The Journal of DementiaCare

For all who work with people with dementia
Vol 33 No 4 July/August 2025

Creative dementia:
the power and potential of the arts

Also inside this issue:

- Gujurati CST: more than a translation
- GREAT CR therapy
- Young Onset Dementia support
- Medications: new series

Dementia Community

learning | sharing | inspiring

Our new name is Dementia Community

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

Dementia Community is the organisation that provides:

The Journal of DementiaCare | The UK Dementia Congress | The National Dementia Care Awards

You are warmly invited to join us!

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

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

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

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

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

www.journalofdementiacare.co.uk

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The Journal of DementiaCare

For all who work with people with dementia Vol 33 No 4 July/August 2025

Inside this issue...

Change and clallenge 12

A message from the editor designate of *JDC*, **Toby Williamson**.

Tribute to Nigel Hullah 13

Nigel Hullah was a well-known campaigner and activist in the dementia world who lived with the condition. Sadly, Nigel died earlier in 2025. Here are two tributes to Nigel: one from *JDC*'s incoming editor **Toby Williamson**, and one from **Peter Middleton**, a person living with dementia who knew Nigel well.

Creative Dementia: Arts for Health and Wellbeing 14

In June 2025 Dementia Community and the Creative Dementia Arts Network staged a conference in Bristol exploring creative arts for dementia. **Maria Pasiecznik Parsons** and **Toby Williamson** describe the event, with some of their personal highlights.

Book review: Understanding dementia and the needs of people living with dementia – A brief focus on Nigeria 20

Book review and author's story: Scarlett Buckling and the Case of the Missing Pictures 21

Creating change for Young Onset Dementia support 22

Debby Lennox of Dementia Forward describes how the charity reinvented local support for younger people with dementia, pioneering a specialist, age-appropriate care and support model that could be shared nationally.

Equality, Diversity and Inclusion: Dementia Community's EDI group undertakes and promotes EDI initiatives 24

The principles and practice of equality, diversity and inclusion (EDI) are extremely relevant to the field of dementia. **Toby Williamson** and other members of Dementia Community's EDI group describe the group's recent work for Dementia Community and the dementia sector more widely.

Gujarati Cognitive Stimulation Therapy: more than a translation 28

Cognitive Stimulation Therapy (CST) is an important non-pharmacological intervention in dementia but may not be accessible for different groups in the population. **Lynde Booth Collard** and colleagues share their co-produced method in adapting CST for a local Gujarati population.

Cognitive Rehabilitation therapy Should it be provided for people diagnosed with dementia? 32

GREAT Cognitive Rehabilitation therapy has been shown to be effective in addressing lost abilities. **Jackie Poo**l and **Emma Marshall** describe how it was used effectively to help an individual and his family, and recommend that this therapy should be offered as a post-diagnostic service.

Medications: common issues and questions answered 37

This article is the first in a series of three aimed at helping people with dementia, their families and care staff manage some of the common issues and questions in relation to medications often prescribed to people with dementia. Here **Stuart Kennedy** considers the medications often prescribed following some diagnoses of dementia (predominantly Alzheimer's disease).

Front cover photos: Sincere thanks to photographer Barnaby Chinnock and everyone involved in Dementia Community's Creative Dementia Conference.

Regulars

The Journal of DementiaCare

WEBINARS

See below for details of upcoming webinars. The programme is updated and webinars available to book on our website; previous webinars have been recorded and are available to watch here too.

See: **https://journalofdementiacare.co.uk/events/webinars-2**

Tuesday 22 July 2025 – 2-3pm

Designing inclusive environments for people living with dementia: how much do we really know?

Presenters: Sarah Waller CBE and Jennifer Bray, Association for Dementia Studies, University of Worcester

Description: In recent years there has been a growing interest in and awareness of the importance of dementia friendly environmental design across all health and care environments as well as for people living with dementia in their own homes. There is now a wealth of information and guidance about how to assess and create internal and external spaces that will enable people living with dementia to live well. However, these are not always evidence based and this presentation will explore the areas where more research is needed. With a focus on the care home and home environment it will also include practical advice on small scale changes that can improve care practice.

Monday 8 September 2025, 2-3pm

Music and Dementia: The UK's First Centre of Excellence

Presenters: Giles Wilmore, Director of Community, Manchester Camerata; Programme Director, UK's First Centre of Excellence for Music & Dementia

Description: This webinar will give an overview of the work of Manchester Camerata and partners, including the Alzheimer's Society, in hosting the UK's first Centre of Excellence for Music & Dementia in Greater Manchester. It will outline the approaches used - Music in Mind and Singing for the Brain – how they work and the benefits they bring to people living with dementia and family members who participate, including the new national learning network for music and dementia.

Tuesday 23 September 2025, 2-3pm

Connecting You to Support: Integrating rehabilitation for people with dementia into allied health professional practice

Presenter: Elaine Hunter, National Allied Health Professions Consultant, Alzheimer Scotland/Visiting Professor, Edinburgh Napier University

Description: Connecting People, Connecting Support (CPCS) is an allied health professional (AHP) policy that seeks to ensure that people living with dementia and their families have better access to AHPs. However, at the heart of CPCS is partnership working, community connections, engagement and the voice of lived experience. This webinar will share a whole system tailored AHP delivery model, incorporating rehabilitation, and consider implementation gaps of policy to practice while also telling a story of transformation in accessible and visible AHP knowledge and skills.

Monday 6/Tuesday 7 October 2025, 2-3pm

Topic, date and time to be confirmed.

Tuesday 21 October 2025, 2-3pm

Dementia Community – Community Space

Join us for our third Community Space – a chance to meet and network. More information to follow.

Please join from 1:45pm to introduce yourself ahead of the 2pm start.

Tuesday 4 November, 2-3pm

Connecting, celebrating and empowering veterans and their partners in care

Presenter: At the Royal Star and Garter: Shirley Hall, Director of Care & Wellbeing; Iuliana Hodson, Head of Dementia; Josephine Mahaffey, Veteran resident; Rahwa Tewolde, Registered Nurse; Natalie Diamond, Wellbeing coordinator; Susan Bignall and Angela Guieme, Day care coordinators, plus a Family member.

Description: This presentation will explore innovative ways to connect former service members with vital care opportunities. It will highlight the importance of tailored programmes, community engagement, and collaboration between organisations. By fostering awareness and streamlining access, we aim to empower veterans and their partners to receive the care that they deserve, enhancing their wellbeing and reintegration into civilian life. Join us in building a supportive network that recognises the unique needs for those who have served.

Tuesday 25 November, 2-3pm

Where are the books for people living with dementia?

Presenter: Sarah Lawrance, Lead for dementia-friendly reading and publishing at Equal Arts, and Gill Taylor, Expert by experience and keen reader.

Description: In this webinar we'll be telling the story behind the development of two new books created with and for people living with dementia. Both Bewick Tales and Dorothy Wordsworth's Grasmere days aim to support people to continue reading for enjoyment. This session will include a short, shared reading exercise, top tips for reading with dementia and opportunities for questions.

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Different voices at the journal

By **Toby Williamson**, editor designate of the Journal of Dementia Care

Greetings to all readers of the *Journal of Dementia Care*. This is my first comment piece as the new editor of the journal (I will take over the role from the next issue onwards). You can read more about me and my hopes for the journal on p12. I feel very honoured to be invited to take on the role of editor (though Sue Benson will continue to play an invaluable role with the journal's production).

This issue is a great reflection of the breadth of dementia care, as well as symbolising Dementia Community's commitment to inclusivity and diversity. Care and treatment for dementia come in many forms. Maria Parsons and I report on a recent conference exploring the use of creative arts in dementia care (p14), while Stuart Kennedy answers questions frequently posed by callers to Dementia UK's helpline, in the first of a series of three articles on pharmacological interventions (p37).

Two articles are included about evidence-based cognitive interventions. On p32 Jackie Pool and Emma Marshall, together with a family carer, discuss the benefits of cognitive rehabilitation therapy, while on p28 Lynde Booth Collard and colleagues describe how cognitive stimulation therapy was adapted to use for a Gujarati community. This second article also reflects the importance of the principles and practice of equality, diversity and inclusion (EDI) in dementia care, and this is echoed by other articles in this issue. Supporting younger people with dementia is a focus in the article by Debbie Lennox on p22, and two book reviews (pp20-21) feature publications with particular groups in the population in mind.

For nearly three years Dementia Community has had an EDI group promoting EDI in the organisation's work and dementia care more widely. On p24, I and colleagues from the EDI group describe its achievements so far and the diversity represented by the group. Inclusion of people with dementia and family carers is a key principle of EDI. As well as our regular Dementia Diaries feature, we pay tribute to Nigel Hullah on p13. Nigel lived with dementia and was a great campaigner and activist but sadly died earlier this year. I hope Nigel would have appreciated the diversity in this issue, and that in the future the journal continues to appeal to as wide an audience as possible. ■

Sue Benson writes: I am absolutely delighted to be handing over the editor's role to Toby Williamson. Toby has been an important and influential figure in the world of dementia care for many years now, and he is the perfect person to continue to shape the journal, its content and its role in the future of our wide Dementia Community.

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

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, Sue Benson: sue@dementiapublishing.community

News round-up

This is a brief selection of the news and resources regularly posted and updated on our website.
Reports by Beth Britton.

Blueprint for proactive and preventative digital care services published

'Unlocking the Power of Proactive and Preventative Care Services - A practical blueprint for planning, implementing and scaling up' has been published by a new national Commission led by the Association of Directors of Adult Social Services (ADASS) and the TEC Services Association (TSA). The Commission engaged with 50+ social care leaders from local authorities and found a lack of evidence, guidance and best practice is holding councils back from scaling innovative, preventative approaches using technology-enabled care (TEC).

The co-produced blueprint - which features case studies, including those of people living with dementia (Sharon and Wyn's story and Marianne's story) - is intended to help councils provide, and invest in, more comprehensive digital preventative services. Download free at: https://www.tsa-voice.org.uk/tec-guidance/resources-library/tsa-adass-commission-blueprint/

Expressions of interest welcomed for Care Technologists project

The National Care Forum (NCF) is looking for people interested in pioneering a new professional role in adult social care: Care Technologist. The role would form a bridge between traditional care and current technological innovations. The aim is to ensure that as technology is widely implemented it meets the needs of individuals drawing on care. The role was created by Scottish Care who have tested it and evidenced positive outcomes. The Care Technologist Training Project is intended to support people who'd like to work in this new social care role to gain the skills they will need. It is funded by the Rayne Foundation through their Better Careers, Better Care programme. NCF would like to hear from people interested in developing the Care Technologist training programme and/or future learners on this programme. Expression of Interest Form here: https://forms.office.com/pages/responsepage.aspx?id=vSG5oaduHUi86481aGlN5C_iW_pwa1NAvSwRoS9yMtdUMFZLNTQ5VU45V1BLTUdPWUJHNzBHMUpCNC4u&route=shorturl

Cambridgeshire Police launch safeguarding scheme

Cambridgeshire Police has launched a Dementia Safeguarding Scheme in which the force will issue hundreds of people with dementia a yellow Herbert Protocol wristband that looks similar to a watch but has built-in smart technology. The technology, known as Near Field Communication (NFC), enables anyone with a smartphone to scan the wristband to help someone who is lost to be reunited with their family by accessing contact details for the person's next of kin.

Detective Chief Inspector Dave Savill, of the force's Protecting Vulnerable People unit, says:
"This new technology is one more important step to ensure we do everything possible to protect vulnerable people in Cambridgeshire. It is crucial that people living with dementia can get to a place of safety and security, with friends or family, as quickly as possible. These wristbands will help to achieve that and reduce the demand on emergency services."
Watch a film about the wristbands and how to use them: https://youtu.be/7AZlbApUiMo?si=JbPLJbzhwg_B4Xey
Find out more from Cambridgeshire Police here: https://www.cambs.police.uk/news/cambridgeshire/news/2025/may/new-dementia-safeguarding-scheme-launched/

CQC report on health and social care support for people with dementia in England

The Care Quality Commission (CQC) has published a report entitled: 'Health and social care support for people with dementia'. Findings, based on engagement with people living with dementia, unpaid/family carers, professionals and providers (both NHS and social care), as well as analysis of information CQC holds, include:

- Health and social care staff do not always understand the specific, personal care needs of people with dementia.
- Care environments, including hospital wards and care homes, sometimes do not support people's wellbeing.
- People did not always feel there was ongoing care and had to seek out community charity support groups themselves.

The report highlights good practice examples, including:

- People who had good support from their primary care services during their dementia diagnosis and ongoing support described the positive effect this had on their wellbeing.
- When a GP provides support and understanding of concerns during an assessment it can help improve the person's experience and lead to a more timely diagnosis.
- Good dementia care is provided in enabling environments with well-trained, compassionate professionals who understand the person and how best to relate to them.

CQC say they will use the findings in this report to develop - alongside people with lived experience, providers and other stakeholders - a definition of what good, joined-up dementia care looks like so that CQC can apply this to all areas of their regulatory activity as part of their Dementia Strategy. Read the report here: https://www.cqc.org.uk/publications/health-and-social-care-support-dementia

DCC shares dementia carers' experiences

Dementia Carers Count (DCC) has followed up their 'What if…I'm not there to care?' by sharing a collection of dementia carers' experiences.

DCC invited dementia carers to share their personal experiences of not having alternative care arrangements in place, their struggles to continue caring and their worries. DCC have shared these experiences with those responsible for supporting dementia carers in England, Scotland and Wales. Helen Pyper, Head of Policy and Campaigns at Dementia Carers Count, says:

"Each nation must fully implement a carers' strategy which outlines carers' rights and what support they should receive. This should include provision for regular, proactively offered and frequently reviewed, assessments of carers' needs and plans for contingency or alternative care. All adult social care must be sustainably resourced to enable delivery of personalised support. What exists on paper must be delivered in practice."
https://dementiacarers.org.uk/content/uploads/2025/05/Sharing-the-experiences-of-dementia-carers.pdf

Care Workers' Charity 2025 Wellbeing Report

The Care Workers' Charity (CWC) has published a report with the findings from their 2025 Wellbeing Survey. The survey had over 2000 responses from care workers across the UK. Most notably around dementia care, the majority of care workers said they were supporting older people with a dementia diagnosis. The report documents care workers' thoughts on issues including financial, mental and physical wellbeing and training and development.
https://www.thecareworkerscharity.org.uk/wp-content/uploads/2025/05/Wellbeing-Report-2025-2.pdf

Journaling with dementia on BBC Morning Live

BBC Morning Live has featured Gail Gregory and George Rook talking about their experiences of living with dementia and journaling/blogging. Dementia Diaries was also highlighted, with Steve Milton explaining what Dementia Diaries is. View the programme here: https://www.bbc.co.uk/iplayer/episode/m002cd30/morning-live-series-7-23052025 (Fast forward to one hour in.)

DementiaNet launched

DementiaNet, a new online platform created to support people living with dementia and those who care for them, has been launched. It's been developed from research and lived experience – two of the three founders of DementiaNet, Brian Schur and Hugh McGouran, have personal experience of dementia - and aims to provide user-friendly, personalised online support. DementiaNet offers a range of information, as well as a digital vault (for securely storing personal information), downloadable planning tools and a step-by-step dashboard to help people tackle things like a care plan.

Brian, talking about his motivation for founding DementiaNet, says of when his mother-in-law was diagnosed in 2022: "Just finding out what to do was impossible. I've worked in the digital world for more than 30 years and despite being savvy online, I still found it a nightmare to do. We were given two leaflets from the GP and basically were sent away."

Hugh, who is chair of a dementia charity in the north-east, adds: "There's an overwhelming amount of information out there, but much of it is generic and it's hard to navigate without being sent down a rabbit hole of links, which lead to hundreds of other results that are not relevant to you at that point. This makes the search for information very upsetting, triggering and often unproductive." https://dementianet.com

Please note: DementiaNet is available free with optional paid features for the secure planner and document store.

DomCare study looking for participants

DomCare - The Benefits and Costs of Domiciliary Care study, a three-year project funded by the NIHR Policy Research Programme, is looking for participants.

Researchers are seeking homecare agencies or housing with care schemes in Kent, Surrey, Sussex, the East Midlands, or Yorkshire & Humber to help with data collection. Their goal is to understand adults' experiences of homecare and its value in improving lives.

Participation involves completing a short survey (Sep–Oct 2025) and distributing survey packs to clients (Feb 2026). There's no cost—materials are provided, with compensation for staff time.

Find out more about the study here:
https://research.kent.ac.uk/dom-care/

Living with Young-Onset Dementia: Our Music, Our Voice film launched

A film produced by the University of Sheffield in partnership with charity Age UK has been launched. Entitled Living with Young-Onset Dementia: Our Music, Our Voice, it features people living with young-onset dementia talking about their experiences and interactions with music, as well as exploring tools and technologies to support the enjoyment of music. The film is part of Dr Jennifer MacRitchie's ongoing research project, Music, Dementia and Technology. You can watch the film here: https://youtu.be/d3CMo5gYzqk?si=ETCdBqi2uXm7z4no

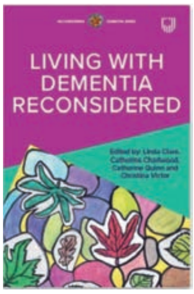
Find out more about the project here: https://www.sheffield.ac.uk/muses-mind-machine/research/technologies-ai/older-adult-wellbeing

Dementia UK launches second podcast series

Dementia UK has followed up the first series of their 'My life with dementia' podcast with a second series. Now hosted by charity ambassador and award-winning journalist and podcaster Marianne Jones (series one was hosted by actor Jim Broadbent), the podcast features personal experiences of dementia. Each story episode is followed up by practical advice from Dementia UK's Admiral Nurses that picks up on key themes.
https://www.dementiauk.org/information-and-support/resources/podcast/

Latest addition to Reconsidering Dementia series is published by McGraw Hill

A new title has been added to the Reconsidering Dementia series: ‘Living with Dementia Reconsidered’. Published by McGraw Hill and written by Linda Clare, Catherine Charlwood, Catherine Quinn and Christina Victor, it is a co-produced publication that shares research findings from a decade of the IDEAL programme. It also includes a dementia manifesto call to action. Find out more about the book here: https://www.mheducation.co.uk/living-with-dementia-reconsidered-9780335252510-emea-group. Use the discount code ‘OpenUp20’ to get 20% off.



ADI call for abstracts for 2026 Global Conference

The call for abstracts for the 2026 Global Conference of ADI, which will take place on 14-16 April 2026 in Lyon, France (in collaboration with France Alzheimer) has been opened by Alzheimer’s Disease International (ADI). There are 48 abstract topics to choose from under seven abstract submission categories, which are:
Dementia as a public health priority;
Dementia awareness; Dementia risk reduction;
Dementia diagnosis, treatment, care and support;
Support for dementia carers; Information systems for dementia; Dementia research & innovation.
Find out more and submit an abstract here: https://adiconference.org/abstracts. The call for abstracts closes on 19 September 2025, 23:59 BST.

Alzheimer Scotland highlights importance of friendship in ‘Every step’ campaign

Alzheimer Scotland has used Scottish Dementia Awareness Week 2025 to highlight the importance of friendship for enhancing wellbeing in every stage of dementia, both for people living with dementia and family/unpaid carers/care partners. Under the banner of their ‘Every step’ campaign, Alzheimer Scotland shared stories from people personally affected by dementia talking about how friendship has helped them. View the films from the ‘Every Step’ campaign and find out more about the role of friendship in the lives of people with dementia here: https://www.alzscot.org/events/dementia-awareness-week/

NAPA announces theme for National Day of Arts in Care Homes

The National Activity Providers Association (NAPA) has announced that the theme for the 2025 National Day of Arts in Care Homes (24 September 2025) is ‘Going Green’. NAPA says: “We chose Green because it offers a rich and versatile source of inspiration for care settings and arts organisations alike. From using recycled, repurposed or natural materials to drawing on the beauty of the natural world, the theme invites creativity, sustainability and connection.”

Find out more, share your plans and download free resources here: https://napa-activities.co.uk/the-national-day-of-arts-in-care-homes-2025

Green Letter Days are back for 2025

Following the success of last year’s Green Letter Days, Dementia Adventure have shared their 2025 Green Letter Days programme. Green Letter Days this year include golf, cricket and tennis experiences, allotment adventures, an online flower workshop and more. Find out more here: https://dementiaadventure.org/green-letter-days/

Participants wanted for evaluation of intergenerational practice in care homes

The National Activity Providers Association (NAPA) is looking for participants to complete their survey on intergenerational practice in care homes in England.

The survey is designed to gather insights from care staff and activity providers about their experiences of delivering intergenerational activities. Access the survey here: https://forms.office.com/pages/responsepage.aspx?id=EShiMk38hEeAqP2ZHu3Zh3x07B6gwHhMvdbxs3w9L7VUMThPN1dPNE00RkNGODQ4QzhVRzczV1RSTC4u

Research study looking for participants with dementia to share their cognitive experiences

Christina MacLean, a postgraduate Psychology Conversion student at the University of Stirling, is conducting an online research study exploring the relationship between memory, imagination, and emotional wellbeing in people living with dementia.

The research aims to improve the understanding of cognitive experiences in individuals with dementia to help inform better care and support strategies.

Participants should be aged 65 to 85, have a clinical diagnosis of mild dementia, and be able to complete the questionnaire independently or with a help of a carer/care partner. Find out more and participate here: https://www.dementia.stir.ac.uk/newsblog/christina-research

Participants wanted for survey into technology being used to support health and wellbeing in care homes

The National Institute for Health and Care Research (NIHR) HealthTech Research Centre (HRC) is running a survey to understand experiences of using technology in care homes to support residents’ health and wellbeing and/or health technologies that would be desirable to improve resident care. Views are sought from care home staff, managers and owners, and NHS/local authority staff working with care homes. The health technologies include devices, kits, apps, machines and tests that help to support, care for or monitor the wellbeing of residents, including:
Falls detection and prevention devices.
Devices to support hydration and nutrition.
Continence aids.
Wound management tools.
Technologies that enable better communication with the wider health and social care team.
Remote monitoring technologies.

Responses will be used to guide engineers, researchers, and industry collaborators when setting priorities about which technologies to make and evaluate for healthcare in care homes. Find out more and participate here: https://forms.office.com/pages/responsepage.aspx?id=kfCdVhOw40CG7r2cueJYFLdU5nwwju5Mr7Y0OQqOLSNURElYWjFWT0dBR1RMTEk3RkxYQVM3OE85RS4u

An update on dementia care policy and practice

The Care Innovation Summit, held in London in June, explored current and future areas of importance for care policy and practice. Toby Williamson reports, highlighting key issues relevant to dementia care.

New developments in dementia care are constantly occurring, affected especially by policy, changes in services and funding, improvements in practice, research, and the voice of people with dementia and family carers. Keeping abreast of these changes can be challenging. The Care Innovation Summit, held in June at the Business Design Centre in London and organised by Broadway Events, helped bring delegates up to date with some of these changes. The programme of presentations covered recent developments in policy affecting dementia care, prevention and early detection, treatments, care practice, and technology.

Is listening to people with dementia and family carers, innovation, or just common sense? This question was posed at by Suzy Webster, Lived Experience Co-ordinator at Dementia UK.

Dementia care had a dedicated stage throughout the day, chaired ably and thoughtfully by ('Big') Ian Donaghy, a dementia campaigner and writer, and Professor Graham Stokes, Director of Dementia and Specialist Service Innovation at HC One.

It was encouraging to hear from CQC about the attention they are paying to dementia. This is especially important in relation to possible reforms in social care that might come out of Baroness Casey's social care review and the forthcoming NHS 10-Year Health Plan. Joe Robertson, MP and Vice-Chair of the Dementia All-Party Parliamentary Group (APPG) stated that social care is one of the APPG's priorities, together with diagnosis and treatment.

The event was held on the same day as the announcement that NICE will not authorise the use of new drugs for Alzheimer's disease. In her presentation, Professor Vanessa Raymont from Oxford University described the latest developments in early detection and treatment of dementia and was cautiously optimistic that better pharmacological interventions may be on their way. She also focused on the importance of preventative measures, and this was echoed by Michelle Reshef, CEO of Dementia Prevention UK. Michelle emphasised how practical preventative measures were still relevant and useful for people with more severe dementia in care settings.

Workforce development and technology were also significant themes discussed. It was good to hear from Kirsty Dallison-Perry, Head of Consultant Admiral Nursing at Dementia UK, that there are now over 450 Admiral Nurses in the UK. I liked the sound of 'Betty's flat', a training environment developed by the home care agency Home Instead, described by their Chief Operating Officer Ruth Brown. A tool for diagnosing people with advanced dementia living in care homes (DiADeM) was flagged up by Dr Ruth Law, a consultant geriatrician. Enabling families to remain involved in a person's support when they moved into care was emphasised by Julia Atherton, Director of Nursing at Barchester Healthcare.

The use of artificial intelligence (AI) in supporting care was a contentious issue, in a session led by Daniel Casson, on behalf of Oxford's Research Institute for Ethics in AI. While some delegates were concerned about losing the human touch, AI is clearly here to stay. But getting AI to listen and respond both safely and appropriately to the needs of people with dementia and family carers may be common sense, but still seems to require further innovation to make it a reality.

Report by Toby Williamson, editor designate of the Journal of Dementia Care and an independent health and social care consultant.

King's Birthday Honours List 2025: Recognition for leading figures in dementia care

The King's Birthday Honours List 2025 has recognised the work of two people living with dementia - Chris Maddocks and Joy Watson – who have both been awarded a BEM. Chris is a Trustee for Alzheimer's Society and has been honoured for services to advocacy and awareness for Lewy body dementia and LGBTQ+ dementia communities. Chris has spoken at UK Dementia Congress in the past and was a joint winner (with Ronald Amanze) of a special award at Dementia Community's National Dementia Care Awards in 2022. Joy is a volunteer who has been honoured for services to people with dementia in Salford. Joy has spoken at UK Dementia Congress in the past and, along with Chris, is part of the 3 Nations Dementia Working Group (3NDWG). Joy represented 3NDWG on our November 2024 webinar 'Driving safely with dementia' https://youtu.be/OiGu_ajY4-U?si=32pQetWz_U63j7HV.

Also in the King's Birthday Honours List is Beth Britton, who has been awarded the MBE for services to people with dementia and their carers. Beth is a former carer to her dad who, in the 13+ years since her dad died, has worked with numerous organisations and individuals affected by dementia, including since autumn 2023 as Communications Lead for Dementia Community.
Read Beth's thoughts on her MBE here: https://bethbritton.com/2025/06/14/mbe-for-services-to-people-with-dementia-and-to-their-carers/

Frank Rothwell, a philanthropist and fundraiser for Alzheimer's Research UK (ARUK), has been awarded the OBE for charitable services to dementia research. Beverley Adey-Morgan, a lead business analyst at the Department for Work and Pensions, has been honoured for services to people affected by dementia, and Emily Wilson, a volunteer for Alzheimer's Society and Chair of Dementia Friendly North Belfast, has been awarded a BEM for services to people living with dementia in Northern Ireland.

You can read the full King's Birthday Honours List 2025 here: https://www.gov.uk/government/publications/the-kings-birthday-honours-list-2025

Support for older prisoners with dementia

Age Scotland report on ageing well in prison
Age Scotland has published a report entitled Ageing Well in Prison – Evaluation Report.

The evaluation is of a seven-week programme prisoners undertook at HMP Shotts. The programme covered evidence-based elements of wellbeing, and included tools for how to build healthy habits for long-term behaviour change.

Participants from HMP Shotts filled in a workbook throughout the programme, and this report includes prisoners' reflections on participating in the programme. You can read the report here: https://issuu.com/agescotland/docs/evaluation_report_-_ageing_well_in_hmp_shotts

ITV News Scotland reports on the challenge of ageing prison population
ITV News Scotland has had access to HMP Glenochil to report on the challenges the prison is facing in caring for its ageing population. In Glenochil, ten percent of the prison population is over sixty, and as well as making adaptations to the prison environment they are also having to use agency social care staff.

The ITV News Scotland report is here: https://www.itv.com/news/2025-06-23/its-more-like-a-care-home-the-prison-struggling-with-an-ageing-population

Report on HMP Frankland highlights 'poor' facilities
The Annual Report of the Independent Monitoring Board at HMP Frankland has been published, highlighting issues around prisoners with dementia.

The report, from monitoring that took place from 1 December 2023 to 30 November 2024, says: "Dementia and elderly frail prisoners remain a problem throughout the prison; facilities remain quite poor and there are number of prisoners with dementia still in normal accommodation. Older prisoner numbers are growing; some of the provision in accommodation and for dementia needs improvement. There are some positive initiatives in place to improve provision, including using assistive technology such as bed and fall sensors or emergency pendants, similar to those found in the community."

The report also documents that HMP Frankland has a dementia pathway scheme.

You can read the report here: https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/13/2025/05/Frankland-IMB-2023-24-annual-report.pdf

If you are involved in work on dementia in prisons, please email Dementia Community on: info@dementiapublishing.community.
We are undertaking some work in this area and are keen to hear from others with relevant expertise.

Award for Ally Cares innovation in night-time care
A pioneering collaboration between North Central London ICB (NCL ICB), North London Councils, Transformation Partners in Health and Care (TPHC), and care tech provider Ally Cares has been named winner of the Connecting Health and Social Care Through Digital category at the HSJ Digital Awards 2025. The award is for tech enabled night-time care that promotes better sleep and the health benefits it brings. More information at: www.allycares.com

Care England – supported by Ally Cares - has published a white paper entitled: The Sleep Gap: The Overlooked Factor Costing Lives, Time and Trust in Care.

The white paper features research and data that shows many care home residents are getting fewer than five hours of uninterrupted sleep per night, and links this poor sleep with an increased risk of falls, infections, malnutrition, cognitive decline, and early hospital admissions. In relation to dementia, the white paper notes: "Inadequate sleep is associated with impaired attention, memory loss, and accelerated cognitive decline. Fragmented sleep patterns are also a known risk factor for dementia progression."

The white paper includes key considerations and recommendations to support care providers and policymakers to prioritise sleep for care home residents. You can read the white paper here: https://www.careengland.org.uk/wp-content/uploads/2025/06/The-Sleep-Gap-The-Overlooked-Factor-Costing-Lives-Time-and-Trust-in-Care-Report.pdf

NIHR Social Care Research Programme new projects
The NIHR (National Institute for Health and Care Research) Research Programme for Social Care (RPSC) has funded 14 projects from its first call.
The £7.5m of newly funded projects include specific work relating to dementia:

- ReCOgNising and SupportIng Distance dEmentia caRe (CONSIDER) - University of Greenwich
- Caring in death: Pilot evaluation of co-produced palliative dementia care resources for care workers who are hesitant to engage with death and dying - University of Kent .

More information at: https://www.nihr.ac.uk/news/nihr-research-programme-social-care-awards-ps75m-across-14-projects

New resources for care homes on person-centred care planning
New resources to support person-centred care planning for older adults in care homes are now available. Created with input from over 100 health and social care professionals and residents' family and friends, the resources are intended to make care planning more meaningful, effective, and inclusive. They have been designed to support everyone involved in care planning—from senior staff to care assistants—and to encourage collaboration with residents and their families and friends.

The resources are as follows:
Quick Guide to Effective Care Planning – A concise tool to

Thrive's Sanctuary Garden

Thrive's new Sanctury Garden in Battersea Park, London was opened on 11 June 2025. The garden has been designed to provide a safe, accessible space for people living with a range of health conditions and disabilities, especially those with dementia and their carers, and this was reflected in the comments from the guest speakers.

Hearing from Neriman (carer to her mother with dementia) about her and her mother's experiences of being involved with the garden demonstrated the value of Thrive's work to champion the therapeutic benefits of gardening. Neriman says of the garden: "It's been a sanctuary from the beginning. It is the gift that keeps on giving."

The garden features multi-level raised planting areas with sensory plants including a wide range of flowers and foliage, herbs and vegetables. There are sheltered seating areas that enable table-top activity - which Thrive's volunteers noted as being particularly supportive for social interaction - and access is for all, with wide and continuous pathways.

Beth Britton, Dementia Community Communications Lead

Thrive (thrive.org.uk) is the gardening for health charity, using gardening to bring about positive changes in the lives of people living with disablities or ill health, or who are isolated, disadvantaged or vulnerable.

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help create care plans that enhance quality of life https://arc-kss.nihr.ac.uk/resource-library/776-quick-guide-to-effective-care-planning-with-older-care-home-residents/file

Steps to Effective Care Planning – A detailed guide with practical tips and real-world examples https://heyzine.com/flip-book/73ed2f75b3.html#page/1

Care Planning poster – A visual reminder of top tips for care planning, ideal for staff rooms or shared spaces https://arc-kss.nihr.ac.uk/resource-library/777-care-planning-poster/file

You can share your feedback on the resources here: https://forms.office.com/pages/responsepage.aspx?id=VvqpUTI_mkSnIT4_Sapemt43BRitDW1DpgDHL14YWPVURVFPRUYyOU9CTUxOMDdEQlRGM1hCNk5JSC4u&route=shorturl

Study links sleep disorders to developing dementia

A study published in npj dementia has linked sleep disorders with a doubling of the risk of developing a neurodegenerative disease such as dementia.

Researchers from UK Dementia Research Institute at Cardiff University and the U.S. National Institutes of Health (NIH) Intramural Center for Alzheimer's and Related Dementias, analysed data from electronic health records to examine the relationship between sleep and neurodegenerative disease.

Professor Valentina Escott-Price, Study Co-Leader and Group Leader at the UK Dementia Research Institute at Cardiff University, says:

"Through analysing over 1 million people's health records, we have found evidence to suggest that having a sleep disorder significantly increases someone's risk of going on to later develop a neurodegenerative disease." You can read the study here: https://www.nature.com/articles/s44400-025-00008-0

Skills for Care seeks employers to pioneer the Care Workforce Pathway

Skills for Care is looking for 90 adult social care employers to pioneer the Care Workforce Pathway as part of a new support programme building towards a national rollout. The pathway is a career structure for adult social care developed by the Department of Health and Social Care and Skills for Care, alongside representatives from the adult social care sector and people who draw on care and support. Adult social care employers who join the programme – in either July, September or October 2025 – will receive support, early access to resources, and the chance to shape future policy and practice.

Georgina Turner, Director of Engagement at Skills for Care, says: "The Care Workforce Pathway is an important opportunity to highlight and solidify the professionalism of our sector, and to provide more opportunities for people to develop their skills and build life-long careers within social care."

Find out more and apply here: https://www.skillsforcare.org.uk/Developing-your-workforce/Care-workforce-pathway/Care-Workforce-Pathway-support-programme.aspx. Spaces are limited and allocated on a first-come, first-served basis.

Change and challenge

A message from the editor designate of *JDC*, Toby Williamson

I feel very excited to be the new editor of the *Journal of Dementia Care*, though also slightly daunted. As a reader and contributor to *JDC* over many years, I've always been impressed by the quality of the journal and its articles, and its breadth of coverage. For anyone providing paid support or care for people with dementia it's a "must read", whether they work in health, social care, housing, statutory, private, voluntary or community sectors.

The journal's championing of the voice of people with dementia is a reminder that their aspirations, needs, wishes, beliefs, values, and rights must always be at the centre of the care and support they receive. Those same factors apply to family carers as well, and they must not be ignored either, as well as the challenges that practitioners face. I want the journal to continue to reflect all those perspectives, and provide meaningful, useful, and practical information, research, news and comments, including solutions to the challenges that dementia poses.

My background ranges across a diverse set of roles including managing community-based mental health services, leading the policy campaign for the introduction of the Mental Capacity Act 2005, helping to establish the Dementia Engagement and Empowerment Project (DEEP), leading numerous social research, evaluation and service development projects involving dementia (including on issues such as truth-telling, human rights, and dementia friendly communities), and teaching on a Masters course in dementia care at the University of West London. I chaired my local dementia action alliance in Southwark, London for five years, volunteer at a drop-in for people with dementia and family carers just round the corner from where I live, and go to Scotland twice a month to support my Mum who has dementia. Although I don't come from a professional background in dementia care, I've worked with most professional disciplines over the years (though the only vocational qualification I have is a lorry driver's licence – perhaps not so relevant to this role). I'm also a sort of doctor, having just been awarded a PhD, for a thesis about rights, values, and evidence in dementia (I'll write about this in a future issue of *JDC*).

A broad and inclusive approach

My somewhat eclectic career means that I will maintain the legacy of a broad and inclusive approach to what is contained in the journal. Over the years it has covered an unbelievably wide range of topics, reflecting the fact that good dementia care is about people's lives, not just the condition. This approach is also a hallmark of activities organised by Dementia Community, such as the UK Dementia Congress and the webinar series, so there will be synergy between these and *JDC*.

I'm also a member of Dementia Community's Equality, Diversity and Inclusion (EDI) group that produced the special edition a couple of years ago (see pp24-26).

So EDI, in the broadest sense, will continue to be a feature of the journal, including the voice of people with dementia and family carers. Dementia can be a disability as well as a disease, and people affected by dementia have rights, so I want *JDC* to include examples of EDI good practice and to challenge stigma, discrimination and exclusion. Unfortunately, it appears that dementia and EDI are either being deprioritised or attacked by some politicians, so I would especially welcome contributions that are robust defences against this, with examples involving community, collaboration, and co-production.

As some of you know, I've also been conducting research into what you think of the journal. We will be letting you know the findings from this, probably in the next issue. It may mean some future changes to ensure it attracts as wide a readership as possible. For example, I would like *JDC* to increase its appeal to people working in domiciliary and home care, and supported housing services, so I would welcome any ideas on how to do this.

From the frontline of services

I'm also aware that many services supporting people affected by dementia are experiencing increases in demand, or pressure on resources and funding, or both. I want *JDC* to be the "go to" publication for articles from frontline dementia services, with examples of addressing these sorts of challenges while minimising any negative impact on the care and support they provide. These could be on a whole range of topics, such as managing referrals, recruiting, training and retaining staff, or maintaining high quality, personalised care despite reductions in resources or funding. Ensuring the rights and protections contained in legislation like the Mental Capacity Act or the Care Act (or their equivalents in the other UK nations) are understood and applied correctly in dementia care is also a topic close to my heart. I would therefore welcome practice examples or research articles about these issues as well. If you think you have something that relates to this which could be turned into an article, please do get in contact.

The research I mentioned earlier has partly come out of a real need to increase circulation and subscriptions to *JDC*. I hope that as a reader, whatever you do, you value the journal as an essential way of finding out what's going on, and hearing about new, relevant and useful practice and research. So please help us, and encourage anyone you know, or the organisation you work for, to take out a subscription to *JDC* (and remember, there's a 25% discount if you pay £1 and join Dementia Community).

Finally, I want to say thank you to Dementia Community for inviting me to be the new editor, and give my thanks to previous editors, Sue Benson, Catherine Ross and Mark Ivory, for the great work they have done with the journal over the years. I hope I can do as good a job as they did, build on their legacy, and see *JDC* flourish for many years to come.

See also Comment p5

Tribute to Nigel Hullah

Nigel Hullah was a well-known campaigner and activist in the dementia world who lived with the condition. Sadly, Nigel died earlier in 2025. Here are two tributes to Nigel: one from *JDC*'s incoming editor **Toby Williamson**, and one from **Peter Middleton**, a person living with dementia who knew Nigel well.

All of us here at the *Journal of Dementia Care* and Dementia Community were very sad to hear of the death of Nigel Hullah earlier this year.

Nigel had been a human rights lawyer but was diagnosed with posterior cortical atrophy (PCA), a rarer form of dementia, in 2012, at the age of 59. He spoke movingly of his initial difficulties in coming to terms with the diagnosis but, thanks partly to the care and support he received, came to accept and live with it. Subsequently, he threw himself into campaigning for the rights of people with dementia, speaking at numerous events including the UK Dementia Congress.

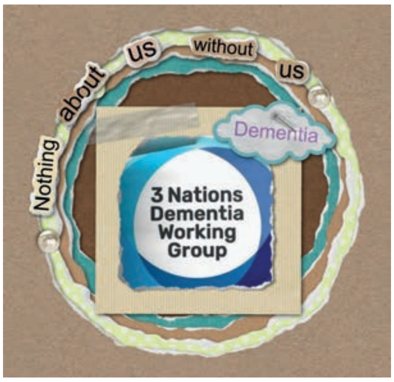
As an activist Nigel was involved in many important initiatives and groups that gave voice to people with dementia. This included being a founder and Chair of the 3 Nations Demenatia Working Group (3NDWG), a member of the European Working Group of People with Dementia, and worked with the Dementia Engagement and Empowerment Project (DEEP) and the University of Worcester Association for Dementia Studies. He was also active in his home nation of Wales, establishing LLeisiau Dementia which gave a voice to people with dementia in Wales, and he was a driving force in the creation of the Dementia Action Plan for Wales.

I met Nigel on a number of occasions and always enjoyed his company, and listening to his views and experience. He was always constructive in his contributions, helped by his cheerful manner, and occasional sense of mischief. I wasn't aware until very recently that he was born into a Roma Gypsy community. Together with his legal background, that gave him additional insights into issues involving equalities, diversity and inclusion. I will miss him, as we all will, and we send our condolences to his family and friends.

There have been many tributes paid to Nigel, including ones from members of Dementia Diaries, to which he contributed. It seems fitting therefore that we include a tribute from someone else living with dementia, and we are very grateful for the contribution here from Pete Middleton, another member of the 3NDWG.

Toby Williamson

Toby Williamson is incoming editor of the Journal of Dementia Care and an independent health and social care consultant. Peter Middleton was diagnosed with Alzheimer's disease in 2019, aged 64. He had a career in the RAF and defence, and now works to raise awareness of dementia through the Dementia Engagement and Empowerment Project (DEEP) and the 3 Nations Dementia Working Group (3NDWG).



Nigel Hullah (pictured above) was not just the Chair of the 3 Nations Dementia Working Group. He was its heart. Its conscience. Its spark. He carried the torch for all of us living with dementia, never letting it flicker in the face of apathy, ignorance, or injustice.

To know Nigel was to be inspired by him. He was a tireless fighter for the rights of people in the dementia community – unyielding, fearless, and principled. But above all, he was deeply human. His strength didn't come from shouting the loudest, but from speaking the truth with unwavering conviction, even when it was uncomfortable. Especially when it was uncomfortable.

He mentored so many of us – not just by teaching or guiding, but by showing us what it looks like to live with dignity, purpose, and defiance in the face of stigma. When the world wanted to write us off, Nigel reminded us that we still had stories to tell, battles to fight, and futures worth shaping.

Nigel believed in inclusion, not just as a word, but as a practice. He knew that people with dementia didn't need sympathy – we needed a seat at the table. And he pulled out chairs for all of us. He fought so that our voices were not only heard, but respected, valued, and acted upon.

But beyond the titles and campaigns, the advocacy and his work with the government of Wales and many dementia organisations and charities both nationally and internationally, Nigel was our friend. He had a wicked sense of humour, a deep well of compassion, and a rare gift for making each of us feel seen. He lifted us when we stumbled. He believed in us when we doubted ourselves.

His legacy is not just in the policies he helped shape or the organisations he strengthened. It's in each of us. It's in the confidence he nurtured, the courage he sparked, and the community he helped build.

So goodbye, dear Nigel. You may have left this world, but your fire is still burning – in our hearts, in our actions, and in the future you helped us imagine.

Peter Middleton

Creative Dementia:

Arts for Health and Wellbeing

In June 2025 Dementia Community and the Creative Dementia Arts Network staged a conference in Bristol exploring creative arts for dementia. **Maria Pasiecznik Parsons** and **Toby Williamson** describe the event, with some of their personal highlights.

On Tuesday 3 June 2025, 150 delegates, speakers and exhibitors gathered at the Museum of Bristol (the M Shed) to participate in the Creative Dementia: Arts for Health and Wellbeing conference. This inspiring event, organised by Dementia Community in collaboration with the Creative Dementia Arts Network, offered a breadth of learning opportunities in a growing field of practice, including presentations by leaders in arts and dementia, skills workshops led by expert practitioners, a bookstall and a range of exhibitors across arts, health and related technology.

Setting the scene: opening plenary session

Suzanne Mumford, Head of Dementia and Lifestyles at Care UK and Dementia Community board member, welcomed delegates and chaired the plenary sessions and presentations. Maria Pasiecznik Parsons, Chief Executive of the Creative Dementia Arts Network went on to welcome everyone in ‘our Dementia Community’. The assembled community included arts, health and culture professionals, practitioners, people with dementia, and family carers, some of them speakers and workshop leaders who greeted the conference and introduced themselves. Following them came greetings and introductions from Pritesh Nathwani, Director of the event sponsors, Symphony Sound, who supplied state of the art acoustic support for the conference, and greetings from all of the exhibitors (see box on p15).

Jayne Howard, Creative Health Associates Programme Manager at the National Centre for Creative Health (NCCH) and Director of Arts Well CIC Cornwell,

The vital role of the arts

There is growing recognition of the important role creativity, arts and heritage can play in dementia care. Benefits for people with dementia and family carers include meaningful engagement, activity, and stimulation, making social connections, improving wellbeing and quality of life, and experiencing fun and enjoyment. Arts practitioners and care staff also find it rewarding; it is informative and helps build relationships.

The Creative Dementia Conference, held in June 2025 in Bristol aimed to showcase examples of work in this field, enable practitioners to network and share learning, and to find possible solutions to the ongoing challenges that prevent the creative arts becoming more embedded in dementia care. The conference was organised by Dementia Community and the Creative Dementia Arts Network.

Reports by Maria Pasiecznik Parsons, Creative Dementia Arts Network/Development Lead, Dementia Community and Toby Williamson, editor designate of the Journal of Dementia Care and an independent health and social care consultant.

Opposite page: The music workshop led by Kate Wilkinson. Above, left to right: Jayne Howard, Programme Director, National Centre for Creative Health gave the opening plenary address; Ronald Amanze (left), who co-led the Box of Smiles workshop, talks to lunchtime seminar presenter Carl Case; lively networking at the conference. Photos: Barnaby Chinnock

began the day's programme with a plenary that introduced the concept of creative health. She sketched out the impetus for the development of arts for health – now known as creative health – was boosted by the seminal All Party Parliamentary Group Report on Arts Health and Wellbeing (2017). This includes a section on arts and dementia.

Jayne described how creative approaches and activities, including arts and culture, are now widely used to improve and support health and well-being across the life span. A key driver is growing evidence of the psychosocial and economic benefits of involving individuals living with disabilities in arts and cultural activities, including their contribution to preventing illness, promoting healthy behaviours, supporting recovery, managing chronic conditions and improving quality of life. Creative health interventions and programmes also include working in partnership with local health and social care providers, and the voluntary sector, with communities experiencing multiple social deprivation.

Jayne spoke about her work with the NCCH which aims to embed creative health approaches and activities into health and care systems. This includes supporting NHS initiatives such as social prescribing and creative commissioning, to show how creative health can play an important part in the new NHS Ten Year Plan, by shifting

The Creative Dementia Conference was sponsored by:

Symphony
Sound

Symphony Sound helps people with hearing loss participate in group situations through their state of the art acoustic equipment and support service for care homes and retirement housing

Thank you to conference exhibitors including companies, charities and professionals:

Painchek is a biotechnology company that has developed a suite of intelligent pain assessment tools now used worldwide in residential care facilities to improve quality of life of patients and residents.

Ally Cares has developed an evidence based acoustic monitoring system for care homes that enables staff to provide safer person centred care for residents.

Little Islands produces artefacts and art works that create unique interactive environments in care homes providing residents with stimulation and meaningful occupation.

Vamos Theatre, established in 2006, is the UK's leading full mask theatre group. producing shows, mask theatre workshops and training for a range of staff.

Equal Arts is a charity that improves older people's lives through arts and creative projects and produces dementia friendly books through their Open Ended Book publishing initiative.

SPH Therapy in Belfast is run by Sean Hughes a psychotherapist offering a range of psychological support services including for people experiencing memory loss and dementia.

BRACE Alzheimer's Research is a Bristol-based charity with a global reach that raises funds for scientific research into dementia carried out by universities in South West England and South Wales.

Pluto Productions focuses on producing plays inspired by true stories including those of individuals and families experiencing dementia which are often commissioned by health and care providers.

National Activity Providers Association (NAPA) is the professional body for Activity Providers who work in care homes and in other health, social care, housing or community settings.

Above left: Carl Case with Josie Reynolds, Academic GP and Clinical Research Fellow at the University of Sheffield, and a masked actor from Vamos Theatre. Above right: Maria Pasiecznik Parsons, Creative Dementia Arts Network gave a presentation on training and workforce development. Photos: Barnaby Chinnock

care from hospitals to communities, leveraging technology, and prioritising prevention over treatment.

Delegates' questions and comments highlighted some of the barriers to scaling up a multitude of participatory arts projects to reach more people living with dementia. Jayne agreed that funding remains a major barrier to increasing access to the arts and she reiterated one of the major themes of her presentation: that partnerships between arts, health and social care are crucial in delivering positive creative health outcomes.

Morning parallel sessions

Following a refreshment break, delegates chose parallel sessions involving workshops and presentations.

Nicola Taylor of Alive Activities and Sharon Parsons of the Bristol Dementia Wellbeing service introduced the Dementia Empathy Suit. The suit enables its wearers to experience the impact of dementia and gain insight into the multi-morbidity of a condition widely believed to be 'just about memory loss'. Rachael Savage from Vamos Theatre volunteered to wear the suit to demonstrate its effects.

Hilary Woodhead (Chief Executive) and Ellie Lucas (Development Officer) of the National Activity Providers Association (NAPA) described its work and the training and support offered to thousands of activity providers in care homes. Every year NAPA organises a National Day of Arts in Care Homes. This year it is on 24 September and has a theme of 'Going Green'.

Helen Jacobs, Head of Learning and Engagement at Bristol's Royal West of England Academy (an art gallery) generously shared the lessons learned (and mistakes made!) in setting up monthly teatime talks for people living with dementia and family carers at the gallery. She highlighted the success of a recent joint project that brought together artists and members of the Bristol Dementia Action Alliance, culminating in a highly-regarded exhibition, showing an arts for dementia programme going from strength to strength.

A participatory workshop involving arts and crafts in care homes was led by Kieun Kwon, Associate Director of Dementia Services at Runwood Homes. The workshop involved making tactile postcards and plasticine prints, and proved so popular participants didn't want to stop when it came to an end.

In a concurrent session Kate Wilkinson facilitated an engaging discussion, describing her work as a musician working with individuals in hospital, and encouraging participants to share their varied experiences.

Developing culturally appropriate resources in arts and dementia

During a lively lunchtime panel session, delegates discussed the question of what helps and what hinders the use of culturally appropriate resources in arts and dementia.

Carl Case, a Dementia Enabler, Trainer and Consultant and co-founder of the Sheffield Memory Hub, Ellie Robinson-Carter, Founding Artistic Director of the Photobook Project, and Dr. Ayokunmi Ojebode, Honorary Research Fellow at the University of Surrey led the discussion and presented two short films they had been involved in producing: one of the films featured Kiyana Wraps, a company whose fashion headwear is also being used to engage people living with dementia from Caribbean and African communities to connect with their cultural heritage whilst second film shown was 'Pirate' about the life of Ronald Amanze, a music producer and poet. Ronald, who narrates his life story and reads one of his poems in the film, was on hand to reinforce his message that art in has helped him to live with dementia.

The discussion and the films highlighted the need for creative practitioners to understand and draw on the cultural heritage of individuals they work with and take account of the double jeopardy experienced by people living with dementia who are members of minority ethnic communities.

Factors facilitating and impeding the full participation of minority ethnic communities in the arts in a multi-cultural society were discussed. These include the need to address systemic discrimination and disadvantage that create

Dementia Community National Art Competition

The Dementia Community Art Competition aims to foster, support and share the artistic work of people living with dementia and that of family carers.

A special part of the conference was the presentation of a prize sponsored by the Creative Dementia Arts Network to the winner of the family carer category of the Dementia Community National Art Competition. Suzanne Mumford presented **Becky Shaylor**, carer for her father Charlie, with a £50 voucher for arts materials, for their painting: *Celebrating Dementia Friendly Alton Assembly Rooms at Christmas (left)*. Becky Shaylor said:

"This painting was co-produced by a father with dementia and his daughter. The subject is Celebrating the first Christmas of Alton Assembly Rooms being home to Dementia Friendly Alton.

"An iconic and familiar building and a service therein which has grown from strength to strength since relocating right into the heart of the town. Contiguous with this conference the painting was used by the Mayor of Alton for the design of the 2024 Town Hall Christmas Card, thus promoting the great value of art and dementia and the amazing service we have locally.

"It was also a personal privilege for this father and daughter relationship which has, for 50 years, been most richly united by a joint love of art and what a joy that this continues to flourish within their lives living well with dementia."

A prize voucher was also sent to **Gail Gregory** who won the person living with dementia category for her painting, *Look Deeper (left)*. Gail Gregory told us:

"At a first glance this piece looks so calming. My protector stands with red flowing scarf, watching over me as I gently navigate the calm waters.

"Look closely - there is a third person! Could that be Dementia? Is my sidekick waiting in the wings to disrupt the calmness?"

All the artwork entered will be displayed on the Dementia Community website in due course

barriers for many people from marginalised communities, including those who seek to train and practise in creative arts and health. This is reflected in Dementia Community's commitment to the principles and practice of equality, diversity and inclusion (EDI) in dementia care and ongoing work including a Special EDI issue of the Journal (September/October 2023).

Afternoon parallel session:
Music, dancing and smiles galore

Highlights of the afternoon included the Box of Smiles workshop run by Ronald Amanze and David Truswell, Dementia Community board member. There were smiles galore, laughter and dancing as Ronald masterfully layered short poems produced by each delegate over dub tracks and took photos which will be shared on Dementia Community's website.

Opportunities to participate in music and dance were a feature of the conference with morning and afternoon workshops. Dance music therapist Richard Coaten led participants in expressive movement and Liv McLennon of Dementia Pathfinders demonstrated the special quality of a circle dance. In another workshop Brian Daniels, a playwright and Chief Executive of Pluto Productions, and Helen Findlay, a family carer, read a play partly based on Helen's experiences. They then engaged delegates in an active process of interpreting and understanding the play's text.

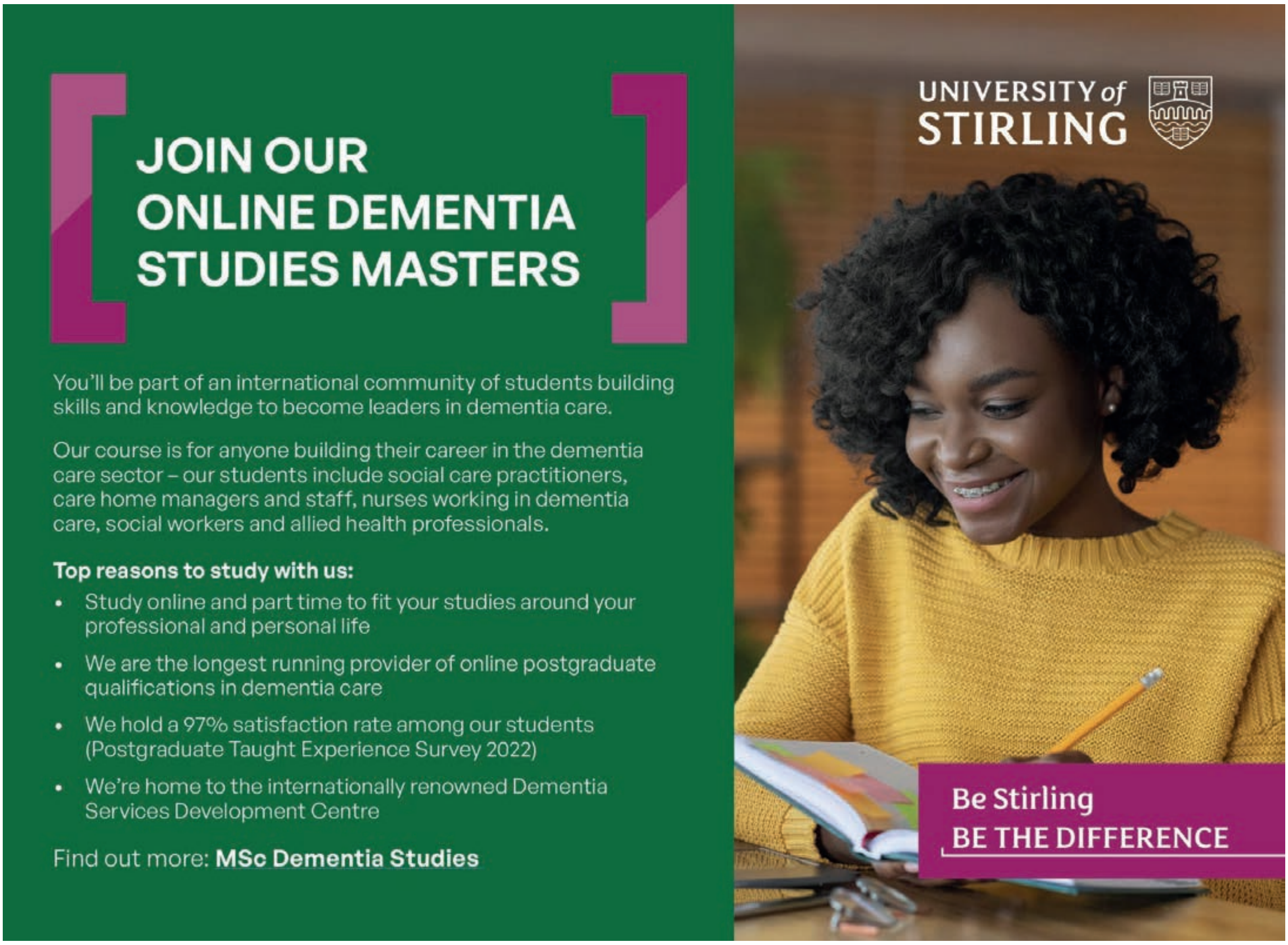
Afternoon presentations included a discussion of training and workforce development (Maria Pasiecznik Parsons, CDAN) and practitioner self-care and support (Julia Pueblo -Fortier, University of Bristol). The importance of creative arts as a social prescribing activity for people with dementia was highlighted by Dr Linda Millar, a GP and National Academy of Social Prescribing Champion. ▷

Thomas Tredinnick, CEO of Ally Cares, introduces the company's work at the start of the Creative Dementia Conference, and participants join Hannah Wood (left) of Equal Arts to examine their co-produced dementia-friendly books.

▷ How can we maintain momentum?

Over tea and vegan chocolate cake, delegates turned their attention to conference legacy in maintaining the momentum of the day. A final panel-led discussion generated ideas on next steps in nurturing the growth of this field of practice. The panel, composed of delegates from organisations attending the conference, agreed that practitioners' needs for training and support were largely unmet, meeting these was a priority, and that organisations involved in arts for dementia should come together to consider whether a national arts and dementia network might help to increase the availability of training and access to support for creative arts practitioners. A meeting to discuss how such a network might coordinate, develop and progress these goals will be organised by panel members.

Overall, the conference illustrated the benefits that creative arts can bring to dementia care and showcased the breadth and vibrancy of this work. Getting creative arts more embedded into dementia care remains a challenge, involving factors such as the need for a greater evidence base to demonstrate its benefits, more funding, training and support for creative arts practitioners and co-production with people living with dementia and developing culturally appropriate resources for diverse communities. Nevertheless, the conference was a celebration of what can be achieved when the creative arts are made available for people affected by dementia.



Dementia Diaries

Diarists share their thoughts and conversations about hearing each other: sensory struggles, shared wisdom, and the power of being involved.

A conversation. A sense of connection. And a reminder of how important it is that people with dementia continue not only to speak, but to be heard by each other.

Wayne, from Kent, shared a powerful three-part reflection on **sensory overload**. He began by enjoying the sunshine and watching the ducks by the river before heading to a local dementia café—an experience he now finds increasingly difficult. Noise, unpredictable movement, and visual busyness have become, in his words, "not just uncomfortable… but scary." What once seemed like background noise is now a constant sensory assault. It's exhausting and, at times, destabilising. Wayne describes having to leave places early, or feeling unsafe and disoriented when the sensory input gets too much.

What's striking, though, is the way Wayne frames this not as something to hide, but something to understand and learn from. He cites Agnes Houston's pioneering work on dementia and the senses—he's moved from curiosity to lived recognition.

https://dementiadiaries.org/entry/22900/wayne-wants-to-highlight-the-sensory-aspects-of-dementia-with-special-thanks-to-agnes-houston/

https://dementiadiaries.org/entry/22904/wayne-talk-in-part-2-about-how-noise-now-bothers-and-exhausts-him-especially-coffee-machines/

https://dementiadiaries.org/entry/22913/wayne-says-it-is-like-losing-a-connection-with-myself-in-part-3-of-his-diary-about-sensory-issues/

Dory offers her own lived experience in response. "Yes," she says, "I've got that too." She shares strategies: wall-facing seating in noisy places, hearing aids connected to her phone to mask anxiety-triggering background noise.

https://dementiadiaries.org/entry/22917/dory-shares-some-tips-about-coping-with-sensory-overload-when-you-are-out-and-about/

Dementia Diaries is compiled and written by Steve Milton, Innovations in Dementia

Then came **Alison**. In her response, she picks up Wayne's theme and holds it gently: "That's something that's always been a challenge for me, but more recently, much more of a challenge." She recounts being at a family engagement party where the volume of the music, and the amplified shouting that followed, left her overwhelmed and disoriented, and she repeatedly had to leave the room to "decompress."

Alison goes on to describe how supermarket freezers and high-pitched laughs now feel physically jarring. "My senses have become much more heightened," she explains. "It's part of dementia I don't think people really understand." Her diary is both a personal reflection and an act of solidarity—one person hearing another and saying, "Me too."

https://dementiadiaries.org/entry/22909/allison-talks-about-her-experiences-of-sensory-overload-with-her-dementia/

This is where **Dementia Diaries** shines. It's not just a platform; it's a peer network. It fosters learning, empathy, and agency from within the community itself.

Which brings us to **Alison's second diary for today.** Her diary is less about sensory issues and more about being **included**—not just accommodated. When a local minister introduced a segregated "dementia-friendly" church service, Alison said no. She didn't want a special slot on a Sunday afternoon. She wanted to continue going with her family, as she always had. What followed was a conversation—and a practical solution. Her church created simplified printed materials, not a separate service. The result? A more inclusive experience for everyone, not just those with dementia.

Her story reminds us of something vital: **well-meaning exclusion is still exclusion**. The solution isn't always to create a separate "dementia version" of something—it's often about adapting the world just enough so people can remain where they already belong.

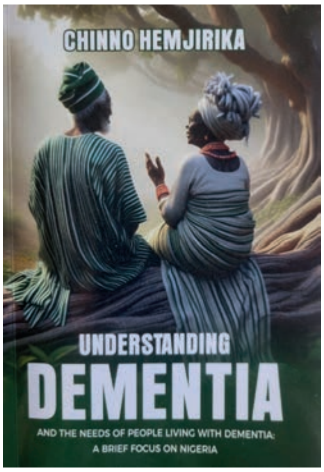
https://dementiadiaries.org/entry/23006/allison-asks-why-segregate-when-we-can-include-people-in-church-services-with-some-small-changes/

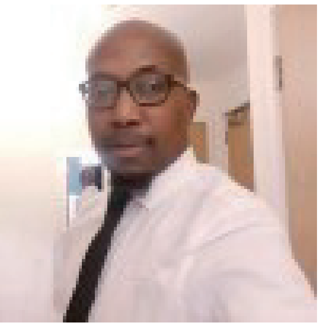
Wayne, Dory, and Alison each shared different experiences—but what unites them is voice, clarity, and purpose. And that's exactly why we need spaces like Dementia Diaries: not just for telling, but for listening—and learning from one another.

Understanding dementia and the needs of people living with dementia – A brief focus on Nigeria

Toby Williamson reviews the first book of its kind to focus on dementia in relation to Nigerian people living in Nigeria and the UK

As awareness grows of the relevance of equality, diversity and inclusion (EDI) in dementia care, there is an increasing need for information and guidance about dementia and dementia care for diverse communities and populations in the UK and other countries. One of these countries is Nigeria, which is the largest African nation by population and also has a large community living in the UK. This book by Chinno Hemjirika, someone of Nigerian heritage who lives in the UK, is a very significant response to that need for information and guidance.





Chinno Hemjirika

As far as I'm aware, it is the first book of this kind that focuses on dementia in relation to Nigerian people living in Nigeria and the UK. The author has academic, practical, and personal knowledge of dementia, and experience of providing care and support to people with the condition, including as a family carer in Nigeria.

The book provides a lot of practical information and guidance about dementia, especially regarding Nigerian people and Nigerian culture. It draws attention to the challenges faced by people living in Nigeria who are affected by dementia because, unfortunately, there are only limited services available to help them, compared to the UK. The book provides very useful information about important aspects of Nigerian culture such as religious and spiritual beliefs, dietary needs, and family roles and structures. I gained a lot of knowledge about these areas by reading the book.

Written in an accessible and at times personal style, I envisage the book being of enormous help to Nigerian families and carers, explaining what dementia is, challenging stigma, ignorance and misunderstanding about the condition, and emphasising the importance of person-centred care and support for people with dementia.

For non-Nigerian carers of people from Nigeria affected by dementia it provides extremely useful, culturally sensitive information about what they need to take into account, such as the role of the family. The book also contains recommendations for improving dementia services in Nigeria. The book would have benefitted from more thorough proof reading, as well as greater attention paid to the layout and referencing. Some of the references in the text are not included in the reference section at the end. The fact that it is written in English also means that Nigerians for whom this is not their first language may have difficulties using the book, but Chinno aims to get it translated into several Nigerian languages.

In conclusion, this book should be of great help to people supporting individuals and families affected by dementia in Nigeria, as well as Nigerians living in other countries. It also represents an important marker for EDI, symbolising the need for practical information and guidance about dementia in relation to different populations and diverse communities in other countries as well as the UK.

Toby Williamson is an independent health and social care consultant, and editor designate of the Journal of Dementia Care.

Understanding dementia and the needs of people living with dementia – A brief focus on Nigeria.
By Chinno Hemjirika. Published by Amazon Digital Services LLC and widely available online.

Scarlett Buckling and the Case of the Missing Pictures

There is a need for more books that engage and explain dementia to children and young people. **Karen Harrison Dening** reviews a new book with a sparky heroine who loves a detective story, and author **Mario Ambrosi** describes his motivation for writing: not only to explain dementia but to highlight the massive contribution of everyone working in social care

When a person is diagnosed with dementia, they and their family members immediately have information needs to mitigate the often-negative psychosocial impact and psychological distress brought about. Children and young people related to a grandparent, or even a parent diagnosed with dementia can often be hidden, unrecognised or unsupported by the mainstream services which are sources of such information, despite their similar experiences and need for such information. Children and young people have additional needs that are both contemporary and subject to change as these align to their stage of development and growth. Therefore, understanding these changes and providing information about dementia that is sensitive to their developmental stage and level of comprehension is crucial in supporting to them to better understand what is happening to their family member, and in enabling them to cope.

There is a small but growing information resource provided for children and young people through story and picture books and fiction-based literature. There are now 'off the shelf books' in high street bookshops that provide information for example, for the very young that describes the function of the brain through pictures and characterisations of the parts of the brain, offering an explanation of what is happening to 'granny's brain'.

However, there is still a dearth of such resources aimed at what (I learned recently) American educationalists call the 'middle-grade' years of 10 to 12. So my interest was piqued when I was approached by author Mario Ambrosi to advise on his manuscript aimed at this age group.

I read about his central character, Scarlett Buckling whose gran had recently gone missing. Scarlett sees her gran as confused, frightened and desperate to find her 'missing pictures'. Alongside her best friend Bournemouth, Scarlett launches an investigation.

We are introduced to Scarlett and Bournemouth and as the story unfolds, we are informed that this sparky little 11-year -old girl loves a detective story, so sets out to find 'the missing pictures'.

The book takes the reader sensitively and cleverly through the plot in such a way that demonstrates integrity, openness, kindness and compassion in the relationship Scarlett has with her gran, which is upheld and not diminished by dementia. I recommend this book, not only to any family member of this age range who is affected by dementia, but also to those who are not, as the messages therein are important for all.

Dr Karen Harrison Dening
Head of Research & Publications, Dementia UK

Mario Ambrosi writes:

Scarlett was born at the end of the pandemic, when most of the UK had largely gone back to normal but Covid tests and facemasks were still a big part of life in care homes.

Working for Anchor, England's largest not-for-profit provider of older people's care and housing, I was acutely aware of what colleagues were doing to make life as positive as possible for residents. At the same time, my uncle was living with dementia, and I needed to explain to my kids why he was behaving in the way he was.

I had two reasons, then, for writing *Scarlett Buckling and the Case of the Missing Pictures*. Firstly, I wanted my kids to understand what was happening with my uncle and feel comfortable asking questions.

I also wanted to show what a massive difference people working in social care make. With the sector facing a recruitment crisis, I hoped maybe to even inspire some care professionals of the future.

Having worked for Anchor in comms and marketing roles since 2005, I've always been amazed at how key facts about someone's life can be clues that help care professionals provide the best care possible. The idea of a 12-year-old girl and her sidekick (the book's aimed at 10-12 year-olds) turning detectives and learning about Gran's life history seemed, as Sherlock might say, elementary.

A former journalist, I spoke with people living with dementia, with their relatives and with several experts – and I'm hugely grateful to everyone who put up with all my questions to inform the story. I was also inspired by the writing of Wendy Mitchell – and was particularly struck by a post of hers that talked about the importance of hope.

Importantly, I also got the views of children. It was a huge boost when the manuscript was made a finalist in the Bath Children's Book Awards, which involves children in the judging, and was great to see their comments.

I also asked teachers for feedback. I am delighted it's been praised by former Education Secretary Lord Kenneth Baker. He said: "I loved meeting the dementia detectives Scarlett and Bournemouth. It is important children learn about dementia, and this sensitive story will help children and adults alike."

Scarlett Buckling and the Case of the Missing Pictures is published by Tiny Tree on 17 July 2025. It is available to order from Amazon and other online retailers.

Creating change for Young Onset Dementia support

Debby Lennox of Dementia Forward describes how the charity reinvented local support for younger people with dementia, pioneering a specialist, age-appropriate care and support model that could be shared nationally

Time Out Together, outward-bound respite service in the local community

Dementia Forward, a North Yorkshire charity, is entering the fourth year of its Young Onset Dementia campaign. The U&ME campaign (because it could be you or it could be me), was created to raise awareness, and keep people living with young onset dementia doing the things they enjoy for as long as possible. It also aimed to deliver a pioneering, specialist, age-appropriate care and support model that could be shared nationally. As part of the campaign, Dementia Forward started an annual conference and this year, the third U&ME conference 'Creating Change' will welcome four times as many people, as the campaign objectives start to come to life. Delegates will hear from professionals and people with lived experience and pertinent topics will be explored in interactive workshops. The conference will be held on 14 October 2025 at Elland Road stadium, home of Leeds United Football Club, in the same month as National Young Onset Dementia Awareness Day (24 October), which the charity launched in 2022 #YODA.

Dementia Forward began supporting people with young onset dementia in 2012, when they took over the running of a support group in the Harrogate area, not realising just how huge and complex the need would be. The support group was meeting in a locked hospital ward, but it quickly became apparent that this was neither suitable nor beneficial for the people who attended. So, with the input of the group members, Dementia Forward reinvented it, creating Time Out Together, a new outward-bound respite service – taking people for a full day out in the local community. Meet-ups suddenly included table tennis, croquet, theatre tours, nature trails, cycling and even a session on the flight simulator at Sutton Bank. Jill Quinn, CEO, says 'We have never looked back from that day when we swapped hospital food for a packed lunch and armchairs for walking boots'. Thanks to funding from the National Lottery Community Fund, this service is now available in three areas of North Yorkshire.

Very early on, Dementia Forward recognised that the data is wrong, understanding is poor and, for people living with the condition looking for support, there is a vacuum. Dementia is described as 'Young Onset' when symptoms develop before the age of 65, and in their young onset services Dementia Forward are mainly supporting people in their 50s, with some as young as 40 years. The stats told them there should be 173 'younger' people living with dementia in North Yorkshire, but by 2020 they were supporting 250.

Dementia Forward's aim for every person who has Young Onset Dementia is to support them to live well in

Key points

- Dementia Forward's model of support for people with young onset dementia extends from pre-diagnosis to end of life.
- Current statistics suggest that people with young onset dementia account for 7.5% of all people living with dementia
- People living with dementia and their families in North Yorkshire can self-refer to Dementia Forward, or be referred through a medical practitioner.
- Dementia Forward is looking for other organisations developing innovative ways to support people living with young onset to join their campaign wwww.youngonsetdementia.org.uk
- Dementia Forward launched a track, written using the words of a man living with young onset dementia. You can listen on their YouTube channel or on your usual streaming service – search for Y.O.D.A

their own homes, doing what they love for as long as they possibly can. The outward-bound group was innovative and provided peer support and a day of respite for carers, but this was not enough, in fact it created a cliff edge. As people began to need more care, it became clear that all that was available was care services for people who were more elderly and frail. Jill Quinn says: "The people we support can have mortgages, problems with employment, teenage children living at home, family carers trying to continue working and all this with friends and family who probably have no knowledge about the condition, so feel powerless to support. We quickly attracted hundreds of families who needed support and realised that we would have to take action".

So, the U&ME campaign was started, with an ambition to address each of the stages of the illness, from the complex and slow diagnosis to the provision of age-appropriate long-term care. The campaign has prompted huge mind-set change, influencing Government and agencies to think outside of the traditional settings and activities currently provided; training and inspiring leaders and practitioners to get care right and using real stories of people affected to demonstrate the need.

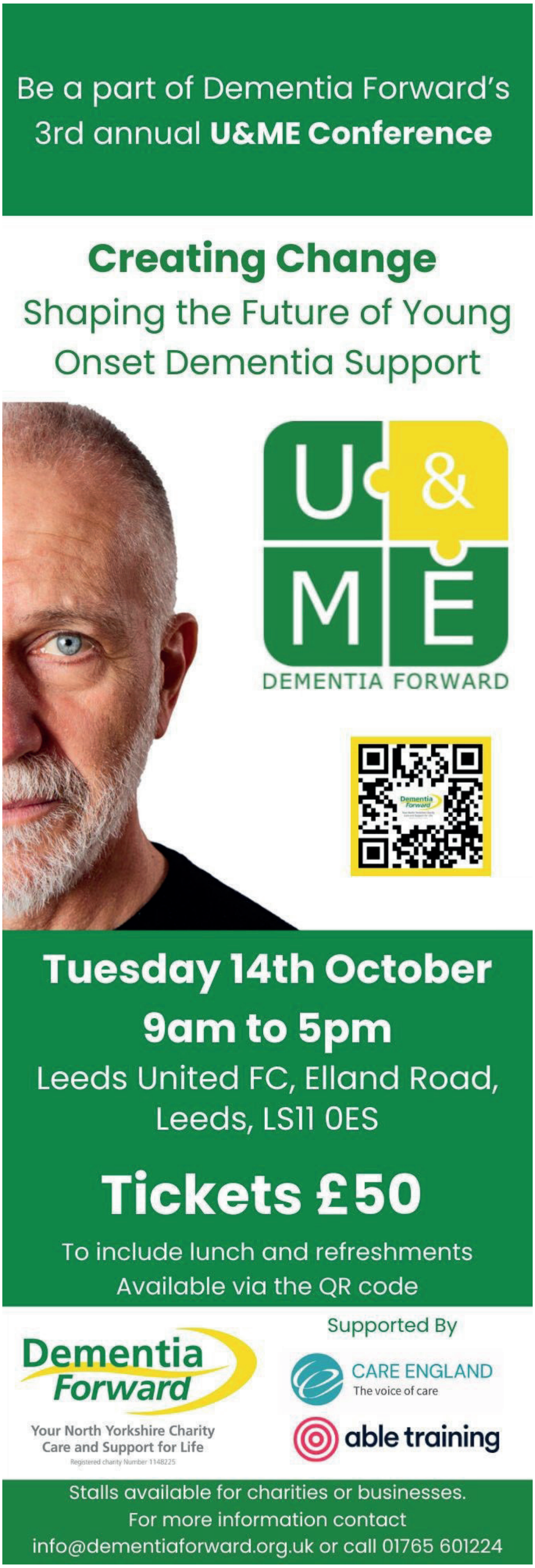
Karen Thomas, Head of Young Onset at Dementia Forward says: "Our vision is to work with people and families affected, so practitioners gather real experiences to base learning on, not simply adapting traditional training, but starting from a blank canvas to create a specialist, age-appropriate care model. We have worked with universities to gather data and to research the experiences people have had; and we have worked with care home providers to develop specialist care facilities. These homes have the right environment, the right menus, the right level of physical activity and, most importantly, the necessary training for staff, so that they fully understand the complexities of the condition."

The campaign, and the annual conference, have helped Dementia Forward to meet others across the country who are supporting people living with young onset dementia and together they have created a voice.

Care England's CEO Professor Martin Green OBE has supported the campaign from the outset saying, "I am so impressed by the way the campaign is committed to cascading the lessons learned from Dementia Forward's own outstanding work to the entire system... This campaign is ground breaking in so many ways, and the creativity and innovation that lies at the heart of this work will be an exemplar for many future campaigns."

The next step for Dementia Forward, starting this summer, is the opening of a Centre of Excellence for Young Onset Dementia. It will be led by a graduate recruited by Leeds Beckett University under a 'Knowledge Transfer Partnership'. It will begin with a training centre and a technology hub for care aids and the university will work with Dementia Forward to refine data and research on what quality care for young onset should look like.

To book for the U&ME conference, or if you are interested in a stall in the marketplace at the event, email info@dementiaforward.org.uk or call 01765 601224. For more information on the charity, visit the website www.dementiaforward.org.uk.



Be a part of Dementia Forward's 3rd annual **U&ME Conference**

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Equality, Diversity and Inclusion:

Dementia Community's EDI group undertakes and promotes EDI initiatives

The principles and practice of equality, diversity and inclusion (EDI) are extremely relevant to the field of dementia. **Toby Williamson** (below) and other members of Dementia Community's EDI group describe the group's recent work for Dementia Community and the dementia sector more widely.

Summary

The principles and practice associated with equality, diversity and inclusion (EDI) are essential to good quality dementia care, despite recent political attacks on EDI initiatives. This article describes the work of Dementia Community's EDI group in promoting an awareness of EDI in the dementia sector, and features contributions from several members of the group to demonstrate its diversity and different perspectives

Issues involving equality, diversity and inclusion (EDI) are central to dementia care, as well as in the work of Dementia Community. EDI is about ensuring equitable access to dementia care and support, recognising and responding appropriately to the different effects that dementia has on people living with the condition from diverse communities, and their different needs. EDI is also about making sure that people with dementia do not experience discrimination or exclusion because of their diagnosis.

The UK's Equality Act 2010 provides a legal framework for EDI by reminding us that people affected by dementia have rights. The Act aims to protect people from discrimination and exclusion on the grounds of their characteristics such as age, gender, race and ethnicity, sexual orientation or disability ('protected characteristics'). Under the Act, dementia can be considered to be a disability.

In 2023 a special edition of the *Journal of Dementia Care* (Vol 31 No 5, September/October 2023) was entirely devoted to EDI. It explored the principles of EDI, provided guidelines for dementia care organisations explaining how to implement EDI, and gave some excellent examples of EDI in practice involving people affected by dementia. You can access the edition for free via a link on the home page of our website: www.journalofdementiacare.co.uk. This special issue was put together by Lucy Whitman and other members of Dementia Community's EDI group.

The work of the EDI group

The group was formed in 2022 by people associated with *JDC* and Dementia Community from a variety of backgrounds. The group aims to raise awareness of the importance of EDI across the dementia sector and ensure that EDI permeates all the work of Dementia Community. This includes issues of intersectionality; recognising that personalised dementia care needs to take into account individuals' multiple demographic characteristics, and how this can lead to people experiencing several forms of exclusion and discrimination.

The group was boosted by several EDI-focused sessions at the UK Dementia Congress in 2022, which were well attended by people wanting to share relevant experiences, and know more about EDI and how to put it into practice. Since then, the group has been meeting regularly, every two months, online. The group is free to join for members of Dementia Community. Most people do this work in their own time and it is largely self-supporting, so members need to be willing to actively help. The group has shared principles and Terms of Reference and its

Toby Williamson is an independent health and social care consultant, and editor designate of the Journal of Dementia Care. John Bond is a PhD Researcher and Postgraduate Representative for Dementia and Ageing in the School of Social Science at the University of Stirling. Dr Chris Knifton is Associate Professor in Neurocognitive and Neurodevelopmental Education in the School of Nursing and Midwifery at De Montfort University, Leicester. Dr Jennifer NW Lim is a Reader in Health Inequalities and Behavioural Science in the Faculty of Education, Health, and Wellbeing at the University of Wolverhampton. Jude Sweeting is a Director of Dementia Community, and chair of two dementia organisations, Resonate Arts and Dementia Pathfinders.

Key points

- The principles and practice of equality, diversity and inclusion (EDI) are central to good quality dementia care.
- Stigma and exclusion experienced by people living with dementia means that EDI can apply to anyone with the condition as well as people with dementia from diverse and minority communities.
- EDI is supported by the UK's Equality Act 2010 that prohibits discrimination based on aspects of people's identity ('protected characteristics') such as gender, race and ethnicity, age, sexual orientation, and disability.
- Everyone has multiple characteristics and this can lead to some people experiencing several forms of discrimination or exclusion. This is known as 'intersectionality'.
- Dementia Community has an EDI Group which is committed to promoting EDI in the organisation and dementia care more widely. People are welcome to join the group to support that commitment.
- The EDI Group has a set of shared principles and its membership reflects diverse communities affected by dementia.
- The EDI Group has successfully undertaken several pieces of work including producing a free, special EDI edition of the *Journal of Dementia Care* in 2023.

membership reflects diverse communities affected by dementia.

As well as putting together the special edition of *JDC*, the EDI group has been active in trying to ensure that EDI continues to feature regularly in the journal. This has involved encouraging articles about EDI initiatives in dementia, and asking that authors include EDI considerations when submitting more generic articles. Similarly, the group has kept a focus on EDI at the UK Dementia Congress, through an expectation that proposals for presentations include reference to EDI. This could include for example, work specifically focused on diverse communities affected by dementia, active involvement of people with dementia, challenging stigma and discrimination, or reference to the rights of people with dementia. The group has also been developing an EDI framework for Dementia Community that will be publicly available via the website to show Dementia Community's commitment to the principles and practice of EDI.

Challenges

Unfortunately there has been a backlash against EDI, most notably in the USA under President Trump, but also in the UK, with crude misrepresentations and derogatory comments about "wokeism". Some EDI initiatives have also been seen as tokenistic, and other terms are being used to denote EDI, such as "belonging". In the face of these challenges, and irrespective of terminology, Dementia Community's EDI group believes it all the more essential to promote the importance of EDI and its benefits and relevance to dementia care. And in the spirit of EDI, to reflect the diverse but interconnecting perspectives of the EDI group, the rest of this article consists of contributions from members of the group.

If you are interested in finding out more or joining the EDI group, please contact info@dementiapublishing.community

John Bond – PhD Researcher & Postgraduate Representative (Dementia and Ageing, University of Stirling)

I joined Dementia Community's EDI Group because my personal and professional journey has shown me how urgently we need more inclusive, representative dementia care. As Director of the LGBTQ+ Dementia Advisory Group, a dementia researcher, a former care professional, and a former unpaid carer, I've seen first hand how identity shapes experience – not just of dementia itself, but of the care, support, and systems surrounding it.

Too often, people from under-represented communities are left out of conversations and decisions that directly affect them. This is particularly true for LGBTQ+ individuals living with dementia, whose needs can be misunderstood, overlooked, or dismissed. Through my work, I've been advocating for environments where people can live and age authentically, safely, and with dignity.

Joining the EDI group felt like a natural extension of that advocacy. I want to help ensure that equity, diversity, and inclusion are not just discussed, but embedded in practice – within the pages of the Journal of Dementia Care, in policy, and across services. The Journal plays a key role in shaping perspectives, and it must reflect the full richness and complexity of the communities it serves.

This work is about justice, visibility, and change. It's about making sure every person affected by dementia – regardless of who they are – has their voice heard and their needs met.

Dr Chris Knifton – Associate Professor in Neurocognitive and Neurodevelopmental Education, De Montfort University, Leicester

As the newest member of the EDI group, I come with a particular interest in supporting greater neurodiversity awareness across the dementia community and to shine a light onto areas of under-representation, such as childhood dementia.

In light of the former, I am open about my own neurodivergence – autism, while also taking time to consider other forms of neurodiversity and its impact on a person's lived experience in dementia. One example can be information-giving for carers (both formal and informal), and how we can better incorporate reasonable adjustments to make information-sharing and support more accessible. I also encourage a broader narrative that, as a neurodivergent community, we also have a lot to offer. We are not just "victims" of our neurodivergences but have strengths too (neurodiverse-ability) that can be used positively to embrace our carer-capabilities-capital within the dementia space.

Regarding the second point I mention above, childhood dementia, it reminds us too that dementia is a large community of practice, but some communities are at risk of being marginalised and not seen. Childhood dementia is estimated by the Childhood Dementia Initiative to affect 700,000 children and young people worldwide and causes 204 deaths in the UK every year, a figure comparable to the 260 deaths annually from childhood cancer. Think for example, when did you last attend a conference or read an article that looked at childhood dementia? For our student and professional audience, was childhood dementia ever discussed in your dementia lectures?

Having voice, facilitating dialogue and sharing experiences (not just challenges but also strengths) remain core to our dementia community. This is notably enhanced through the EDI group, and has created a safe space to embrace our collective EDI commitment.

Dr Jennifer NW Lim – Reader in Health Inequalities and Behavioural Science, University of Wolverhampton

Dementia Community's EDI group was established in 2022 to promote equitable dementia care for marginalised communities in the UK. As a researcher of Chinese heritage, I joined the group to advocate for the dementia-related needs of the UK's Chinese population and to highlight the cultural, linguistic, and socioeconomic diversity of that population. Despite being one of the UK's largest ethnic minority groups – with a population of over 600,000 – the Chinese community remains severely under-represented in dementia research. When the Chinese community is included in studies, research often relies on small, localised samples near academic institutions, overlooking and failing to recognise the needs and experiences of the widely dispersed majority. Additionally, the community's rich diversity – rooted in varied migration histories and places of origins – is frequently overlooked. Having led the first nationwide dementia intervention aimed at prevention across six cities in England and Wales for the Chinese community, and conducted research into dementia awareness within this population, I am committed to raising the visibility of this overlooked population, in both research and policy through the work of the EDI group.

Jude Sweeting – Director of Dementia Community, Chair of Resonate Arts and Dementia Pathfinders

My interest in the Dementia Community EDI Group is rooted in over 30 years of experience as a woman working in various roles in dementia health and social care, and in my personal journey caring for my parents, who both lived with dementia between 1995 and 2003. These experiences showed me how inequality – like water to a fish, unseen but ever-present – shapes the experience of both living with and caring for someone with dementia, especially where protected characteristics intersect. Gender profoundly shapes this landscape but is often overlooked. Dementia disproportionately affects women – not only are they more likely to live with the condition, they also make up the majority of unpaid carers (and paid carers), often at great cost to their health, financial wellbeing, and independence.

Attending the 2022 UK Dementia Congress refreshed my thinking. I was struck by something Ronald Amanze, who lives with dementia, said to a room mainly full of professionals: "You **don't** listen!". It made me realise, emotionally rather than intellectually, that many people are *still* not within earshot. That uncomfortable moment reshaped my approach: I asked for help, and I was immediately and effectively assisted by a member of the EDI group. Since then, at Resonate Arts, I've been working differently to embed EDI through small yet bolder steps – within the limits and possibilities of a small charity in a very diverse inner-city community.

To the EDI group I bring lived experience, a commitment to collaborate, and a deep belief that equity must guide all Dementia Community Board decisions – it's a unique force driving the learning and sharing needed for the inclusive community we all deserve.

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Gujarati Cognitive Stimulation Therapy: more than a translation

Cognitive Stimulation Therapy (CST) is an important non-pharmacological intervention in dementia but may not be accessible for different groups in the population. **Lynde Booth Collard** and colleagues share their co-produced method in adapting CST for a local Gujarati population.

Summary

Cognitive Stimulation Therapy (CST) is a non-pharmacological intervention recommended by UK NICE guidelines. It has a decade-long presence in the evidence base for improving cognition and quality of life for people diagnosed with dementia. Although memory services offer CST, it tends to be delivered in the English language. This can exclude people for whom English is not their first or preferred language of communication, and this was evident in our diverse population here in the London Borough of Brent. Our aim therefore was to reduce inequalities by improving access for people with the second most spoken language in the borough, Gujarati.

The adaptation process involved a community-based developmental approach, incorporating the Formative Method for Adapting Psychotherapy (FMAP) protocol. The approach at Brent Memory Service included collaboration with stakeholders such as mental health providers, community organisations, and engaging cultural consultants to ensure cultural relevance.

The adapted Gujarati CST programme consisted of ten weekly sessions, each lasting 75 minutes, featuring culturally relevant activities such as categorising objects, food, and playing traditional games. Family carers were also involved in the adaptation process, providing feedback to refine the sessions further. This process of checking and re-checking was vital to the development of a relevant programme for the intended group.

The project highlights the importance of culturally adapted interventions in enhancing the relevance of CST, but in way that is far more inclusive than a simple translation of English concepts or developing a 'one size fits all' approach that is never re-checked and revised.

The UK's Memory Services National Accreditation Programme (MSNAP) recommends that memory services offer a Cognitive Stimulation Therapy (CST) group to patients recently diagnosed with a dementia (Jethwa *et al*, 2025). CST has a robust evidence-base; it has been shown to significantly improve cognition and quality of life (Aguirre *et al* 2013a; Orrell *et al* 2014; Spector *et al* 2003). CST is the only non-pharmacological intervention recommended to promote cognition for people with dementia by UK National Institute for Health and Clinical Excellence (NICE) guidelines (NICE, 2018). CST has been known to improve communication skills, thinking, memory, quality of life and wellbeing. It also provides an opportunity to socialise, to practise staying physically and mentally healthy, and to explore and share one's strengths and difficulties. The original manualised CST programme which was developed by Spector *et al* (2003) consists of up to 14 group-based face-to-face sessions. CST has been adapted, translated and validated in various cultures and languages across the globe and is currently being used in over 29 countries (Marinho *et al*, 2020). As CST was developed in the UK, some activities became less relevant and effective in populations and cultures that CST was not initially intended for.

Community Profile of Brent and the Formative Method for Adapting Psychotherapy

The London Borough of Brent is a diverse borough (the second most ethnically diverse borough in London) with 149 languages spoken. Gujarati is the most commonly spoken language (after English) in Brent as the Asian-African diaspora came to Brent in the 1960s-70s. A community-based developmental approach was chosen for assessing the relevance of any CST adaptations, known as the Formative Method for Adapting Psychotherapy (FMAP) protocol. As seen in Table 1, FMAP is a five staged, bottom-up approach to collaborate with the communities being worked with, and generate meaningful adaptations in therapy (Hwang, 2009). The approach included working with community consultants at the first stage to develop ideas for therapy adaptations. When CST was being adapted it required generating knowledge and collaborating with stakeholders relevant to

Lynde Booth Collard is a Dementia Behavioural Specialist with Central London Community Healthcare NHS Trust and Central and North West London NHS Foundation Trust. Sonia Davda is a cultural consultant with Brent Memory Service and a professional interpreter. Dr Navi Nagra is the Lead Clinical Psychologist for Brent Older Adults and Healthy Ageing Mental Health Services and Memory Service. Dr Abhishek Shastri is a Consultant Psychiatrist for Brent Memory Service, Central and North West London NHS Foundation Trust

Above left to right include; Lynde Booth Collard (OT), Sonia Davda (Interpreter and Cultural Consultant) and Dr Navi Nagra (Lead Clinical Psychologist). Top Right – some traditional Gujarati breads and pastries. Bottom Right – popular childhood game of Carrom Board.

Gujarati customs and groups. Stakeholders included service users, mental health providers, community-based organisations and agencies, spiritual and religious organisations and professional interpreters. Stakeholders were consulted on a continuous basis to further assess and make modifications to the intervention.

Starting as we mean to go on

As we progressed utilising FMAP, it was important to hold in mind the principles and steps at every stage of development and delivery. This included CST group content, leaflets, letters and outcome measures being adapted, translated and re-checked with cultural consultants (See Figures 1 and 2).

For all referrals that were accepted, an invitation letter was sent to the person's home for a 'Chai Afternoon' screening assessment at clinic. To demonstrate the welcoming of service users into the memory clinic, staff facilitators wore traditional Indian attire and provided culturally appropriate snacks and homemade chai in between screening sessions.

Incorporating 'chai screening' enabled people to locate the clinic, learn more about CST, and meet each other in a social setting demonstrating the principles of CST from the start. Group facilitators were also able to meet each person in advance of a group starting, in order to assess their suitability and complete group outcome measures with them. People were provided with a description of the CST programme in English and Gujarati, by the lead clinical psychologist and Gujarati co-facilitator. Those who did not wish to continue with the group or wanted more information about support available in the borough were introduced to a dementia charity partner who also attended the assessment day.

Applying CST using FMAP to Brent's Gujarati Population:
1 Generating general community and cultural knowledge with stakeholders – pre-planning meetings with Gujarati staff and cultural consultants
2 Applying general community and cultural knowledge to CST theory – adapted PowerPoint slides, handouts, outcome measures
3 Review adaptations – adaptations sent to other cultural consultants, approach people in the community, Gujarati staff
4 Testing the adaptations – delivering adapted CST and getting on the spot feedback, as well as through staff/ family carer catch-up sessions.
5. Finalising the culturally adapted intervention

Table 1: Five Stages of FMAP with Brent Gujarati CST

The inclusion criteria for the Gujarati CST group were as follows:

- female or male participants;
- aged 65 or older;
- diagnosed with dementia, with their cognitive impairment assessed at 'mild to moderate' (not 'severe');
- be able to tolerate being in a group environment without their main family caregiver;
- be able to follow basic Gujarati conversation and engage in activities with other group members. ▷

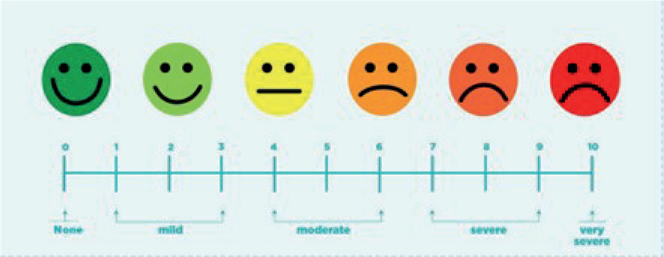


Figure 1 (above): Mood scale utilised for pre- and post-measures

Figure 2 (right): Translated 'Save the dates' poster

Gujarati CST GROUP

SAVE THE DATES

Fairfield's House, Fairfield's Crescent, Kingsbury, NW9 0PS

બુધવાર/Wednesdays 1pm-2.15pm

Session 1: 5th June 2024
Session 2: 12th June 2024
Session 3: 19th June 2024
Session 4: 26th June 2024
Session 5: 3rd July 2024*
Session 6: 10th July 2024
Session 7: 17th July 2024*
Session 8: 24th July 2024
Session 9: 31st July 2024
Session 10: 7th August 2024*

*loved ones can also attend

▷ The CST group took place at a clinic located in Brent. Service users needed to understand the purpose and nature of the group in order to provide informed consent for their participation.

Performance scoring on cognitive screening tools such as the Addenbrooke's Cognitive Examination (ACE-III) or Rowland Universal Dementia Assessment Scale (RUDAS) took place during the initial assessment at the memory clinic. Information was also used from the facilitators clinical assessment to support the facilitators overall judgement.

In addition, family carers were invited to an online carers' session before the CST group started. The online carers' session provided carers with evidence-based research information and resources which they could use with the person outside the ten CST sessions. They were also provided with information about venues in London deemed "dementia friendly" that the carer could visit with the individual, and an email address was given to the carers, linking them to a dementia advisor.

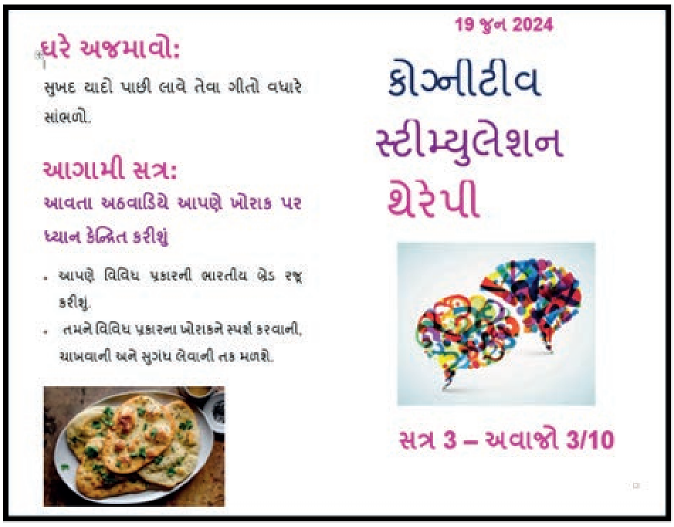
Gujarati CST – small adaptations

The Gujarati CST group involved ten FMAP-developed sessions of one hour and fifteen minutes each, taking place weekly. In line with the CST protocol, the group chose and agreed a team song which was played at the start of every session. The song was followed by use of an orientation board to highlight and review the day, month and location. After this a discussion about current world affairs took place. The session included a chai break whereby individuals could socialise while enjoying their tea, followed by a task with a certain theme incorporated into every session. Activities such as categorising culturally relevant objects and scents found in a home or garden made connections (emotional, cultural, etc.) with a sense of home and a feeling of safety (Knocker, 2024). This included listening to different sounds, tasting and smelling a variety of foods and spices, which embodied the power of senses in terms of linking these with identity. Guessing famous faces and landmarks are incorporated into other intervention sessions.

Key points

- Cognitive Stimulation Therapy (CST) is a recommended intervention, shown to improve cognition and quality of life for people with dementia.
- CST was culturally adapted for Gujarati speakers in a London borough through collaboration with local stakeholders, using an approach known as the Formative Method for Adapting Psychotherapy (FMAP).
- CST sessions included activities linked to participants' cultural identity, such as popular arts, reminiscence, and food tasting.
- Continuous feedback from participants and family carers refined the CST programme to be culturally relevant.
- The work highlighted the importance of feedback and reflection, with plans to expand CST access to neighbouring areas.

Additionally, carers were invited to attend two sessions involving physical games, comprising of a carrom board (a flat, square table game with pockets in each corner, typically made of wood, where players use a heavier striker disc to flick smaller carrom discs into those pockets) and playing seated cricket with participants. Each session ended with the song and a Gujarati-translated handout summarising the session and suggesting activities to try at home (see Figure 3 below).



ઘરે અજમાવો:

સુખદ યાદો પાછી લાવે તેવા ગીતો વધારે સાંભળો.

આગામી સત્ર:

આવતા અઠવાડિયે આપણે ખોરાક પર ધ્યાન કેન્દ્રિત કરીશું

- આપણે વિવિધ પ્રકારની ભારતીય બ્રેડ રજૂ કરીશું.
- તમને વિવિધ પ્રકારના ખોરાકને સ્પર્શ કરવાની, ચાખવાની અને સુગંધ લેવાની તક મળશે.

19 જુન 2024

કોગ્નીટીવ સ્ટીમ્યુલેશન થેરેપી

સત્ર 3 – અવાજો 3/10

Figure 3 – Example of translated and consultant-checked handout

Service users	Carers
“Samosa was good” *Note – this was in relation to the relevant adaptations made through the food activity.*	“*We like the adaptations made by you*”
“I liked that everything was explained in Gujarati. Whatever staff are doing, they are doing well., they are doing well”	“*We think everything has been relevant*”
“*Yes, everyone is of similar age and similar*”	“*My father has been enjoying the group and would occasionally speak about the group at home*”
“*I liked sharing food*”	“*We think it’s relevant – it could be discussions about Gujarati culture*”

Table 1: Feedback from CST service users and carers at the midway point

Ongoing product of co-production

As part of the FMAP and co-production ethos of the work, ongoing feedback was sought from participants and carers. A mid-point catch up meeting was scheduled in with participants to ask for feedback on the adaptations we had aimed to be culturally relevant. To gain additional information about adaptations made to the programme, family carers also provided informal feedback to facilitators to further refine the sessions. Aguirre *et al* reported that working with diverse CST groups requires the assembly of feedback that can be used to produce validated adaptations of the programme (Aguirre *et al*, 2013b). Table 1 (above) depicts some of the feedback from both CST group members and carers at the halfway point of the sessions. This allowed a check in with those accessing CST in real time and supporting or adapting the suggestions from external cultural consultants.

Closing remarks

In conclusion, the experience of co-producing and adapting CST to connect to part of our Gujarati community has been truly rewarding. The warmth in the connection through shared meaning and relevant content made the CST group a place to honour both personhood and the principles of CST.

Some learnings and future directions we have gained include:

Having clear lines of communication when adapting and translating the materials is important. This ensures FMAP steps were not missed or neglected.

Providing and protecting time for self-reflection. It can be tempting to assume one is culturally relevant by adapting CST materials, but what this approach has shown is that meaning is different at every step and for each group worked with. Therefore, one cannot assume an adapted CST group will be just as relevant for another Gujarati speaking group. Ensuring regular check-ins with participants for feedback and utilising supervision to self-monitor accessibility is important.

Engagement with CST has been improved for the community by raising awareness of how to access CST and its importance for living well with dementia, with group attendees and cultural consultants. These endeavours have also allowed neighbouring boroughs to consider their populations and a cross-borough referrals system is being discussed.

Sharing information about the group in different settings, platforms and webinars has allowed the message to reach wider audiences and improve practice.

To hear more reflections from our cultural consultant, interpreter and CST co-facilitator Sonia Davda, please scan the QR Code, right.

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Cognitive Rehabilitation therapy

Should it be provided for people diagnosed with dementia?

GREAT Cognitive Rehabilitation therapy has been shown to be effective in addressing lost abilities. **Jackie Pool** and **Emma Marshall** (left to right below) describe how it was used effectively to help an individual and his family, and recommend that this therapy should be offered as a post-diagnostic service.

Summary

This article describes the use of a cognitive rehabilitation therapy programme to address lost abilities of a person diagnosed with dementia. It demonstrates how it is possible to learn from an accessible e-learning course to deliver the personalised programme in a few sessions in order to support an individual to improve in function and in well-being. The programme is evidence-based and the course and tools are free to access.

In this article, the journey from being diagnosed to benefiting from the cognitive rehabilitation programme is related by the family and illustrates how difficult it can be for individuals to currently receive enabling support. It suggests that GREAT Cognitive Rehabilitation therapy should be available and accessible via statutory services to all people who are living with dementia.

Traditional dementia care has focused on a model of passive care which, even when at its most person-centred, is likely to be disabling and disempowering as carers tend to compensate for the person's difficulties by stepping in to do the things the person is struggling with. Evidence now requires us to disrupt this outdated model which, whilst well-intended, may be viewed as acting against the disability rights of individuals who are living with dementia.

This is the story of Jim and his daughter Jenny. Their names have been changed to protect their anonymity but their story is real and true. It begins with an interview with them about their post-diagnostic experience following Jim's diagnosis of dementia from his GP in July 2024. This followed a gradual decline in his ability to find words which impacted on his participation in conversations and on his emotional well-being.

JP: What were your expectations of treatment and support when you received the diagnosis?

Jenny: I expected that a specialist would explain the diagnosis - as with any other condition - and explain what support and treatment options there were for us. Instead the Memory Team communicated the diagnosis to the GP who then communicated it to us. We heard that medication was not appropriate, but nothing else was offered except support groups for people with dementia and their carers.

I had hoped for something which would help keep my dad as well as possible for as long as possible, managing independently as much as he could and helping us build on strengths. I also wanted something which would educate us in how to support my dad, maybe correct some 'wrong' attitudes which can imply blame or end up putting energy in to things which are not helpful.

JP: Were you provided with any information about how you could address the difficulty in doing things caused by the memory problems?

Jenny: No nothing like this was offered. I asked about cognitive support and later received a leaflet about CST (Cognitive Stimulation Therapy). At that point we made a self-referral, but we have never heard back.

So, I went online and also began talking to people. Someone sent me a link to the Exeter University GREAT CR therapy work and from there I found the Alzheimer's Society Living Well guide. At that stage my dad was so pleased to read something that helped him understand that he was not so isolated, that this was an illness not a failure. I looked up GREAT CR therapy and searched 'rehabilitation' to find different providers. Peartree came up in the search and I saw that they did some work with

Jackie Pool is an Advanced GREAT CR Practitioner, retired occupational therapist and Campaigner for Occupational Justice for people living with dementia
Emma Marshall, is Specialist Neurological Occupational Therapist working for Peartree Community Services.

people experiencing dementia. I phoned up one Friday afternoon and spoke with the manager who did not know about, but was so interested in, the GREAT CR therapy work that I became much more hopeful.

I also contacted Jackie Pool via a friend she had supported when her mum had dementia. Jackie offered to remotely support the Peartree OT and also provided us with the link to the free GREAT CR therapy e-learning course, which the OTs at Peartree completed.

JP: How did you feel about paying Peartree for the service they provided?
Jenny: I was happy that I had Peartree who would be able to do the work, however I found it very difficult to persuade my parents that this was something good that could really help us but which was not available on the NHS. It would have been easier if the GP had been familiar with the approach and could have recommended us to go to Peartree, but instead it was my suggestion with no one else to say this is good.

JP. What were you expecting from the Peartree service?
Jenny: I wanted someone to come to visit my parents at home and introduce us to the concepts and work with us long enough for us to be able to apply the principles in other situations. I expected excellent engagement with my dad as an individual, getting to know him and seeing what he could do as well as what is more difficult for him. I expected the therapist to build rapport with my mum so that she felt confident to ask questions and support my dad with the techniques. I wanted feedback to me so that I could support the whole process and encourage my parents.

Focus on rehabilitation

Rehabilitation-focused care is proactive and enabling: identifying the impairments that cause functional difficulties and either repairing the damage, compensating for the damage, or restoring function. Repairing the damage to neurons that is causing a cognitive impairment is currently not possible but, by bypassing the damaged areas and utilising intact faculties it is possible for the person to learn a new way of achieving their functional goal. So although actual physiological repair is not possible, cognitive rehabilitation approaches can restore lost abilities.

GREAT Cognitive Rehabilitation (CR) was first used as a title for the research study into the specific therapy programme that was developed by the University of Exeter research team and published in 2019. The acronym GREAT stands for Goal oriented cognitive Rehabilitation for Early-stage Alzheimers (and related dementias) Trial. The therapy programme itself is now referred to as GREAT Cognitive Rehabilitation or GREAT CR, and those who have completed the course and are delivering the GREAT CR therapy programme are known as GREAT CR practitioners.

Key points

- It is possible for people diagnosed with dementia to learn new skills and information or to relearn lost skills and information
- GREAT Cognitive Rehabilitation therapy is an individualised, one-to-one programme of six sessions of 1 hour per week
- There is a free e-learning course to enable professionals and care givers to become GREAT Cognitive Rehabilitation practitioners
- GREAT CR therapy should begin with a SMART goal that is meaningful and important to the individual
- SMART goals support practitioners to plan the enhanced learning techniques that will enable the goal attainment
- SMART goals support the individual's and their care partners' motivation to participate in the programme through measurement of their progress
- Involvement by family or other care partners in the programme helps to embed and maintain the individual's progress
- GREAT Cognitive Rehabilitation therapy should be provided as a post-diagnostic service

GREAT CR therapy

GREAT Cognitive Rehabilitation (GREAT CR) therapy is a personalised intervention that supports functional ability through a one-to-one programme of around six sessions with a trained practitioner. It helps people with mild to moderate dementia to maintain their independence by more effectively managing the impact of dementia on their ability to engage in everyday activities. There are two types of cognitive rehabilitation: restorative treatment and compensatory treatment. Restorative treatment involves using enhanced learning techniques and practising skills to improve them, while compensatory treatment involves learning how to work around deficits or injuries.

Jim's difficulties

Following Jim's diagnosis in July 2024, he felt that his word-finding difficulties had deteriorated leading to him withdrawing and being anxious in social settings and when meeting new people. He was also struggling to join in the weekly family video calls.

Jim: "I don't want to be remembered like this, I feel useless… have lost my identity. I find conversation challenging to follow and have difficulty finding relevant words and topics. I also struggle with names and remembering what has happened, I forget to take my medication too. I have tried making notes to remember things but I even forget to make the notes." ▷

▷ Jim explained to Emma that that being able to recall what he has done during the day is really important to him as a step towards being able to talk about this with his family. He had found communication with his family increasingly challenging, causing him to feel very low in mood and isolated. Jim described that he felt that one of the main barriers to communicating with friends and family was around not being able to freely think of or recall recent events and come up with conversation or things to say.

Emma noted when she visited that Jim had multiple note pads that he tends to misplace. Through her initial occupational therapy assessment it became clear that the main areas of cognitive difficulty hindering functional participation and performance were around information recall and word retrieval.

Emma supported Jim to set two SMART goals (Specific, Measurable, Achievable, Relevant, Time specific) to address the medication difficulty and his word/topic finding conversational difficulties.

Goal One: *I will take my medication every morning with my cup of tea.*

Goal Two: *Every day at dinner time I will write down, on the correct date in my diary, three things that I have done that day and then say them out loud without referring to what I have written.*

Identifying needs and formulating goals with the person with dementia is central to the cognitive rehabilitation process. Working with the person to help them to identify what is important to them ensures that the intervention will be personalised and meaningful to the individual. In addition, having a specific therapy goal provides a positive focus for the person, their care supporters and their cognitive rehabilitation practitioner. This 'SMART goal' approach ensures that the intervention is measurable as the practitioner can break the goal down into smaller components in order to use a graded approach to achieving the whole goal. In turn, this enables the person and their care supporters to identify and celebrate progress, and this in itself is motivating. The grading of the goal activity also supports the practitioner in their clinical reasoning about which cognitive rehabilitation strategy and approach to use.

The BGSI-S (Clare *et al* 2020) was used to record each goal as the full (100%) achievement and then each goal was broken down into achievable steps which also supported the measurement of the level of goal attainment towards the full achievement. This helped Jim to see the result of his hard work towards the goal and the progress he was making, which was highly motivating and impacted on his self-esteem.

Emma, Jim and his wife worked together to create a cognitive rehabilitation plan of strategies and techniques that would help him to address his goals. These needed to not only address his cognitive difficulties but also fit with their lifestyle.

Impact on relationships — and sense of self

Consideration needs to be given to the impact of the dementia on the relationship between the person and their family and social network and also on their own sense of self. The stigma of dementia in society and the dehumanising belief that the person is no longer 'themselves' can impact on the belief that improvement is possible and therefore on engagement in a rehabilitation programme.

Alternatively, over-enthusiasm in the process can lead to unrealistic goals, and the practitioner must provide guidance here. Likewise, if the person or their care supporters do not allow rest time in between the rehabilitation practice, the person will become exhausted and so the practitioner must also give guidance on pacing the rehabilitation practice.

Goal One

A combination of compensatory and enhanced learning strategies were used for Jim's medication goal:
I will take my medication every morning with my cup of tea.

Compensatory strategies:

- The dosette box acted as a memory aid to support Jim to recognise whether he had taken the medication, this worked well for Jim as he was generally well orientated to the day.
- Moving the dosette box from the busier kitchen environment to Jim's bedside table made it more noticeable. This also worked well in terms of the task association – taking the tablet with the cup of tea which Jim places on his bedside table to have in bed every morning.

Enhanced learning strategies:

- Action-based learning – Jim was the person who carried the dosette box upstairs and placed it on the bedside table.
- Expanding rehearsal - Practised "going through the motions" from the kitchen where Jim makes his morning cup of tea, to upstairs where he would put his cup of tea on the bedside table next to the dosette box and then open the correct day. Repeating this process every day to support habit formation.
- Prompting – Jim's wife provided verbal prompts as needed, initially these were more direct and then gradually faded.

100% goal attainment was reached over the course of six sessions.

Goal Two

Enhanced Learning strategies were used for Jim's second goal of being able to recall the day's events as topics of conversation with his family:
Every day at dinner time I will write down, on the correct date in my diary, three things I have done that day, and then say them out loud without referring to what I have written. ▷

The potential of GREAT CR: Emma's comments

Carrying out GREAT CR therapy with a client has shown how rehabilitation has a valuable role within dementia care, it is not just about compensatory strategies. I have seen how, through the enhanced learning strategies, there has been an improvement in Jim's cognitive functioning in the areas of information recall and word retrieval.

Having a friend/family member/carer to support intervention is vital for carry over and goal achievement. In situations where the care partner may have challenges themselves (for example their own cognitive difficulties or age related changes, difficulties around fatigue or difficulties coping) it is important to look at what extra support can be utilized. In this situation, Jim's daughter was a key support.

GREAT-CR therapy provides a good framework for education when talking about strategies; this then also adds to motivation and engagement. For example, with Jim, the use of expanding rehearsal to recall written information at increasing time intervals and mnemonic/semantic/multimodal elaboration techniques to encourage information retrieval led to discussion on the importance of continuing to work on and challenge memory.

We then linked this to the neuroplasticity principle of "if you don't use it you'll lose it" and how it is important to train the brain as you would the body. Through practising and explaining the techniques and linking them to real life meaningful functional tasks, people can then start to see how these could be transferable in other situations and also how other tasks can be beneficial from a rehabilitation perspective. For example Jim's wife asked if the idea of expanding rehearsal and prompts as used with the diary goal could be used after watching a TV programme or reading the paper together as a way of "exercising the brain".

Implementing techniques can be challenging if someone is "set in their ways". For example, initially Jim was not keen on keeping his dosette box on his bedside table as his medication had always been kept in the kitchen. Education provided a helpful way of overcoming this, through reminding Jim of the rationale behind placing the dosette box on the bedside table - to link the task of taking medication with a routine task that happens every day when he would be wanting to take his medication i.e. morning cup of tea, which he places on his bedside table and has in bed. This led to a good discussion around memory strategies and the benefit of linking a new task with a routine task to form a habit, and the benefits of getting into a good routine with consistent medication taking now while he is only on one tablet in case more are added in the future.

It is really important to not overload or overwhelm with too many goals at once. The active involvement of Jim's daughter was key in supporting carryover between sessions and overall goal achievement. In future cases, where there is a lack of care partner support, involving rehabilitation assistants (RAs) to help bridge this gap would be important to consider and highlights a potential training need within our service. Depending on individual cases, the use of RAs could also help reduce cost and increase accessibility of intervention for clients, with sessions being a mix of occupational therapy and rehabilitation assistants.

▷ In order to do this, there needed to be some initial preparation, and Jenny supported her parents to obtain a page per day diary that was always be kept in the same place and in the location where the task was to be carried out. They agreed that the best time of day was after dinner and so the diary was kept on the dining room table. They decided to use a diary elastic to bookmark the correct page and Jim elected to use his daily newspaper to double-check that he was writing on the correct page.

Enhanced Learning Strategies:

- Action based learning – Emma wrote three prompt questions on a loose page that Jim could refer to each day:
  What have I done today/who have I seen?
  What have I had to eat/drink today that I have enjoyed and why?
  What am I thankful for today?
- Prompting – Jim's wife prompted him to write in the diary each day at dinner time and also to support information recall.
- Fading prompts – Initially Jim's wife provided daily reminders to write in the diary, but with the task repetition and habit forming the prompts decreased in specificity and frequency from "You need to write in your diary" to "Is there something you need to do?"
- Errorless learning – Jim used the diary elastic to support navigation to the correct day in the diary and his wife supported him with this if needed, by providing positive prompts to ensure diary entries were on the correct days. They chatted about their day over dinner and his wife encouraged him to recall things he had done, using the prompt questions to help him to recall the details.
- Effortful processing – Thinking about, writing down and saying our loud what he was writing as he did so supported the use of cognitive abilities and the formation of neuronal networks. In addition, Jim read the diary entry out loud after he had written it, then covered the page and recalled the points.
- Mnemonic, semantic and multimodal elaboration – When chatting about their day, Jim's wife used word/topic association and rhyming to help prompt recall. These were chosen by Jim so that they had personal meaning and therefore would be more memorable. They included phrases such as "I ate my curry in a hurry", "The mental lentils", "Shrinking spinach" and, colour-word association (such as green broccoli) and hints of "it begins with" and providing the first letter of the word.

▷

- Expanding rehearsal – Jim practised saying out loud as a list, the things he had done that day, without looking at his diary. He repeated this after 1 minute, 2 minutes, 4 minutes, 8 minutes and 15 minutes) each evening after dinner.
- Emotional Support – One of the written prompts asked: ‘what I have done today that I am thankful for’ to support Jim with positivity and well-being.

Jenny also took an active role in supporting both her parents in working towards this goal, through a mix of face to face and telephone contact to support with the expanded rehearsal aspect in particular—her Mum found this harder to grasp, and struggled with at times due to her own fatigue.

Jim attained 100% of this goal over the course of seven sessions. He was able to complete the diary entry correctly and say out loud three things that he had done that day. Emma also observed how his responses to these questions became more detailed and elaborate throughout the process, which was lovely to see. Jim was able to see this as well by looking back through the diary. At the beginning his responses to the questions tended to be one or two word answers, and then gradually developed into full sentences with more description.

Emma noted that there was a general improvement in Jim’s mood, engagement and social interaction as the sessions progressed. This was particularly evident in the diary goal, with noticeable improvement in terms of Jim’s ability to offer up and elaborate on information and engage in more meaningful and abstract discussions.

While there continues to be an improvement in Jim’s conversational ability and confidence, the video calls have become more difficult because of unrelated health issues within the wider family. This has compromised the ability of Jim’s circle of support to continue, and it illustrates the importance of the need for the statutory services to provide the continuity that would ensure that the rehabilitation model is sustained.

JP: Did anything surprise you?
Jenny: I did not realise occupational therapists have such a wide ranging role, and I was so impressed with the rehabilitation/enabling way of working. I saw how my dad was becoming less withdrawn and that my mum was grasping concepts about the importance of routine and linking things together (eg. tea and tablets, dinner and diary).

JP: Did anything feel too difficult?
Jenny: My mum was too tired in the evenings to really do the rehearsals but we found a way of doing this through other family members by phone and it gave us more contact points with my dad.
JP: What was your Dad’s main achievement because of the sessions with Emma?
Jenny: Keeping the diary every day and spending time thinking and writing, then talking about it later. It stopped the days passing in a fog of frustrating things which weren't working (forgetting what he had forgotten, pushing paper round a desk and not finishing anything)

Jenny’s final thoughts:
JP: Do you think that the service that Emma provided was helpful?
Jenny: Yes very much so. I think we were lost without it and it has given us a common vocabulary to talk about what my dad needs, and given us some tools to support and encourage him and us.

JP: Is there anything else that you would like to share about your experience of GREAT CR?
The degree of involvement and understanding Emma had of my dad's illness and my mum's support of him meant that she was able to suggest things which have made a difference to how they are approaching things. The targets steered him away from dangerous things (chopping wood in the dark) to safer things which were still empowering (making sure the fire was laid after breakfast when he is stronger and more alert and it is day light)

I would like more people to know about GREAT CRT so that people like me who are looking for something can find it more easily. Ideally it would be available on the NHS so that there is an offer of help after diagnosis. The return on investment could be high if it keeps people able, well and happy for longer.

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Medications: common issues and questions answered

This article is the first in a series of three aimed at helping people with dementia, their families and care staff manage some of the common issues and questions in relation to medications often prescribed to people with dementia.
Here **Stuart Kennedy*** considers the medications often prescribed following some diagnoses of dementia (predominantly Alzheimer's disease).

Summary

Medications commonly prescribed for Alzheimer's disease and some other forms of other dementia are a source of common questions posed to the Dementia UK Admiral Nurse Helpline. This article aims to provide accessible and useful advice, as would be offered to a caller to the Helpline.

In answering some of these common questions the aim is to empower callers with knowledge around a drug's action and its side effects, what action to take for missed doses, advise on different versions of the medication and whether or when to stop taking these medications.

As a mental health nurse for over 35 years, a non-medical prescriber (21 years) and an Admiral nurse (four years), a significant part of my work with people with dementia and their families has been support in managing pharmacological interventions.

The more recent part of my clinical journey involves fielding a diverse range of questions from helpline callers and their need for the expert clinical advice an Admiral nurse can offer. Frequently raised questions around medications for dementia (often referred to as "cognitive enhancers") occupy much of this and there are some common threads which are worth explaining for the sake of all who may have similar questions.

The aim of this article is to provide a brief guide to common topics that relate to the currently available treatments for dementia. Those accessing such treatments (and their families) should be assisted and empowered to have confident conversations with prescribers.

My role sits within a telephone helpline model, and so the following is general advice I would often give in response to questions. However, we always recommend that any issues relating to medication are discussed with the prescriber.

Common questions

At the national Admiral Nurse Dementia Helpline, we collate data on common themes of calls and receive many in relation to dementia medications. The following are among the most common:

- How can I manage unexpected side effects?
- What should I do if I forget to take my tablets?
- Can I ask for further treatment if already prescribed a cognitive enhancer?
- My new supply has a different brand name, should I worry?
- I don't think the medication is working any more; should I stop taking it?

Diagnosis of dementia

Memory assessment services have become the single point of access for most people requiring assessment and potential diagnosis of dementia, and they remain recommended by NICE (2018) as best practice. Some people may, however, be diagnosed in other care settings, such as acute hospitals, neurology clinics, private providers and in some cases by their GP. The prevalence of dementia over the coming decades poses immense challenges to NHS memory assessment services who are already struggling to catch up after the effects of Covid on service delivery. New approaches to treatment (sometimes referred to as disease modifying treatments or DMTs) are certainly "on the horizon", but approval is just the first stage in a complicated process requiring significant changes to NHS services, and is likely to be many years away, sadly.

Anti-dementia drugs (cognitive enhancers)

Four medications are licensed for (what most would agree is) mild improvement in some of the symptoms of dementia, specifically attention, memory and the ability to

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The second article in this series will cover antipsychotics, and the third antidepressants.

carry out daily activities. There are three acetylcholinesterase inhibitors (AChEIs or ChEIs), which are donepezil, rivastigmine and galantamine. The first of these drugs, donepezil, has been available since 1997. Memantine, the last to be added, works in a different way (see below). NICE (2011, 2018) recommended this drug to prescribers later, for managing moderate and late-stage Alzheimer's disease, whereas the other three are licensed for mild to moderate Alzheimer's disease.

The effect of AChEI treatment is largely based on something called "the cholinergic hypothesis". There are many chemicals in the brain which aid communication between nerve cells (these are called neurotransmitters). One such chemical is acetylcholine; people with Alzheimer's disease and dementia with Lewy bodies (DLB) have a reduced concentration of acetylcholine in the brain . The three AChEIs aim to reduce the rate at which acetylcholine is broken down, thereby increasing its concentration and so enhancing chemical communication between nerve cells.

Memantine sits in a different class of medications and acts on the glutamatergic system by blocking NMDA-type glutamate receptors. This type of medication blocks the effects of excessive amounts of a chemical called glutamate which is responsible for some damage to nerve cells. The rationale underpinning this is that damaged nerve cells, found in conditions like Alzheimer's disease, may release too much glutamate which can cause further nerve cell damage. Memantine is, therefore, thought to afford some degree of protection from further damage to nerve cells (Wenk *et al* 2006).

Collectively all of these are licensed for use in Alzheimer's disease. Rivastigmine is additionally licensed in Parkinson's disease dementia (PDD). NICE (2018) recommends its use in mixed dementia (where vascular dementia is accompanied by Alzheimer's disease, PDD or DLB). NICE (2017) also supports the AChEIs being used for mild to moderate DLB (galantamine if the other two are not tolerated), donepezil and rivastigmine for severe stage DLB, and memantine for DLB if AChEIs are not tolerated. The table below demonstrates their current use in the UK

Effects of poor medication knowledge

Much has been published on this topic, often with a focus on the financial cost of poor medication management. Importantly however, poor medication adherence is associated with poor clinical outcomes (Kengne *et al* 2023). Failure to take medication as prescribed may stem from wide-ranging factors, including deteriorating cognition, poor sight, inability to learn use of devices, poor dexterity and much more. Callers to the Helpline may ask about medication and, although Admiral nurses are experienced dementia nurse specialists, we will always caveat that our advice is just advice, and any medication changes must be discussed with the prescriber.

With that in mind let's dig a little deeper and review some of the themes.

Managing unexpected side effects

The common side effects of these medications are well covered elsewhere, for example in the British National Formulary and Maudsley Prescribing Guidelines (see Resources below). There are, however, some side effects that may occur years after initiation of the medication, and which may be modifiable. While again reiterating the need to consult with the prescriber, I will outline a few side effects for which people may seek advice.

Insomnia, vivid dreams, nightmares

It may be that information about the medication was discussed some time ago at a diagnostic appointment and some or all of its content now forgotten. Both donepezil and galantamine can give rise to both insomnia and or an increase in dream activity which most describe as "vivid". It is believed that such sleep disturbances might result from the heightened cholinergic activity (release of neurotransmitter acetylcholine) that can lead to increased cognitive activity. Simple strategies would be to discuss with their prescriber whether to alter the timing of taking

Drug name	Licensed use	Recommended additional use (NICE)
Donepezil	Alzheimer's mild/moderate	Mixed dementia DLB mild/moderate PDD mild, moderate (offer) and severe (consider)
Galantamine	Alzheimer's mild/moderate	Mixed dementia DLB mild/moderate (if other AChEI not tolerated) PDD severe (consider)
Rivastigmine	Alzheimer's mild/moderate PDD mild/moderate	Mixed dementia DLB mild/moderate PDD severe (consider)
Memantine	Alzheimer's moderate/ severe	DLB if AChEi not tolerated or are contraindicated PDD if AChEi not tolerated or are contraindicated

Dementia medications licensed and NICE recommended use. (adapted from British National Formulary (2025), NICE NG97 (2018) and NICE NG71 (2017)).

“Behaviour” as a symptom of dementia

The term Behavioural and Psychological Symptoms of Dementia or BPSD is often used by mental health staff and in research studies. It was originally coined at a meeting of the International Psychogeriatric Association (IPA) in 1996 (Finkel *et al* 1997). Behaviours had been described previously, and this term attempted to define specific types of behaviour commonly observed in people with dementia.

Historically, new behaviours emerging after a person was diagnosed with dementia were often considered to be as a direct result of damage to the brain from the underlying disease processes. However, a more enlightened view is that such new or unexplained behaviours are more likely to arise from an expression of need, often due to the person’s inability to verbally express a need or in their recognition of their need. Increased understanding in this area was pioneered by the work of Tom Kitwood who argued that many behaviours observed are valid responses to inappropriate or unsuitable environments (Kitwood 1997). When such behaviours are misunderstood or ignored, this in turn can give rise to expressions of stress or even distress in the person’s behavioural responses to their need(s) as they remain unmet.

the medication from evening/night to morning and/or reduce the dose. Ultimately, however, this may be an area in which a balance is to be struck between the discomfort of side effects and the benefits of the treatment.

Urinary incontinence

Research (Hashimoto *et al* 2000, NICE 2024) suggests a link between AChEI medication and changes to urinary continence in some, particularly night-time incontinence and/or loss of bladder control. These are rarer side effects and exploration of other possible causative factors should be considered first — for example, functional incontinence (when a person cannot reach the toilet in time), or urinary tract infection. A reduction in the dose of the AChEI is also an option which should be balanced against the impact of the side effect, the likelihood of reversing the side effect and possible further cognitive loss if the medication is stopped (see discontinuation below). If night-time incontinence has occurred, switching to taking the medication in the morning may also be worthwhile. A sudden change in a person’s continence, however, is unlikely to be caused by an AChEI and will require further investigation.

A note of further caution may be of value here. Incontinence is often treated with a class of drugs called antispasmodics or anticholinergics. This includes drugs such as oxybutynin, tolterodine and solifenacin. When taken alongside an AChEI, there is the potential for these types of medication to interact with and reduce the benefits of AChEIs. This group of medications has also been linked to some increase in the risk of dementia in those without a diagnosis (Iyen *et al* 2024)

What should I do if I miss a dose?

Adjustment in medication dose should be managed with clear clinical advice to the person with dementia and their carer as each of the medications has a different level of tolerance for missed doses. Detailed exploration of medication adjustment, based on clinical review, can be found in appendix (4) of a local guideline (LLRAPC 2022).

However, a person on the lowest possible dose of a medication will not need re-adjustment after missing doses for days or weeks. Re-adjustment advice is based on the premise that extended periods of missing a higher dose and re-starting on that dose may lead to side effects. If a person with dementia has missed several weeks or even months of the medication there is a theoretical risk of this leading to a worsening of their cognition which re-starting the medication may not reverse.

It’s important to stress that detecting ongoing benefit in these drugs is fraught with challenges. Memory is not routinely re-tested once a person has been discharged by memory assessment services, so there is no ongoing comparison. Furthermore, the widely held view is that use of the medications only slows progression of the condition. It is important that people with dementia and their families understand that re-starting the medication without readjustment (where indicated) is not necessarily dangerous but is potentially uncomfortable. Discontinuation of these medications altogether is discussed separately below.

Can I ask for further treatment when already diagnosed and prescribed treatment?

This is a very common thread in calls where there is often a lack of awareness in families affected by dementia on whether other treatments can be used alongside these medications. Increasingly people contacting the Helpline may be managing care at a stage in the condition whereby further deterioration is apparent or new or seemingly inexplicable behaviours have emerged.

So-called “challenging behaviours”

In the past, if a person with dementia started to behave differently, this was often assumed to a direct result of damage to the brain from the underlying disease processes and thus described as BPSD (Behavioural and Psychiatric Symptoms of Dementia). Although the term BPSD is still in common use in case notes (see box, left above), it is now understood that new or unexplained behaviours are more likely to arise from an expression of need, often due to the person’s inability to verbally express a need, or in their understanding of the need.

Thus, NICE guidance (2018) recommends the use psychosocial approaches as a first line approach.

If these psychosocial approaches do not help and attempts to identify and address the need being expressed are unsuccessful, memantine can be used alongside other AChEIs. There is sufficient evidence that this is a safer approach than the use of antipsychotic medications (Radakovic *et al* 2021). Unless there is an urgency to treatment (psychotic symptoms with high level of risk to self or others, unmanageable aggression, etc), a re-referral to a memory assessment clinic should be considered, especially if the person is not currently prescribed memantine. Complementing donepezil, galantamine and rivastigmine with memantine is accepted practice and endorsed by NICE (NICE 2018). Specifically NICE states that those with moderate disease should be considered for, while those with severe disease should be offered, memantine. This type of prescribing can often be undertaken by GPs (with reference to original memory assessment clinic correspondence or by consultation with them) but is mostly part of a re-referral. It is important that people with dementia and their families know this option exists and ask the GP if they feel the time is right to go back to the memory assessment service.

The medication has a different brand name: should I worry?

This question arises periodically and, if poorly understood, could lead to poor concordance through misunderstanding. From a purely pharmacological perspective the medication is required to meet bioavailability (the ability of a drug to be absorbed and used by the body) requirements meaning it can only vary in small ways. This is not to say that the drug is exactly the same and some versions may contain small amounts of a substance or ingredient not found in the original. If a person reacts to a particular named brand all attempts should be made to avoid that version. But for most there should be no difference when the primary ingredients are identical.

I don't think it is still working, should I stop taking it?

This question is debatable, and the answer may depend on who you ask. Certainly, there will be stages where all medications are being reviewed and rationalised such as in palliative and end-of-life care, but otherwise we have one influential piece of research which guides this question. The Domino Trial conducted by Howard *et al* (2012) examined discontinuation in a cohort of 295 people with dementia taking the medications (largely donepezil and memantine). Although considered a small number of participants, this study demonstrated further loss of functional abilities (feeding self, independent continence management, etc) in subjects where the medication was stopped who were thought to be benefitting little on the medication.

I have personally spoken to families whose relative with dementia was admitted to an acute hospital and the medication discontinued as the hospital doctor thought "it wasn't working anymore". Doctors working in acute care settings may not be aware of the full aspects to consider in respect of making such a decision, especially where there is limited evidence (Howard *et al* 2012) to guide practice and prescribing. Unless there is a clear medical reason to stop the medications during hospitalisation, the decisions are perhaps best left to the person's GP who knows them and their family well. In other research, abrupt discontinuation of AChEI (discontinuing without gradual tapering down of dose) has been related to experiencing hallucinations (Singh & Dudley 2003).

Ultimately, this is a case-by-case question and one requiring detailed review of all a person's circumstances. For example, does the person still live at home, do they live alone, etc, with dose reduction perhaps the first action, but stopping because "it's not working as well as it once did" is not a good enough reason to stop altogether.

Key points

- Some side effects can occur years after the medication is first taken and as such, may be less well understood or discussed. Some simple strategies (such as altering timing) can help mitigate the effects.
- Missed doses should be discussed with a prescriber, particularly if the person is taking the maximum dose or misses three days or more.
- NICE guidance supports the augmentation of AChEI with memantine, however, such prescribing decisions are often made locally.
- The decision around if or when to stop taking these is subjective, but some evidence suggests value in continuing the treatment while a person lives at home.

Conclusion

This paper is written in response to large numbers of caller enquiries to the Admiral Nurse Dementia Helpline on this issue. It aims to serve as a reminder and answer some of the common questions relating to dementia medications and their management, and to support families to be well informed and empowered. As an Admiral nurse holding a non-medical prescribing qualification my perspective is possibly unique. My role on the Helpline service is to support callers with their concerns and provide the best evidence while promoting and empowering the caller to discuss any changes to treatment with the responsible and prescribing clinician. "Knowledge is power".

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Resources

British National Formulary (BNF). Available at BNF (British National Formulary) | NICE

Maudsley Prescribing Guidelines. 15th edition available to order online at Welcome to the official Maudsley Prescribing Guidelines website

Editor's note on the terms we use:
Challenging behaviour/Behaviours that Challenge/ Stress and distress

'Behaviours that Challenge' is the current widely-used term, preferred by the British Psychological Society's Division of Clinical Psychology in their recent guidelines. In *JDC* we have tended to prefer 'Stress and distress', but discussion and debate continues.

Useful guidelines have been produced by KYN: https://www.kyn.co.uk/assets/files/uploads/kyn-lets-talk-about-dementia-guidelines.pdf

See also:

James EA, Reichelt K (2024) New national guidelines on non-pharmacological response to behaviours that challenge . *Journal of Dementia Care* 30(3) 20-22.

James I, Randall C, Reichelt K (2022) Thirty-six simple ways to de-escalate 'behaviours that challenge': Helping carers know what they already know by improving 'Dementia Care Literacy'. *Journal of Dementia Care* 30(5) 29-33.

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, Theresa Ellmers. We welcome suggestions of papers to be included: please contact sue@dementiapublishing.community

Special issue: Psychosocial care and support in dementia

The journal Behavioral Sciences is creating a special issue on psychosocial care and support in dementia. This special issue focuses on the development, evaluation, and/or implementation of psychosocial care and support in dementia to advance research, practice, and policy. Reviews and original research articles are welcome focusing on these topics targeting any dementia types, stages, and care settings. The deadline for manuscripts is October 2025.
https://www.mdpi.com/journal/behavsci/special_issues/424GJ6V7OF

End of life care

In this qualitative study using 10 workshops, minority ethnic people and economically disadvantaged people reported poor experiences of multiple aspects of palliative and end of life dementia care. Analysis found that that there was mistrust of health and care services, but also of palliative care which was sometimes perceived as harmful within some minority ethnic communities. For practitioners, findings emphasise the importance of clear and compassionate communication about the intentions and rationale behind medical treatments at end of life. This, coupled with stigma surrounding care homes, and a lack of awareness about dementia as a life-limiting condition, underpinned significant barriers to accessing equitable end of life care. The authors suggest there is a need to improve multiple aspects of care, including access and coordination, and this paper identifies several areas for development for practice, policy and research.

Tomkow L, Poole M et al. End-of-life dementia care: a qualitative study of the experiences and perceptions of minority ethnic and economically disadvantaged groups. Age and Ageing. Published online June 2025. https://doi.org/10.1093/ageing/afaf168 (Open access)

Pain management in care homes

This article discusses ethnographic research about pain management in people with dementia in nursing homes, focusing on the resources people with dementia have and how healthcare personnel can support and integrate these resources into their clinical practice. The article describes how people with dementia express themselves in the moment and nurses integrate these moments into a coherent whole. Some examples are discussed of how people with dementia have individual resources and strengths that are important for pain management. The paper advocates for a narrative care approach underpinned by knowing the resident and relational continuity and that residential homes are well placed to create such continuity. The authors conclude that with support from healthcare personnel, people with dementia can be active participants in pain management processes.

Kreppen Overen C, Eriksen S et al. Pain Management in People With Dementia Living in Nursing Homes: A Focused Ethnographic Study. Dementia. Published online July 2025. https://doi.org/10.1177/14713012251358003 (Open access)

Co-existing hearing loss and dementia in social care settings

Hearing loss is often overlooked in people living with dementia, resulting in under-diagnosis and lack of appropriate management. The presence of both conditions can mask each other, presenting challenges for both diagnosis, treatment and support. The aim of this study was to explore the experience, needs and opinions of how to manage hearing loss in people living with dementia in social care settings. Five themes were identified: (i) inclusion; (ii) communication, (iii) hearing aids, (iv) health services and (v) training of care staff. Findings highlight the need for comprehensive training to help support the management of hearing loss in people living with dementia. Training on the use and maintenance of hearing aids would be particularly valuable for staff. Due to the progressive nature of both conditions, individuals using social care should be reviewed regularly to ensure that care provision is adapted to suit the progressive nature of the conditions.

Broome E and Green A. Management of Co-existing Dementia and Hearing Loss in Social Care Settings: A Focus Group Study. Dementia. Published online June 2025. https://doi.org/10.1177/14713012251356010 (Open access)

Singing support services

Community-based singing services can offer beneficial post-diagnostic support for people living with dementia and their carers. This study examined the barriers and facilitators to access and engagement with a singing community support group. Twenty-six people participated in the study including people living with dementia, unpaid carers, session leaders and volunteers. Three overarching themes were found relating to barriers to access and engagement with singing intervention services: (1) travel, (2) increased reliance on carers and (3) health comorbidities. Two further themes relating to facilitators were found: (1) engagement with music and (2) promoting effective communication and accessibility. Some of the identified barriers relating to accessing community groups have the potential to disproportionately impact people from lower socioeconomic status and those living in rural areas. The authors also note how singing groups should make creative use of props and other engagement methods, as well as ensuring the groups are appealing to everyone including people with young onset dementia or people from different cultural backgrounds.

Polden M, Giebel C et al. Barriers and Facilitators to Accessing and Engaging With Community-Based Singing Support Services in Dementia. Health & Social Care in the Community. Published online April 2025. https://doi.org/10.1155/hsc/9480037 (open access)

Social support for depressive symptoms

Depressive symptoms are common in people with dementia, significantly reducing well-being and potentially exacerbating dementia symptoms. The objective of this study was to investigate the role of social support for depressive symptoms in people with dementia over a four-year period, and used data from 334 people. At the beginning of the study, 13.8% of people with dementia reported mild to severe depressive symptoms. People with more social support showed fewer depressive symptoms overall over the 4-year period. In addition, a decline in a person's social support was associated with more depressive symptoms. These effects were stable even after controlling for sociodemographic (age, sex, education) and clinical factors (cognitive and functional status, comorbidities). The paper argues that the social environment plays an important role in depressive symptoms in people with dementia—beyond clinical factors like cognitive and functional abilities, and that improving social support could be a lever for alleviating depressive symptoms.

Blotenberg I, Jeran L et al. The Role of Social Support for Depressive Symptoms in Dementia: A Four-Year Longitudinal Study. Innovation in Aging. Published online July 2025. https://doi.org/10.1093/geroni/igaf047 (Open access)

Dementia in farming communities

Farming communities experience significant rates of dementia, and are also impacted by geographic isolation that creates barriers to timely diagnosis and access to healthcare services. This scoping review focused on the experiences of dementia in farming communities. Eighteen articles were included in the review. The majority were grey literature including magazine and newspaper articles, demonstrating a large research gap in this area. Thematic analysis generated thirteen sub-themes that are presented within two overarching themes: 'challenges' and 'fostering resilience'. A stakeholder meeting was organised with representatives from eight organisations that support farmers in Wales, to discuss themes and gain additional insights. Findings indicate a unique set of challenges faced by farming communities in relation to dementia, that are in addition to those faced by people living rurally in general. This review also highlights advice around opportunities for fostering resilience in people living with dementia and their families in farming communities. The findings of this review could be used to guide the development of healthcare information and support tailored to the unique needs of farming populations.

Roberts J, Morgan B et al. Experiences of dementia in farming communities: A scoping review. Journal of Rural Studies. Published online May 2025. https://doi.org/10.1016/j.jrurstud.2025.103710 (Open access)

People with Down syndrome and dementia

People with Down syndrome have a substantially increased risk of developing dementia and this scoping review aimed to identify challenges for providing medical care to this group of people. For several reasons, the diagnosis and treatment of dementia in people with Down syndrome must be designed differently. From this review the authors identified three major issues to be highlighted: (1) lack of available services, (2) lack of knowledge and skills leading to under-diagnosis of dementia or misdiagnosis, and (3) special characteristics of this population.

Gievel G, Raszke P et al. Deficits and barriers in medical care of people with down syndrome and dementia: A scoping review. Journal of Intellectual Disabilities. Published online July 2025. https://doi.org/10.1177/17446295251351508 (Open access)

Preventing constipation

This articles discusses the available evidence on strategies to guide the prevention of constipation in people with dementia. Focusing on prevention, rather than management, seven studies were identified, including three randomised controlled trials, and using a range of non-pharmacological strategies. Strategies to prevent constipation in people living with dementia included encouraging adequate dietary fibre and fluid consumption, probiotics, individualised scheduled toileting, exercise and staff education on bowel health. Traditionally, constipation prevention strategies have been generalised from the broader population, but the authors argue that these alone may not adequately address the unique care needs of those living with dementia. Most strategies were multicomponent and targeted at nutrition and hydration and the existing evidence suggests that tailored strategies specific to persons living with dementia are scarce.

Schnitker L, Alrababah S et al. Best Practice to Prevent Constipation in People Living With Dementia: A Scoping Review. International Journal of Older People Nursing. Published online June 2025. https://doi.org/10.1111/opn.70033 (Open access)

Cancer care for nursing home residents living with dementia

Limited research has examined the care and support needs of people with dementia and comorbid cancer (DCC) in nursing homes (NHs). This ethnographic study explored the care experiences of NH residents with DCC, their families, nursing home staff (NHS) and healthcare professionals (HCPs), and aimed to identify challenges and good practices in order to develop recommendations for practice improvement. Two themes were developed (1) complexities around cancer referral and treatment decision-making and (2) relative invisibility of a resident's clinical cancer diagnosis. Findings suggested residents with DCC were not included in best interest decision-making due to the potential distress knowing about a cancer diagnosis would cause. Families, HCPs and NH staff made collective decisions on the behalf of residents. Often cancer referral was deemed not appropriate. Therefore people with dementia had a clinical-only cancer diagnosis, resulting in limited formal information about the cancer in care documentation and staff knowledge. Potential consequences of having a clinical-only cancer diagnosis included: misattributing cancer symptoms to dementia, reactive care responses to cancer symptoms and the possibility of inadequately managed cancer symptoms. The paper concludes that implementing earlier discussions about feasible care outcomes is crucial. These conversations should include considerations around hospital referral for oncology care or care through palliation in the NH. Without appropriate recognition of a clinical-only cancer diagnosis and support for staff it could lead to advancement of symptoms that might be challenging and less well managed. Several recommendations are made to support NHS to deliver person-centred care to residents with DCC.

Robinson O, Surr C and Ashley L. Understanding Cancer Care for Nursing Home Residents Living With Dementia: An Ethnographic Study. Psycho-Oncology. Published online June 2025. https://onlinelibrary.wiley.com/doi/10.1002/pon.70184 (Open access)

AI to support quality of life of people with dementia

This article aimed to synthesise the scientific evidence and grey literature on how Artificial Intelligence (AI) can support the quality of people with dementia. From thirty studies, three AI categories were identified: (1) monitoring systems, (2) social robots, and (3) AI approaches for performing activities of daily living. Most studies were feasibility studies, with little active involvement of people with dementia during the research process. Most AI-based approaches were monitoring systems. The authors conclude that AI applications for enhancing quality of life in people with dementia are still in early development, with research largely limited to small-scale feasibility studies rather than demonstrating clinical effectiveness. It is suggested that despite the potential of AI-based approaches to innovate and enhance care, much remains to be explored and validated in real work environments.

Steijger D, Christie H et al. Use of artificial intelligence to support quality of life of people with dementia: A scoping review. Ageing Research Reviews. Published online June 2025. https://doi.org/10.1016/j.arr.2025.102741 Published online June 2025 (Open access)

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