frightened and more accepting of their diagnosis. "Their relationship with their dementia, in effect, changes," he writes.

The final section addresses working with people who are more fragile due to their social and personal environments as well as living with more complex impairments. He illustrates the work throughout with moving personal stories from his clinical practice - a valuable gift from all involved.

An exploration of the limitations of using a social adjustment model would have been an added bonus as for some people their engagement requires a much more reciprocal approach of both people in the relationship not knowing the path ahead.

The overall message of this book is how helpful psychotherapy can be and how in addition people can bring therapeutic qualities of active listening, empathy and emotional validation to their day to day relationships with people living with dementia and their families.

Kate White, a member of *Let's Reimagine Dementia: A Coalition for Social Justice*

Resources

Gardening for health charity Thrive has produced a garden action pack called **Get Gardening Without a Garden**. The pack, intended for people with dementia among others, gives tips on experiencing the wellbeing benefits of gardening without having a garden. There are sections on containers, window boxes, house plants and much more. Research by Thrive indicates that nearly 80% of people living with dementia believe gardening helps improve their mental wellbeing. In a partnership with Dementia Adventure, the charity set out to improve gardening information for people with dementia and their carers. Advice on gardening is given in an accessible format and is suited to people with any level of horticultural knowledge.

www.thrive.org.uk

A podcast and video, published to mark Dementia Action Week in May, explores the skills of storytelling and listening as a way to connect with older people with memory loss. Produced by Royal Star & Garter, which runs care homes for armed forces veterans and their partners, the online learning tools were made following workshops and one-to-one meetings with staff and relatives. Made with storytelling experts Narativ London, the video – **Everybody has a Story** - looks at techniques and tips on initiating discussions and conversations that can trigger reminiscence and memories among people with dementia. In the podcast there are reflections on the workshops and excerpts from what relatives and staff had to say.

Video: www.vimeo.com/783631009

Podcast: www.spreaker.com/episode/53818842

Eminent historian Professor Joanna Bourke recently gave a lecture on the **cultural history of dementia** now available online, in which she looks at how it has evolved from being considered a “normal part of ageing” to being considered “a disease that demands a cure.” She argues for a more open attitude to cognitive difference and concludes by saying that “embracing cognitive alterities is good for all of us.”

www.gresham.ac.uk/watch-now/dementia-history

A charity specialising in medical ID jewellery, which is working with the police to trace and support people with dementia who become lost, is offering **first year membership free**. MedicAlert UK has launched the “Safe & Found” programme in the UK, in which the charity holds a copy of the Herbert Protocol Form containing a photo and relevant information about anyone with dementia who may go missing. Thanks to sponsorship from the McLay Dementia Trust, more than 800 people living with dementia in the UK will be able to enjoy free membership of the scheme for one year.

www.medicalert.org.uk/mclay-dementia-trust

Care home residents’ favourite recipes are contained in a new book called **Nellsar Care and Cookery**, which has been published online as a “celebration of person-centred catering, nutritional support and seasonal recipes”. The cookbook is a collection of 28 recipes favoured by

residents at the family run care group Nellsar, based in the south of England. Among the authors is Cosmin Cristea, head chef at the Princess Christian Care Centre in Woking, who said that the cookbook “embodies everything Nellsar stands for in terms of nutrition.” <https://nellsar.com/care-and-cookery/>

Dementia care to meet the needs of a wide range of ethnic groups is the focus of a new guide from NHS England. Titled **Intercultural dementia care: A guide for health and care workers** and written in collaboration with Alzheimer Europe, it draws on the experience and knowledge of experts and builds on previous reports by those with direct experience of providing dementia care to people from many different ethnic communities. One of the issues taken up in the guide is how to reach people with dementia and carers who need support and care.

www.england.nhs.uk/wp-content/uploads/2023/05/intercultural-dementia-care-guide.pdf

Landscaped gardens can be created in line with the latest research on sensory and cognitive impairment, a newly revised factsheet suggests. **Landscape Design Principles for Dementia Care** (2nd edition) is an updated Housing LIN Factsheet (no 35), which shows how well designed gardens can enhance residents’ quality of life in housing with care developments. It highlights the potential of landscape design to promote the physical and mental health of people with dementia while mitigating the impact of cognitive decline. The authors are Angeli Ganoo-Fletcher and Helene Saulue, respectively director and associate at PRP. www.housinglin.org.uk/assets/Resources/Housing/Support_materials/Factsheets/HLIN_Factsheet35_Landscape_2023.pdf

A toolkit to help care staff in the housing sector give a better quality of life to people as they approach the end of their lives has won recognition in an awards ceremony. Provider Octavia scooped the workforce development award at the Housing with Care Awards for its **Better Lives, Better Endings** toolkit. The toolkit, co-designed by Octavia and St Christopher’s CARE, assists staff in addressing challenges faced by extra care providers in meeting residents’ wishes towards the end of life.

www.octavia.org.uk

Advice on **How to support somebody living with dementia in hot weather** has been produced online by Alzheimer’s Society. It focuses mainly on how to prevent dehydration by making drinks more accessible and by leaving prompts and reminders, among other things, but also gives tips to help people with dementia stay cool when it’s hot. In further online advice, the Society has posted **10 ways to make dressing easier for people with dementia**. It includes using signs on furniture and laying out a full outfit against a plain background.

www.alzheimers.org.uk

The Young Dementia Network has made its June webinar about a **young onset dementia nurse-led service** available on catch-up. The webinar is presented by Jenny Kerti, community psychiatric nurse manager, alongside

colleagues from the Younger Persons with Dementia Team in Northamptonshire. It reveals how the service offers continuity of support from GP referral for a diagnosis onwards.

www.youngdementianetwork.org

Admiral Nurses share tips on **Supporting children and adolescents when a parent has young onset dementia** in new advice from Dementia UK. Topics covered include juggling parenting and dementia, supporting your child, recognising themselves as young carers, and changing family dynamics.

www.dementiauk.org

Food supplier **apetito** won **three awards** at the British Frozen Food Federation Awards for three of its dishes, suited to people with swallowing difficulties or with dementia. The winners were the Level 4 Puree Petite Spaghetti Bolognese, Level 5 Minced Sticky Toffee Pudding, and Chicken Tikka Finger Food Bites. The awards recognised innovation and creativity in the frozen food category.

www.apetito.co.uk

The Dementia Services Development Centre (DSDC) at Stirling University is encouraging care providers to make use of its **Environment for Ageing and Dementia Design Assessment Tool (EADDAT)** by inviting them to **self-certify** free of charge during July. The DSDC said self-certification would reassure people with dementia using providers' services that their needs were being actively supported. If the environment meets one of two levels, organisations can complete a checklist and request self-certification.

www.dementia.stir.ac.uk

Blogs I'm watching—by Mark Ivory

Wendy Mitchell writes about a visit to London to promote her new book, *One Last Thing: How to live with the end in mind*. As the title suggests, the topic is death and in the book Wendy explores dying with dementia, how we prepare for it and talk about it. The London visit is a heady round of radio interviews – the Today programme on Radio 4, the Michael Ball show on Radio 2, Jane Garvey on Times Radio – and there is a good deal of press interest in the book too, the third and apparently the last in her series of books drawing on her own experience of dementia. You can find the epilogue in a link from

Wendy's blogpost on 23 June, where her "partner in writing" Anna Wharton talks about how important it was to get it right "as it would be the last time I would embody Wendy's voice." Wendy says she doesn't remember what she said to Michael Ball, but she provides plenty of photographic evidence including hugs with Michael not to mention singer-songwriter Beverley Knight who was on the show before her. When it's all over, naturally she embarks on a long walk around London. "Finally on my own, I could enter my own little world," she says.

<https://whichmeamitoday.wordpress.com/blog>

Could similar underlying changes in the brain explain similar symptoms in frontotemporal dementia (FTD) and motor neuron disease (MND)? That is the question posed by Dr Chris Henstridge in his Dementia Researcher blogpost, "Fading stars: disorder in the galaxy of the brain." The answer appears to be "quite possibly". Brain scans of the frontal cortex in MND patients have revealed changes that look like those observed in people with FTD. And, in research funded by MND Scotland at Dundee University, Chris has shown that synapse loss occurs in the frontal cortex of MND patients with cognitive decline. On the face of it, there is a marked overlap between the two conditions. "I believe it's very important for different funders to work together and look at some of the commonalities between different diseases. [Alzheimer's disease], FTD and MND are different diseases, they mostly affect different brain areas, different cell types are particularly vulnerable, clinical presentation is predominantly distinct, but there is a lot to learn in the areas of overlap... As we advance our understanding of brain disease, I hope one day we will be able to ensure that everyone's galaxy shines bright into old age."

www.dementiaresearcher.nihr.ac.uk

Now that there have been some modest successes with monoclonal antibody drugs such as lecanemab and donanemab, Alzheimer's Research UK (ARUK) has opted for a bold refresh of its brand. "We exist for a cure" shouts the website home page and – for the avoidance of doubt – the charity logo now includes the catchphrase "For a Cure". ARUK chief executive Hilary Evans blogs about the "new optimism" in the field. "We have a new sense of urgency fuelled by opportunity," she says. "This has culminated in a fresh look for Alzheimer's Research UK, which will provide a bold new foundation for us to step up our campaigning."

www.alzheimersresearchuk.org/blog

Journal of Dementia Care Webinars

Tues 26 September 2023, 2-3pm

Developing a Virtual Reality Dementia Training programme for homecare staff

Experiential learning and simulation have been found to be helpful delivery methods for supporting staff working in dementia care to develop empathy for people with dementia and confidence in delivering care to this group. Virtual Reality (VR) offer an opportunity to widen access to experiential and simulated learning opportunities. Homecare provider Anglian Care has partnered with VR training company Moonhub and Leeds Beckett University to develop

a programme of VR-based dementia training. This presentation will describe the process of co-developing the interactive training content which includes features such as identifying person-centred/non-person-centred care practices and how the physical environment might impact a person with dementia. It will also share findings to date from the evaluation and discuss next steps for VR training from this partnership.

Presenters: Professor Claire Surr, Leeds Beckett University and Charles Cross, Anglian Care

Recordings of earlier JDC webinars from 2023 are available free on our website:

<https://journalofdementiacare.co.uk/events/webinars-2>

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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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