

The Journal of DementiaCare



For all who work with people with dementia

Vol 33 No 1 January/February 2025



The growing potential of social farms

**Also inside
this issue:**

- Cognitive rehabilitation in the community
- Person-centred language
- Dementia: the Musical



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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@dementia-community



■ **Living Well with Dementia –
A specialist research focus at Wolverhampton University** 14

CAIR is a new research centre at the University of Wolverhampton with a specific focus on improving the health and wellbeing of our diverse population. A specialist research cluster, Living Well with Dementia, includes a range of important areas of study, described here

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with young onset dementia – the first three years** 15

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John Killick sings the praises of a ground-breaking production written by Ron Coleman and involving three founder members of the Scottish Dementia Working Group. The show played two sell-out performances in Edinburgh, then went on to tour throughout Scotland. Its message has wide relevance, and artistic experiences of this quality are a powerful way to influence hearts and minds

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Justin Mazzotta reports on a Cognitive Rehabilitation pilot project in the community. Six participants — Billie, Brenda, Mike and Lynne, Chris and Lorraine — also describe their experiences of CR and the varied ways it helped them

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language in dementia care case notes** 31

Ian Davies-Abbott and **Emma Roberts** describe a ten-month quality improvement project in which they reviewed and analysed the language used by healthcare staff in case notes. They then developed guidance that staff were keen to embrace, and which led to more insightful, less stigmatising entries



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Front cover: Sincere thanks to everyone involved in Beetle Bank Social Farm in York, run by Partners in Dementia, and photographer Matthew Fawcett of Eagle Eye Images. See articles on pp23-29.



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 28 January 2025

Ask an Admiral nurse

Presenter: Vic Lyons, Head of Digital Service Delivery and Dementia at Work, Dementia UK

Description: This presentation will showcase Dementia UK's work, the evolution of Admiral Nursing, and examples of their day-to-day roles. Vic will explain how to become an Admiral Nurse, share essential dementia care tips for nurses, and discuss future plans to support more families. With Vic's experience hosting interactive XSpaces and Q&A sessions, this event will feature a live "Ask an Admiral Nurse" segment. Questions can be submitted in advance or asked live during the session. To submit a question in advance, please email: bethb@dementiapublishing.community

Tuesday 11 February 2025

Changing the Cultural Approach to Care with Namaste Care International

Presenter: Rishi Jawaheer, Director, Namaste Care International

Description: Journey with us as we explore how Namaste Care International is reshaping dementia support by shifting from task-oriented care to meaningful human connections. Drawing from global experiences across 14 countries, learn how this approach honours individual cultural identities while creating a more responsive, person-centred care environment. Discover practical strategies for implementing Namaste principles to transform your organisation's culture and enhance the quality of life for people living with dementia.

Monday 24 February 2025

Understanding the impact of sight loss for people living with dementia

Presenter: Linzi Sansum, UK Training and Development Officer, RNIB Health and Social Care Training team and Eye Care Liaison Officer, RNIB.

Description: This webinar will help to increase understanding and awareness of the causes and impact of sight loss for older people living with dementia. We will also provide information on how sight loss can be "hidden" and information on resources available to enhance supporting people with sight loss and dementia.

Tuesday 11 March 2025

Caring for dementia and continence

Presenters: Prof Cathy Murphy, Professor of Continence, and Dr Barbara Bradbury, Senior Research Fellow, School of Health Sciences, University of Southampton

Description: People living with dementia are more likely to have problems with continence than people of the same age who don't have dementia. These problems can be hugely challenging for the person and those who care for them, but common management strategies might not work. We'll discuss why the problems happen, why a different care approach is needed and the resources we've developed to try to help.

Tuesday 25 March 2025

Dementia, Communication and Swallowing

Presenter: Dr Lindsey Collins, Associate Professor, Lead Dementia Care Consultant and Trainer, RCSLT; National Clinical Advisor (Dementia and Dysphagia), Centre for Applied Dementia Studies, University of Bradford

Tuesday 29 April 2025 – 2.00pm-3.00pm

Dementia Community Space


Your Open Forum Webinar


Join us for our second Community Space, an open forum webinar where we will address the question: "What can you contribute to and/or share with Dementia Community?" Join us to network with Dementia Community members, share your work, ideas, projects and future plans relating to dementia care and support, and find out more about Dementia Community.

Tuesday 13 May 2025

Family carers and dementia

Presenter: Ruth Eley, tide and Frances Lawrence, Dementia Carers Count with Experts by Experience

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

The 3 Nations Dementia Working Group –

Alzheimer's Society (with Nathan Bolton)

David Truswell, Dementia Alliance for Culture and Ethnicity

Jane Ward, Dementia Friendly Hampshire

Dr Nadia Wahid, Dementia Primary Care Clinical Lead,
Birmingham

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

How we talk about dementia

By **Emma Hewat**,

Director of Dementia Care, KYN.



I have been involved in many initiatives over the years to promote and support the use of positive, person-centred language in a variety of dementia care settings, helping employees to understand why some words they use when writing and talking about people living with dementia are unhelpful at best, but stigmatising and damaging to the care provided at worst.

In 2023, I worked with Innovations in Dementia and a group of people living with dementia to review and update the 2014 DEEP language guidelines, referred to in the excellent article by Ian Davies-Abbott and Emma Roberts (pp31-35) describing their project 'Reducing labelling and promoting person-centred language in dementia care case notes'.

These guidelines were created to educate employees, families, and professionals working in health and social care as well the wider public including the media. They are used during induction at KYN to help employees reflect on why some words do not support a person-centred approach to care. Sometimes people find it difficult to understand why certain words are wrong, for example 'wandering', 'irritable' and 'difficult'. In their article, David-Abbott and Roberts describe so well that it is not necessarily the words themselves but the context in which they are used that make them harmful. Confusion around which words to use can be exacerbated by cultural differences and language barriers as well as lack of knowledge.

Sadly, efforts to change the language used in health and social care to reflect a more person-centred approach are often met with initial enthusiasm but little lasting change as team members revert to what is quickest to write, often copying others' poor practice. This is not helped by electronic recording systems for medication and care that reinforce poor practice with their consistent inclusion of words such as 'refused', (non) 'compliant', 'aggressive' and 'challenging behaviour'. If systems use negative words then surely its ok for team to use them, isn't it?

In their article Davies-Abbott and Roberts report that around 25% of care time is spent on documentation. This suggests that more needs to be done to help employees understand that the recording of care and support is as important as providing the care itself. It is not something that can be done on the go, but needs dedicated time for employees to be able to think about the impact of what they are writing. Regular review, as described in this project, should be factored into homes' employee development programmes to give them time to discuss and reflect. Only then are we likely to see a permanent reduction in non-person centred language in care and case notes.

'How We Talk about Dementia, good practice guidelines for words and images' is available to download here kyn-lets-talk-about-dementia-guidelines.pdf ■

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 round-up of the news and resources regularly posted and updated on our website.

New Year's Honour's List 2025:

Recognition for leading figures in dementia care

Dawn Astle, Founder of The Jeff Astle Foundation, has been honoured with an MBE for her services to footballers with dementia. Dawn is the daughter of footballer Jeff Astle and founded The Jeff Astle Foundation after her father died from chronic traumatic encephalopathy (CTE), a condition he developed from repeated, low level brain trauma believed to have been caused from regularly heading footballs. The Foundation aims to raise awareness of brain injury in all forms of sport and to offer support to those affected. Dawn was Dementia Community's guest speaker at the National Dementia Care Awards at Winchester Cathedral in 2022.

<https://thejeffastlefoundation.co.uk>

Alongside Dawn, Penelope Watson has been awarded an MBE for services to dementia care in football. Penelope is a dementia campaigner and wife of former England international football player Dave Watson, who was diagnosed with dementia in 2014. More about her work here: <https://www.bbc.co.uk/news/articles/cgrwpvllkxkeo>

Four more people have been recognised for their work with people who have dementia. They are:

Asma Pandor BEM - Lead Admiral Nurse, Dementia UK, Gloucestershire Hospitals NHS Foundation Trust. For services to Nursing (Gloucestershire).

Evelyn Blumenthal BEM - Volunteer, Royal Free Charity. For services to Hospital Volunteering and to Caring for People with Dementia (London, Greater London).

Eileen Gibson BEM - Nurse, Social Worker and Area Manager, Northern Health and Social Care Trust. For services to Older People with Dementia and Adults with Learning Disabilities in County Antrim (Carrickfergus).

Roisin Flynn MBE - For services to People affected by Dementia in the Western Health and Social Care Trust Area (Londonderry, County Borough of Londonderry).

NIHR School for Social Care Research

The NIHR (National Institute for Health and Care Research) School for Social Care Research (SSCR) has secured fourth phase funding.

The new funding, up to £31million over 5 years, will enable the NIHR SSCR to continue working to improve adult social care practice by support the School's core vision to provide better evidence for what works in adult social care and how this can be applied across the country. Professor Yvonne Birks, Social Policy Research Unit at the University of York and new Director of the NIHR School for Social Care Research, says:

“As a discipline, social care research has come such a distance with unprecedented investment from NIHR and we no longer have to justify the need for investment. Our efforts need to address building capacity for our community of excellent early career researchers and demonstrate real impact.”

NIHR SSCR Phase four brings together six academic centres:

The University of York (lead University)

The University of Birmingham

University of Bristol

A collaboration between the Universities of Leeds and Leeds Beckett

The London School of Economics and Political Science

University of Sheffield

Find out more here: <https://www.nihr.ac.uk/news/school-social-care-research-secures-fourth-phase-funding>

People with dementia wanted for workshops on PPIE

Dr Sarah Griffiths, from University College London, is running a series of workshops with people who are living with dementia.

The workshops are part of Dr Griffiths work into how more people living with dementia can be involved in Patient and Public Involvement and Engagement (PPIE) research. Dr Griffiths wants to find the best ways of improving communication between people with dementia and researchers in PPIE.

For more information, please contact Dr Griffiths via email: s.a.griffiths@ucl.ac.uk or call: 020 3108 6699.

SPIN-Dementia Network Plus

The SPIN-Dementia Network Plus is looking to build its network, to work with researchers, professionals, people living with dementia and unpaid carers. SPIN-Dementia Network Plus is looking at ways to reduce the risk of dementia, delay the onset of early symptoms and lessen the impact of dementia through care and support interventions. Find out more and register your interest here: <https://spindementianet.org>

Casey Commission into adult social care announced

The UK Government has announced an independent commission into adult social care. The Commission will be chaired by Baroness Louise Casey and will aim to inform government about the work needed to deliver a National Care Service. The Department for Health and Social Care say of the Commission:

“Split over two phases, the commission will set out a vision for adult social care, with recommended measures and a roadmap for delivery. The first phase, reporting in 2026, will identify the critical issues facing adult social care and set out recommendations for effective reform and improvement in the medium term.

“The second phase, reporting by 2028, will make longer-term recommendations for the transformation of adult social care. It will build on the commission's first phase to look at the model of care needed to address our ageing population, how services should be organised to deliver this, and how to best create a fair and affordable adult social care system for all.”

You can find out more here: <https://www.gov.uk/government/news/new-reforms-and-independent-commission-to-transform-social-care>

The Long Goodbye

Statement by the Board of Directors of Dementia Community about Alzheimer's Society's 'The Long Goodbye' campaign

Kate White, Jude Sweeting and Barbara Stephens, on behalf of the Board of Dementia Community, met with Alex Hyde Smith (Chief Marketing Officer and Executive Director) from the Alzheimer's Society on 8 November 2024 to open a dialogue with the Society about the future of our working relationship.

We discussed The Long Goodbye, other recent Alzheimer's Society communications, the shared and differing values and perspectives of our two organisations and the reactions and views of Dementia Community members who have spoken out. We emphasised the key role Dementia Community has in fostering constructive debate and creating a space for its community members to express a diversity of opinions and perspectives safely. The meeting had a positive tone, we felt acknowledged, listened to, and heard.

As a former care partner, Kate White spoke about the distress and pain that had been experienced by people living with dementia who felt that the The Long Goodbye offered a "no hope" message, suggesting that a diagnosis of dementia signalled "the end" with loss of personhood, devastation and a series of ongoing deaths.

We talked about this story being "one family's story" and that many other stories could be told which would present a more nuanced and balanced picture. We highlighted ways in which people diagnosed with dementia and their families, when all are supported, continue to live life contributing to their community and can have an improved experience at the end of life.

We also discussed our concerns regarding the use of pejorative language such as "death" and "devastation", which, in our view, undermined years of campaigning against stigma.

In addition, we raised our concerns about Alzheimer's Society's consultation process with people with dementia about the The Long Goodbye

and its seeming lack of compassion. Alex acknowledged that the Society had not identified the limitations of the consultation process, which had been described as co-production, and would seek to more clearly articulate how people with lived experience are involved in consultations of this kind in the future. We suggested there was an important opportunity for the Society to have a reparative conversation with those who had been involved.

Alex explained the rationale for the advertisement and the campaign and spoke about the research outcomes that had informed the decision to produce the advertisement. Alex also detailed the planned further phases of the campaign that will offer "help and hope" and convey a fuller picture of how people with dementia can be supported to live with purpose and fulfilment.

He expressed their intention to make dementia a more pressing issue for those without experiences of dementia and to raise awareness of the later phases of the illness when many are not experiencing "living well".

To support further dialogue, Alex made it clear that the Alzheimer's Society is comfortable with fielding all questions and comments, including from their own staff. He encouraged Dementia Community members to express their views and perspectives.

We asked for our community to be included in future discussions and consultations, in the spirit of "critical friendship" and this was agreed.

The Alzheimer's Society is a longstanding supporter and contributor to the *Journal of Dementia Care* and a valued partner of UK Dementia Congress. The Directors of Dementia Community are committed to upholding an ongoing dialogue with Alzheimer's Society about The Long Goodbye and other relevant matters, and there is a reciprocal commitment from the Society.

Dementia Community, November 2024

If you would like to add your comments regarding this advert, please send them by email to: voices@dementiapublishing.community

Carers UK celebrating their 60th year in 2025

Carers UK has begun celebrating and reflecting on their 60 years of campaigning for unpaid carers under the theme of Equality: today and tomorrow.

Carers UK's history goes back to 1965, when Rev Mary Webster founded the first ever national unpaid carers organisation to raise awareness of women who were ignored and invisible whilst caring for older relatives. You can find out more about Carers UK's milestone year and planned events here: <https://www.carersuk.org/news/carers-uk-the-national-campaigning-charity-for-unpaid-carers-to-mark-60-year-milestone-in-2025/>

New training course:

LGBTQ+ Inclusivity in Ageing and Dementia

The University of Stirling Dementia Services Development Centre (DSDC) is launching a new course entitled LGBTQ+ Inclusivity in Ageing and Dementia. The course will look at topics such as historical discrimination, unconscious bias and celebrating diversity. It is intended to support health and social care staff to better understand the needs of the ageing LGBTQ+ community. David Wilson-Wynne, Co-designer of the course and Senior Dementia Consultant at the Dementia Services Development Centre, says:

“Ageing for the LGBTQ+ individual brings unique challenges. A lifetime of marginalisation can create mistrust in healthcare systems, and if they have dementia these feelings can be exacerbated and make them feel even more vulnerable. These are all issues we aim to address with the new course.”

‘LGBTQ+ Inclusivity in Ageing and Dementia’ launches on 27 March 2025, with a further date of 12 June 2025 also available to book. <https://www.dementia.stir.ac.uk/newsblog/addressing-the-unmet-needs-of-older-lgbtq-individuals-and-those-living-with-dementia>

Course co-designer John Bond has written a blog for Dementia Community Voices entitled, ‘Promoting Inclusivity in Dementia Care: Supporting LGBTQ+ Staff.’ You can read the blog here: <https://journalofdementiacare.co.uk/promoting-inclusivity-in-dementia-care-supporting-lgbtq-staff>

Lewy Body Society celebrates five years of funding LBD Admiral Nurse

The Lewy Body Society has celebrated five years of funding Rachel Thompson’s role as the UK’s first Consultant Admiral Nurse for Lewy body dementia. Jacqui Cannon, CEO of Lewy Body Society, says: “We are so proud to have been funding this vital role for five years, it feels like a real milestone in the care of such a misunderstood and underdiagnosed disease.” To enquire about referral to the Lewy body Admiral Nurse service, call free on 0800 888 6678 or email helpline@dementiauk.org.

New resources to involve people with lived experience in events

Social Care Future, In Control and Think Local Act Personal (TLAP) has published two resources under the banner of ‘Inclusive and Insightful Events’ to support involving people with lived experience in events.

‘Research into people’s lived experiences’ and ‘A practical guide to support speakers with lived experience at your event’ give information and advice, noting that people with dementia are often under-represented in events, especially if they are living in a care home. <https://thinklocalactpersonal.org.uk/resources/inclusive-and-insightful-events/>

Home Instead YouTube channel to support families

Home Instead has launched a YouTube channel dedicated to raising awareness of dementia and helping families who are impacted by dementia.

<https://www.youtube.com/@homeinsteaduk>

Dysphagia white paper published

Care England has collaborated with Oak House Kitchen to produce a white paper on dysphagia.

The paper looks at best practice for supporting people with dysphagia, a condition that is estimated to affect four million people and often develops as a person lives with dementia. Read the white paper here: <https://www.careengland.org.uk/wp-content/uploads/2024/11/Care-England-x-OHK-White-Paper--Nov24-digital.pdf>



Launch of End of life care is everyone’s business

The Coalition of Frontline Care for People Nearing the End of Life has published a report entitled: ‘End of life care is everyone’s business.’

You can read the report here: <https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Coalition%20of%20Frontline%20Care%20Report%20November%202024%20-%20compressed%20-%202026.11.24%20edits.pdf>

Participants wanted for survey exploring stigma towards people with dementia in extra care housing

John Bosco Tumuhairwe, a PhD Researcher from the Association for Dementia Studies, University of Worcester is conducting a study to explore stigma towards people with dementia living in extra care housing.

If you are a manager/senior care staff member/dementia specialist in an extra care housing scheme or village and are interested in taking part in a survey for this study, please visit: <https://app.onlinesurveys.jisc.ac.uk/s/ucw/survey-exploring-stigma-towards-people-with-dementia-living-i-1>

People living with dementia wanted to pilot home monitoring system

Supersense Technologies is looking for people living with dementia to pilot their SenS2 hub, which is one of the shortlisted technologies for the Longitude Prize on Dementia <https://journalofdementiacare.co.uk/finalists-longitude-prize-announced>.

The SenS2 hub is described as a unique monitoring system which works without cameras or microphones, and can help a person living with dementia to retain independence and the ability to remain in their own home for longer. You can register your interest in taking part in this pilot here: <https://supersensetech.com/sign-up/>

Find out more about Supersense Technologies here: <https://supersensetech.com>

Sheffield to Stirling – return for a Windrush pioneer with dementia

Sheffield Memory Hub and the Dementia Trust has enabled Muriel Richards, a pioneering Windrush lady who came to Stirling from Barbados in 1955, to return to the Scottish city having moved to Sheffield almost 70 years ago. Muriel now lives with dementia and has had a long-held dream of returning to Stirling and visiting the Allan Park Hotel where she worked and enjoyed her 21st birthday celebrations. Muriel had a 4-day visit to Stirling recently in a trip primarily funded by the Dementia Trust. It was led by Carl Case whose organisation, Cultural Appropriate Resources, works internationally to make a difference to people with dementia from African and African Caribbean communities.

Carl says: “Muriel’s return to Stirling is more than just a personal journey; it is an opportunity to raise awareness about dementia, the importance of reminiscence, and the deep historical ties between Scotland and Barbados.” ▷

▷ Watch a film about Muriel's life and return to Stirling here: <https://youtu.be/WAdpxFHRJo?si=245DyOnVvaQjI9IG>

See behind the scenes photos here: <https://dementiatrust.org/projects/scotland-a-journey-of-return-and-discovery>

Read an article about Muriel here: <https://www.voice-online.co.uk/news/uk-news/2024/11/11/windrush-woman-reunites-with-her-past-in-scotland/>

'You are not alone in feeling lonely' – A new report from Age UK

Age UK has published a report presenting new evidence about the scale of loneliness among people aged 65 and over, and details why loneliness is harmful to older people's health, wellbeing and quality of life.

<https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/loneliness/you-are-not-alone-in-feeling-lonely.pdf>

Tide grant for peer support groups for carers of YOD on Merseyside

Tide (Together in Dementia Everyday) has been awarded a grant by the Dementia Trust to begin some peer support groups for carers of people with young onset dementia (YOD) in conjunction with the Alzheimer's Society.

The groups will be in the Merseyside area, initially beginning in Liverpool and Sefton. Those supporting someone under the age of 65 with dementia in these areas, should email carers@tidecarers.org.uk. Others can join tide's online Young Onset Carers Group which meets monthly. Find out more here: <https://www.tide.uk.net/young-onset-carers-group/>.

Principles published for the ethical and responsible use of AI in social care

The Digital Care Hub, in conjunction with the Oxford Institute for Ethics in Artificial Intelligence (AI), has supported a small group of individuals with knowledge in this area to produce a guide about the ethical and responsible use of AI in social care. A set of seven guiding principles has been published to aid social care commissioners and service providers in their use of AI.

<https://www.digitalcarehub.co.uk/ethical-principles-for-ai-in-social-care-frameworks-for-the-future/>

AI technology and music for people from South Asian backgrounds living with dementia

Anglia Ruskin University and British healthtech company MediMusic has received £183,682 of funding from Innovate UK (part of UK Research and Innovation) to investigate how AI technology and music can ease anxiety amongst people of South Asian backgrounds living in care homes with dementia. It is believed to be the first time music therapy research has been carried out specifically involving people of South Asian backgrounds living in care homes in the UK. MediMusic is technology that digitally fingerprints music to develop relaxing playlists to help ease pain, anxiety and stress. After expanding the libraries of Indian and Pakistani music on MediMusic, the researchers will explore how this machine learning-based music recommendation app can be used as a form of

therapy to support Indian and Pakistani care home residents with dementia, as well as their professional carers.

Find out more from Anglia Ruskin University here: <https://www.aru.ac.uk/news/mixing-music-with-ai-to-assist-care-home-residents>

Visit MediMusic here: <https://medimusic.co>

Link between air pollution and dementia

The Chief Medical Officer's Annual Report for 2024 has been published, this year focusing on Health in Cities. In his report, Prof. Chris Whitty, Chief Medical Officer for England, looks at a range of health challenges in urban areas including health inequalities and deprivation.

Dementia is mentioned most notably with the link to air pollution, which features in the Lancet Commission study on risk factors for dementia <https://journalofdementiacare.co.uk/the-lancet-risk-factors-for-dementia>.

You can read Prof Chris Whitty's report here: <https://assets.publishing.service.gov.uk/media/6756e67b43b2de5fee8dae87/cmo-annual-report-2024-health-in-cities.pdf>

'Wintering Well' booklet from Alzheimer Scotland

Alzheimer Scotland has published a 'Wintering Well' top tips booklet. The booklet features information and advice on staying well and safe during the winter season.

You can download the booklet here: <https://www.alzscot.org/sites/default/files/2024-12/Wintering%20Well%20Top%20Tips.pdf>



Australian Government launch 10-year action plan

The Australian Government has launched its 2024-2034 National Dementia Action Plan. It aims to raise national awareness, address risk factors, and prioritise better quality care for those living with dementia.

: <https://www.health.gov.au/our-work/national-dementia-action-plan> and download the plan here: <https://www.health.gov.au/resources/publications/national-dementia-action-plan-2024-2034>

So Many Beauties Dementia Friendly Music Festival

A film has been released sharing a snapshot of the So Many Beauties Dementia Friendly Music Festival that happened at Manchester's Bridgewater Hall on Friday 20 September 2024.

Over 600 people gathered at the event for the end of an 18-month project giving people living with dementia and their communities the chance to curate their own day long festival, taking over the entire Bridgewater Hall.

You can watch the film here: <https://www.youtube.com/watch?v=6UFAP3qFyl4&t=663s>

Find out more about So Many Beauties here: <https://somanymybeauties.org/current-projects/>

Dementia Diaries

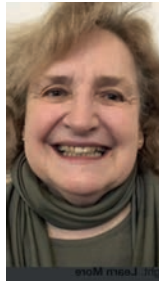
Celebrations in the world of people living with dementia

Who would have thought that there would be anything to celebrate about having dementia?

If you've watched the latest media portrayal of Nigel in Eastenders, as your only point of reference, you would think that his life is only destined for doom and gloom. He has walked out on his life not wishing to be a burden on his wife.

Through Dementia Diaries and the work of groups like Dementia NI who are part of the DEEP Network, we know all too well how much people with dementia can and do contribute to awareness and education; but also, how engaging, empowering and supporting each other makes such a difference. If only Nigel could listen to stories of hope and support.

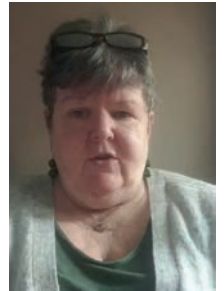
I recall Shelagh Robinson telling me of a 'new recruit' to the world of dementia. "Yesterday, I was introduced to someone who has a recent diagnosis of dementia, and is very, very frightened and very, very negative – as I guess we all are in those first weeks of dementia. She said, when we were introduced, "I don't want to talk to you; I can't be like you." Of course you can't; we all deal with dementia in our own, different ways. But I suggested to her that she went online and had a look at some Dementia Diaries. I saw her again this afternoon, and she gave me a big hug, and said, "That was the best thing you could have ever given to me to do. They were all so different; it was like entering a world that I could be in – I could be positive in." <https://dementiadiaries.org/entry/11626/listening-to-dementia-diaries-opened-a-positive-world-to-a-lady-who-is-newly-diagnosed/>



In 2022 the UK DEEP Network celebrated 10 years of engaging and empowering the voices of people living with dementia. On a cold wet Sunday 2025 afternoon at home in North Wales, Dementia Diarist Teresa Davies (known as Dory) reflects on a 'memory I will never forget'. The North Wales DEEP Celebrations brought together people from across the UK to celebrate the connections and the friendship that the DEEP Network gave them. <https://dementiadiaries.org/entry/22547/dory-reflects-on-deep-10th-anniversary-celebrations-in-2022-a-memory-i-will-never-forget/>



2025 marks the 10th anniversary for Dementia NI. Allison Batchelor, living with dementia, is now, very proudly, one of the Directors and co-chair of Dementia NI. In this diary recording she reflects on the strength and growth of the group across the whole of Northern Ireland. <https://dementiadiaries.org/entry/22530/allison-talks-about-her-involvement-with-dementia-ni-and-their-10-year-celebrations/>



So, wherever you are and whoever you work with perhaps think of ways you can celebrate what contributions can still be supported by you for people with dementia to take part no matter how small a thing that may be. Being valued is one of the core things we all need in life.

This piece of music created in 2022 reflects the voices of many from across the UK – the power of "I've got you" should never be underestimated. https://www.youtube.com/watch?v=H3EHg3JdOM0&list=PLYEHjkaV2Fx2aw18MZzCYQTO_7uUaIXW4

Finally, February 22nd marks the year anniversary of the death of our very treasured friend Wendy Mitchell. We all still feel her great loss, but we also still feel her presence. Her work continues to be shared, and helps so many people across the world. So, a final positive word of celebration and hope for Wendy, with love and a virtual hug.

<https://dementiadiaries.org/entry/13594/wendy-has-written-a-poem-about-about-belonging-to-deep/>



Do you know somebody living with dementia whose voice should be heard? Contact us at Dementia Diaries DementiaDiaries@outlook.com

Rachel Niblock, Innovations in Dementia

You can find out more about Dementia Diaries at: <https://dementiadiaries.org>

UK Dementia Congress 2024

Congress brought together speakers, exhibitors, sponsors and delegates to inspire and learn from each other at Coventry Building Society Arena on 26-27 November

Reading Well: working together

Congress began with a focus on co-production in action, as people living with dementia and family carers described their work with the Reading Agency to choose books for the Reading Well with Dementia list. Maxine Linnell described her desire to read, “but most books I found were medical and/or by carers and supporters—nothing by people with dementia themselves. I wanted to know, what will it be like? What will it feel like?” And beyond individual experience, as Keith Oliver commented, “I want reading to stretch my imagination and empathy beyond what I know—including talking about dying.”

Scotland’s Strategy: Everyone’s Story

Also in the opening plenary, Graham Galloway and Ron Coleman of Meeting Centres Scotland, impressed the largely English audience as they described how people living with dementia have been involved from the very start and all along in the development of Scotland’s National Dementia Strategy.

Post-diagnostic care a priority

In a packed plenary session on 27 November, Dr Jeremy Isaacs, consultant neurologist, St George’s Hospital and Kingston Hospital, and National Clinical Director for Dementia and Older People’s Mental Health, NHS England, set out his priorities and ambition.

He emphasised that prevention – delaying the onset of dementia for everyone – is a necessity so that we can handle demographic ageing. However, only a third of people know it is possible to reduce their risk of dementia, and inequality is a big factor: only the least deprived have so far benefited from dementia risk reduction.

The dementia team at NHS England is small and prioritisation is essential, he said, but “The number one thing I want to fix in my time in this role is post-diagnostic care and support, so that no one feels abandoned after diagnosis.”

Question Time

The Question Time panel fielded questions on a wide variety of topics, including research and evaluation.

Isabelle Latham noted that the dominance of certain methodologies “ties our hands” when seeking to show an intervention has benefits. Researchers need to be more



Speaking in the opening plenary session of the UK Dementia Congress 2024, left to right: Graham Galloway, CEO and Ron Coleman, Chair of Meeting Centres Scotland; Alex Osborne, Deputy Head of Policy, Alzheimer’s Society. Inset: Keith Oliver and Maxine Linnell.

flexible in their research methods, she argued. Karan Jutla agreed that researchers need to challenge the dominance of RCTs. This is starting to change, she said: “We are working on ways we can demonstrate the impact of an intervention - that it has made a difference - with more emphasis on case studies.”



The Question Time panel left to right: Ron Coleman, Meeting Centres Scotland; Karan Jutla, University of Wolverhampton; Jan Beattie, Meeting Centres Scotland's Strategic Advisor (formerly Professional Advisor to the Scottish Dementia Policy Unit who developed the new Scottish National Dementia Policy); Jeremy Isaacs, NHS England; Graham Stokes, HC-One; Isabelle Latham, Hallmark Health Care.

UKDC 2024: Debate and discussion continues

Whose reality is foremost?

In the Tom Kitwood Memorial session on 26 November we were reminded of Tom's words: "He didn't talk about truth and lies but about genuineness and treachery - emphasising that it is the *intent* that matters." Jane Murray (right), an experienced nurse and assistant professor at the University of Northumbria, gave a presentation "Whose reality is foremost? Can lying be used to support personhood?" to stimulate a wide-ranging panel and audience discussion. She concluded with key messages:



- Be genuine
- Validate the recipient's emotions
- Do it for the right reasons.

There was lively discussion during the session, and it promoted further reflections from participants, below:

Toby Williamson, session chair:

It's a long-standing truth in the field of dementia care that the question of lying to people with dementia is a source of intense debate and often stark differences of opinion.

This was certainly the case at in this session at congress, where we considered the questions of whose reality should be prioritised when a person with dementia has a very different perception of the world around them from those that are caring for them. The session also considered whether lying was compatible with efforts to support personhood, and the tool that Jane Murray presented for judging when lying might be necessary.

I chaired the session and, having led a national project that explored the issue of truth-telling in dementia care, I continued to feel uncomfortable with the way the term "lying" was used, even though I recognise that honesty isn't always the most appropriate response. This discomfort was also partly reflected by comments from someone with lived experience in the audience, who expressed deep mistrust of the main presenter and panel members, who they felt were endorsing lying too casually. I had a discussion with the person who made the comments after the session. They were not wholly against dishonesty, but felt that it should be discussed in advance with the person with dementia, and their views about being lied to noted and respected. Maybe not an easy discussion to have, but an important one, and best to try and use terms like 'going along with' rather than the 'L' word, to keep it constructive. Whose reality is it anyway?

Ruth Eley, director and chair of tide:

The panel discussion prompted some heated debate amongst delegates. Having had time to reflect, here are some further thoughts from tide member Katey Twyford (right, above), who was on the panel:

The debate at UK Dementia Congress on "Whose Reality – truth and personhood" revealed the complex issues carers navigate daily. There is no linear relationship between truth and lies—the very word 'lies' can place emotional guilt on the carer.

The taxonomy presented by Dr Jane Murray prompted

me to reflect on how we try to remain true and kind to the person of someone living with dementia when their worldview is ever shifting. Dad's Life Story helped others understand the context for dad's changing world view. When dad commented that he hadn't seen my (dead) brother for a long time I would respond that neither had I. It gave breathing space to interpret dad's reality and give an opportunity to talk together about my brother's death if appropriate. It was kinder to give room for dad to remember for himself that my brother had died rather than catapult him into fresh bereavement each time someone told him his son was dead. The breathing space meant I could gently steer the subject away to something less emotional if dad really believed he was still alive."



Katey Twyford

Cecilia Toole, another tide member, added: *As my dad's carer, I had some surreal moments. One early morning, he called out through the baby monitor from his downstairs bedroom. "Are you okay, Dad?" I asked. "Yes, I can't find my overalls," he replied. Instantly, I knew he was back in his joiner days from 25 years ago. I went to him and asked where he thought they were. "On the end of the bed," he said. I pointed out they were actually on the floor. He thanked me, and I wondered if he was dreaming. That moment, though odd, is a happy memory for both of us.*



Cecilia Toole

These experiences illustrate the importance of trying to enter into the reality of the person with dementia. The topic has generated discussion in the Tide Advisory Group. Members have agreed that we should explore whether we can develop some resources for carers as part of our Carer Development Programme to help them think through what can be a challenging and distressing topic to navigate as a carer.

Sally Knocker, Meaningful Care Matters:

At an intellectual level, I could accept much of the rationale for accepting that a range of lies are often a part of the repertoire of relating to people who are in different realities, and those of us on the panel shared positive examples of this. However, both before and after the debate, I couldn't get away from my deep-rooted discomfort about the potential breakdown of trust when we deceive people, albeit in what we regard as their best interests. This was reinforced by the vehement and angry reaction from one of the audience members at the end of the debate, who said that he "wouldn't want any one of us to be his carers", as we had essentially advocated dishonesty. This was a reminder to me that the power we hold to enhance or undermine what Kitwood aptly described as 'personhood' can never be treated lightly.

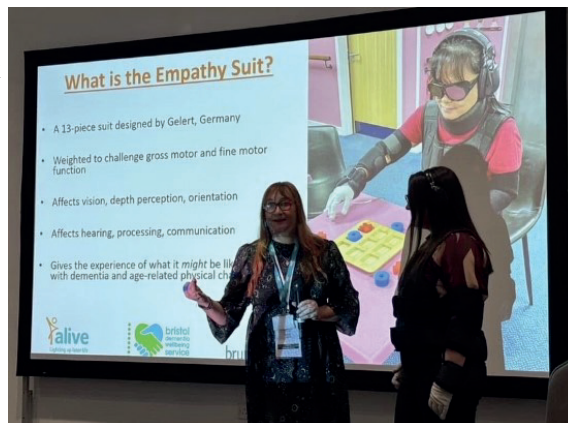
You can hear Jane Murray talking on this subject in our 21 May 2024 webinar – 'Can lie telling be used to support personhood?' www.journalofdementiacare.co.uk—select Webinars then the link to our YouTube channel.

The Empathy Suit workshop

In a popular Early Bird workshop at UKDC, presenters from Bristol Dementia Wellbeing Service, Brunelcare and Alive Activities collaborated to explain how an empathy suit works and then gave participants the opportunity to try the suit. The experience prompted a conversation on Facebook between Sally Knocker and Anna Park:

Sally: It was an interesting experience trying on the empathy suit. I had mixed feelings but think it could be a helpful addition to our training.

Anna: I think if you are a natural empath who understands all the sensory changes that can be caused by dementia you probably don't need it — though I acknowledge that it may help to remind people of a less obvious impairment. Everyone's



experience of dementia is so different though, so surely an empathy suit is only ever going to communicate one example - it's a one size suit. Better to watch for cues from the person's own unique experience of the disease, I'm sure if someone living with dementia put one of them on they'd say, that's not my dementia! But for people who might struggle to empathise I can see how wearing this suit might help by mimicking disorientation, visual disturbances, heaviness, coordination issues etc,

Sally: I agree Anna — I am quite ambivalent about these simulation experiences, but it does give a sense of feeling less in control and less easily able to do everyday activities. I think it could be a lively addition to training as long as it is debriefed well. The macular degeneration glasses gave me an emotional connection and insight into my mum's life right now.

More comments on the UK Dementia Congress 2024 from social media

Fantastic couple of days at UK Dementia Congress 2024 talking all things dementia and flying the flag for the work Mersey Care NHS Foundation Trust does in this area including post diagnostic support in the Chinese community with Chinese Wellbeing and Tree of life on our wards. Tired but inspired now!

Sarah Butchard

Thank you to Dementia Community for connecting us and inspiring us at UK Dementia Congress 2024! We led a moving workshop of the Empathy Suit with Bristol Dementia Wellbeing Service and Brunelcare, and our partnerships manager and CEO also leading a discussion about love and dementia - a moving way to finish the conference. *Alive Activities*

Big thanks to the committee for a meaningful conference, linking researchers beyond academia to practitioners, charities, and communities. Powerful talks, chats, lived experiences. Really insightful questions and conversations followed our talks. So many important issues were raised—access, stigma, post-diagnostic support—thoughtfully discussed. UK Dementia Congress 2024 has been a meaningful platform, bringing together stakeholders to drive change & share solutions. *Xiaoxiao Hou*

A big thank you to Dementia Community for having us last week. We were delighted to share more about our project on reducing inappropriate psychoactive medication for people living with dementia, as well share an overview on our practical dementia resources project. *Care Inspectorate, Scotland*

Such a great conference for catching up with wonderful people doing fabulous work. *Kate Gridley*

What a fabulous two days at the UK Dementia Congress where I got to reconnect with old colleagues, formed new friendships and collaborations, and shared our work at the Centre for Applied and Inclusive Health Research at the University of Wolverhampton. It is a privilege to work alongside like-minded people such as Jag Brar-Orghill, Carl Case and Chris Knifton - all of whom continue to inspire me their dedication through their lived experiences. *Karan Jutlla*

There is a BIG problem with UK Dementia Congress. The problem is I leave wanting to change the entire world. I was so inspired by the stories, the people and the community of people getting together to create a better world for people living with dementia. I went from talking about the importance of garden spaces to focusing on the amazing outcomes that can be delivered by PainChek; not many places you can do that in the space of 20 minutes. *Alexander Fleming*

A fabulous (and exhausting!) two days - so valuable for those of us committed and connected to people living with dementia. *Isabelle Latham*

Thank you for such a well-structured, informative conference. The supportive environment facilitated open discussions and learning points throughout the two days. It's the best conference I have attended all year! *Carrie Pilgrim*

Thought-provoking day at UK Dementia Congress 2024 - the importance of active listening, therapeutic value of play, and debate around 'lie telling' and redirection in dementia are take home messages for me. *Anna Hockley*

Really thought-provoking day at UK Dementia Congress 2024 hearing from people living with dementia, their families and professionals on a whole range of topics. Mind buzzing with ideas! *Rachel McMurray*

Living Well with Dementia

A specialist research focus at Wolverhampton University

CAIR is a new research centre at the University of Wolverhampton with a specific focus on improving the health and wellbeing of our diverse population. A specialist research cluster, Living Well with Dementia, includes a range of important areas of study, described below

The Centre for Applied and Inclusive Health Research (CAIR) at the University of Wolverhampton has a specific focus to develop and deliver research that can improve the health and wellbeing of our diverse population, reduce health inequalities and advance health care professional practice. The centre focuses on a range of health disciplines via research clusters co-ordinated by a multi-disciplinary team of academics.

Dr Karan Jutlla leads the Living Well with Dementia research cluster, which aims to improve the lives of people living with dementia and their families in our diverse society across the dementia care pathway. The health inequalities in dementia care are well evidenced with research demonstrating those from under-served communities experiencing huge disparity and inequity in support services. To address this gap, a range of projects are being led by academics, including:

- Funded by the National Institute for Health and Care Research, Dr Karan Jutlla is leading a project entitled “InvolveD” which aims to explore and evaluate an approach to working collaboratively with people from South Asian, Black African and African Caribbean communities in designing better dementia support.
- Funded by Alzheimer’s Research UK, Dr Jennifer Lim implemented the Chinese Think Brain Health Project to increase understanding of dementia and brain health among Chinese communities in the UK. Awarded by the Academy of Medical Sciences Networking Grant, her next project involves paving the way for dementia prevention and diagnosis in Malaysia.
- Professor Ruoling Chen has undertaken research on the demographic and socio-economic influences on community-based care and caregivers of people with dementia in China. His latest work focuses on establishing the determinants of dementia and depression in older adults.
- Doctoral studies involve: Exploring the use of digital health technology for pain assessment amongst paramedics (Alan Clarke); exploring the impact of personalised and culturally appropriate music interventions for people living with dementia from African Caribbean backgrounds (Faith Nyandoro); supporting South Asian families affected by dementia (Emaan Syed); the priorities



CAIR has developed strong community partnerships: “We can co-produce and co-create the research agenda with those who experience health inequalities in dementia care”. Dr Karan Jutlla (left) leads the Living Well with Dementia research cluster.

for dementia care curricula in higher education: the views of carers of people living with dementia and Admiral Nurses (Sharon Yates); an evocative autoethnographic study of familial caring of an African Caribbean elder with Dementia with Lewy Bodies (Angela Aitken).

CAIR’s inclusive focus to health research is to ensure that it is representative of our heterogeneous population and health care professional groups, using co-production and inclusive research methodologies and knowledge exchange activities to generate applied knowledge. Our strong community partnerships and dedication to knowledge exchange means that we can co-produce and co-create the research agenda with those who experience health inequalities in dementia care. We achieve this by ensuring that our research is developed *with* people with lived experiences as opposed to *for* them. Our Experts by Experience continue to help us learn, grow and drive research and education to help people live well with dementia from all communities.

For more information, visit: <https://www.wlv.ac.uk/research/research-centres/centre-for-applied-and-inclusive-health-research/> or contact, Dr Karan Jutlla: K.Jutlla@wlv.ac.uk

Together Stronger Creative Arts

for children of parents with young onset dementia — the first three years

Arlene Astell and colleagues describe a community-based creative arts project that has shown promising results in promoting confidence, self-esteem, creativity and skills among young people who have a parent living with young onset dementia

Together Stronger is a community-based project co-created by a parent, an Admiral Nurse, a charity (Younger People With Dementia [YPWD]) and a museum (Museum of English Rural Life [The MERL]) which is managed by the local university. Researchers from the university became involved during the planning stage and provided some contents in the first year, as well as developing an evaluation process (AA). Funding was secured through small grants from the university and other charitable funders.

The impetus for the programme came from a parent (HW) whose partner was diagnosed with young onset dementia when their two children were just five and six years old. She found limited resources, and books aimed at explaining dementia to children were about grandparents and did not speak to their situation.

The family were supported by an Admiral Nurse (LH) who was also working with a second family with similar aged children. This led to the idea of the children meeting each other and doing art together.

As the idea developed, two more families with children were referred and the YPWD (CD) charity became involved. As a specialist charity serving Berkshire, YPWD was already working with The MERL running activities for people living with dementia. The MERL's Learning and Engagement Manager (PH) who was involved in these activities, was enthusiastic about a new activity for children with a parent living with young onset dementia.

Planning for the programme took place over the Winter of 2021 and Spring of 2022, during the COVID-19 pandemic, with the first of eight sessions held in March 2022. It was initially thought that all sessions would be delivered online, but as the lockdown restrictions started to lift, a hybrid model was developed. This saw alternating sessions every two weeks, with in-person sessions lasting 90minutes, while online ones were 60minutes. The taster activities were developed around the museum's collections, spaces, and principles of object-based learning. The programme developed over time with taster activities evolving month by month in response to



The children were overwhelmingly positive about the creative activities. They particularly liked that the group did not focus on their parent's dementia. As HW the original parent reported, "This was a time where this isn't about your dad, this isn't about your mum, this is about you, this special time – it was brilliant for them."

The programme is feasible and acceptable to a wide age range, and our learning over the three years suggests this could be replicated in other museums or galleries.

what the young people loved and what they did not enjoy. In the first series art activities, crafts & making, sport and physical health, cookery & baking, and creative writing, were all explored. The young people's favourite activities were repeated and shared as part of a YPWD Family Day at The MERL in June 2022.

Developing skills and activities

Building on the successful evaluation and feedback from the young people and parents, funding was secured for a second programme, which ran in Summer 2023, once a month at The MERL. Based on discussion with the young

Hannah Wrankmore¹, Lizzie Harrison², Charlie Draper¹, Phillipa Heath³, & Arlene Astell^{4,5}

1. Younger People With Dementia, Wokingham RG41 2GY.

2. Berkshire Healthcare NHS Foundation Trust, Bracknell, RG12 2U.

3. Museum of English Rural Life, University of Reading, RG1 5EX.

4. School of Psychology & Clinical Language Sciences, University of Reading, Reading, RG6 7BE.

5. Psychology Department, Northumbria University, Newcastle upon Tyne, NE1 8ST.

A textile artist was employed to co-create a wall-hanging inspired by the museum's textile collections, to celebrate both the individual children and the strength of their collaboration and community

people, the second series focused on further developing skills and experiences they most enjoyed. This involved various activities inspired by the museum collections and spaces, including painting, and nature tiles. At the end of the year 2 sessions, their work was shared publicly at a pop-up at the final workshop (August 2023) and then again at The MERL's Youth Manifesto launch event.

Planning for year 3 extended the programme to other young people unable to participate in person. To facilitate this a textile artist was employed to co-facilitate the programme to collaboratively create a wall-hanging. Inspired by The MERL's textile collections, the wall hanging was intended to celebrate both the individual children and the strength of their collaboration and community. The wall-hanging was completed in August 2024 and will be on display at The MERL and going on tour around the YPWD community venues in Berkshire and Surrey.

Evaluation at the end of year 1 indicated the young people's well-being improved and they were overwhelmingly positive about the creative activities. They particularly liked that the group did not focus on their parent's dementia and provided a break from what was going on at home. The children also enjoyed the social aspect and appreciated the opportunity to spend time with other people in the same situation. As HW the original parent reported "This was a time where this isn't about your dad, this isn't about your mum, this is about you, this special time – it was brilliant for them."



Over the past three summers, Together Stronger has shown promising results in terms of promoting confidence, self-esteem, creativity, and skills among young people who have a parent living with young onset dementia. The programme is feasible and acceptable to a wide age range and our learning over the three years, suggests this could be replicated in other museums or galleries. We are happy to share our experience and welcome enquiries from anyone interested in setting up a similar group.

Dementia Community Voices

Do you have something you'd love to share with Dementia Community? Would it work as a 500-word blog post? Find out more about sharing your views/thoughts/projects and items of interest in our new blog space: Dementia Community Voices
<https://journalofdementiacare.co.uk/category/voices>



Time Bandits or The Alchemy of the Arts

Judy Seall and Isabelle Latham tell the story of Time Bandits Arts Club, a flexible, relationship-centred approach to intergenerational arts activities in a care home

Time Bandits Arts Club is the creation of Judy Seall, a family member at Hallmark Care Home's Henley Manor. As Head of Drama at a local, independent school, Judy understood that the arts can build confidence and provide a platform for connection and joy. The aim of the club was to push the boundaries of intergenerational and arts work with people living with dementia by moving away from highly-structured activities. Instead, Time Bandits offered a more flexible and relationship-centred approach in which regular club afternoons encourage creative activities between the same small group of young people and residents.

Judy explains her inspiration for the project:

Can you remember your first kiss? Probably. What about your fifth kiss? Unlikely. A memory can be fleeting or something that we hold on to tight for years until it quite suddenly and unexpectedly disappears altogether. I can remember the yellow front door of the first house I grew up in, the taste of the cheese bread that only my long dead grandmother knew how to make but I have no idea what I ate for dinner last Thursday.

According to the Alzheimer's Society, every three seconds someone is handed a diagnosis of dementia. Every family will be touched by this disease. Both my mother and father died of the disease, my mother spending her final years living at Henley Manor. Could the arts have an impact on individuals living with dementia, and what might a project look like?

Out of all this thinking Time Bandits became a thing. Seven brave students of Dolphin School, aged between 11 and 13 – and two equally brave teachers - fearlessly volunteered to visit the care home on a weekly basis. They met with seven even braver residents living with dementia who had been invited by care home staff. Together we were the Time Bandits, and we met each week during the summer term to collaborate on a variety of Arts projects. Here to change the world, or to tilt it slightly and look at it through a different lens? We were inspired by the work of the theatre company, Fevered Sleep, whose strapline is 'Changing the world one unlikely arts project at a time'."

What happened at Time Bandits?

One of the exciting things about Time Bandits – that set it apart from other inter-generational activities the care home had taken part in - was that the club members decided on their activities themselves each week. This led to an eclectic programme across the 8 weeks, as Judy explains:

During our first session young Bandits were paired up with resident Bandits and given a box of brightly-coloured



The young Bandits at Henley Manor

conversation starters: Questions that did not rely on memory: If you could go up in a hot air balloon, where would you travel? If you were King for the day, what would you do first?

Henry, one of the resident Bandits, immediately impressed Seren his young partner with his answer to this royal question:

"My very simple philosophy in life is try and be fair. It sounds very simple but it's bloody difficult to do."

Seren later reflected just how much she learnt from talking to Henry, just in this first meeting:

"What surprised me about working with the resident bandits - they were very knowledgeable. Henry knows so much about animals. He taught me loads about quite a few animals and I really enjoyed that."

Relationship building was intentional, not accidental. Younger and resident Bandits came together as equal partners, with a common purpose. It was therefore important to encourage all to take the lead on arts activities, so Martha suggested doing some magic tricks and Paige thought of playing board games together. Henry wanted to meet my dog and Julie said she was happy with "the young ones deciding". Each session began with a warm-up activity: We created soundscapes to an original story featuring the Bandits, played instruments, sang, and completed voice and movement exercises. ▷

Time Bandits club in action (right)

▷ Over the weeks we drew, played board games, formed a choir, created models, followed a mindfulness visualization, painted a large mural and laughed. A lot! During the activities individuals were encouraged to make up their own rules, explore their artistic talents and increase each other's self-esteem. Everyone's favourite week was probably when boxes of wigs, moustaches, sunglasses and random props arrived with cameras. A photography session! The Bandits dressed each other up and then took photos of each other. Young Bandit Jack commented,

"I had a great time this week because I had a top hat from one of the costume boxes and every time I walked past, (resident Bandits) Barbara and Donald would compliment me. Every time! And one time Barbara said to me 'You've got to keep that hat on - I can't let you take it off!'"

Above all, the aim was to encourage everyone in the room to experience joy, humour and human connection.

How did we measure success?

We wanted to make sure we could assess how effective the club had been for residents, learn for future projects and ensure that the residents were able to tell us about their experiences in their own words – even when some found it difficult to express themselves.

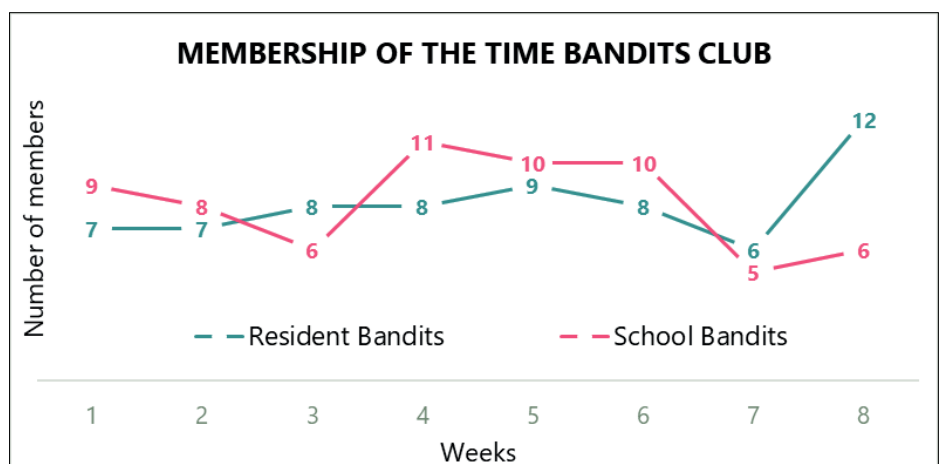
To do this we gathered the following data:

- The number of attendees each week.
- The care home's record of each resident's experience per session, (a total of 67 records)
- Residents' responses each week to the immediate post-session question "Did you enjoy the afternoon?"
- A reflective diary by the Director of the club
- Interviews with the care home's Dementia Care Manager.

Findings

Session attendance and feedback

The number of club members who attended varied each week because of illness, choice and other commitments. By week three, additional students and residents wanted to join and attended if space allowed. The figure above shows membership of the club over eight weeks.



Of the seven original resident members:

- Two attended all eight sessions with all others attending six or more.
- Six more residents (who were not originally invited) showed an interest in joining
- 98% of individual resident records rated the session as positive (with only one rated neutral and one negative from 65 ratings).

The image below (on p19) shows the resident Bandits' responses at the end of each session. These were overwhelmingly positive and accompanied by smiles, nods and eye contact from those who couldn't easily find words. ▷



▷ Lessons for the future

Analysis of the interviews and diary revealed the following key learning:

Relationship-building

- Student and resident Bandits made good friendships that strengthened each week.
- Repeated contact between the same student and resident Bandits each week was central to relationship-building.
- Lots of residents and students wanted to take part, but having a small group helped foster relationships.
- Doing a “warm up” together before starting each week helped the group to bond
- Care home staff really enjoyed seeing the residents taking part and with encouragement would join in.

Planning and organization

- Music on arrival helped the room feel welcoming and bypassed hesitation from the resident Bandits
- It was helpful to have the young Bandits ready and waiting in the room before the resident Bandits arrived as this helped the group to feel more familiar and welcoming. However, this required careful coordination in the care home and took additional time because several resident bandits required one-to-one support to move.
- The young Bandits were often more successful at inviting their partners to attend each session than care home staff.

- All Bandits liked doing different activities each week although the resident Bandits were often happy to let the young Bandits decide. This flexibility was enabled by a confident and creative group director.
- Considerations of space and safety were important, but not always recognised by the young Bandit group. The care home needed to take the lead in setting limits for group size and supporting residents to move.
- The group could have benefitted from additional time each session, but this was limited due to the travel time from the school to care home. A more local group may have been able to have more flexibility.

Case study: Robbie and Bill

Bandits Robbie and Bill were paired together the first few weeks. In week one, Resident Bill gave clear instructions to Robbie on how to draw a hand and Robbie followed diligently, prompting Bill to remark “He’s a very intelligent boy, that one”. In week two they played Jenga together, although quickly dispensed with the rules to build a tower, Bill daring Robbie to test his construction by balancing a full glass of juice on top! Robbie was very proud that the tower was up to the task. When arriving for week three, Bill was unsure whether he wanted to attend but when he saw Robbie in the room he remarked “There’s my boy” and headed towards him. As he got closer, Bill asked in French “How are you?” and Robbie put his French learning to the test in reply.

Isabelle Latham is researcher in residence, Hallmark Care Homes



From the show: (left above) Kirsty Malone, Fiona Wood and Ross Allan; (right above) Pauline Lockhart and Fiona Wood. Photos by Kelman Greig-Kicks

Dementia: the Musical

John Killick sings the praises of a ground-breaking production written by Ron Coleman and involving three founder members of the Scottish Dementia Working Group. The show played two sell-out performances in Edinburgh, then went on to tour throughout Scotland. Its message has wide relevance, and artistic experiences of this quality are a powerful way to influence hearts and minds

On 6 June 2001 in Glasgow the first Scottish presentation on dementia by people with the condition was given. I know, I was there.

So was James McKillop, one of the three protagonists of this musical. Agnes Houston and Nancy Macadam joined later, and the Scottish Dementia Working Group (SDWG) was formed. This may have been the first homegrown pressure group of its kind in the world; it was certainly the first movement of its kind in the UK. Over the next twenty years or so the Group grew in size and influence and has had a profound effect on the debate and the provision of services in Scotland and, through its speaking engagements, across the world.

On 12 October 2024 in Edinburgh the premiere of *Dementia: the Musical* was given to the first of two full houses. I know, I was there. So were all three of the subjects. Further performances have happened across Scotland, the last of which was in Paisley on 9th November.

So was this fundamentally, a historical account of an important social and medical occurrence? Well an awareness of an eventful couple of decades was certainly there, but this of itself would have lacked dramatic impetus.

The decision was taken by the author of the book (Ron Coleman, a man with the diagnosis from Stornoway) to adopt an activist scenario in which the three characters, James, Agnes and Nancy (who incidentally are today still living in their own homes) are facing the prospect of being taken into care. The state does not recognise the contribution to society they have made, and an interlocutor has been appointed to cross-question them about their attitudes. The European Bill of Human Rights has been replaced by a British Bill of Rights and this is being used by society, including care homes, to control all aspects of the lives of people with dementia. At the end the audience is invited to pronounce judgement on the case. ▷

John Killick is a poet and author.

Acknowledgement and thanks to the following for permission to use material in this article: Ron Coleman and Howard Gordon for the lyrics of *Loud and Clear*. Sophie Bancroft for the lyrics of *Rigid System*, *The Enemy of the High-Backed Vinyl Chair* and *Nancy*, *How Does Your Garden Grow*. Kelman Greig-Kicks for photographs

▷ *In the panel opposite, writer Ron Coleman and director Magdalena Schamberger describe how the production was conceived, grew and came to fruition.*

The spirit and message of the drama

To enable readers to enter into the spirit of the event, I will quote some lyrics from the musical. Here is part of a chorus that encapsulates the overall message of the drama:

Upon their shoulders we stand tall
Held by them we cannot fall
Because they chose to answer the call
That's the reason we are here.

The story's theirs alone to tell
Ten per cent heaven, ninety hell
They kept upright when they should have fell
That's the reason we are here

James McKillop, high command
First activist to voice our demands
Fearless fighter, dedicated man
He's the reason we are here

Nancy McAdam, Agnes Houston
Giants of the revolution
Fought the systemic order
They're the reason we are here

HEAR THEIR VOICES, HEAR THEIR VOICES
LOUD AND CLEAR, LOUD AND CLEAR
HEAR THEIR CHOICES, HEAR THEIR CHOICES
LOUD AND CLEAR, LOUD AND CLEAR

A key character is played by Rigid System. She comments throughout and attempts to counter the individual songs of the three protagonists and also their group contributions. Here is part of her song:

How can you tell me that I'm wrong
Can't you see my motivation to help is strong
I don't want you telling me what you need
I know exactly what you need
So let me be
I wear a suit 'cos I know what's right
I'm educated, liberated, held in tight
I believe in the system I represent
A technocrat, a bureaucrat from your government.

And here is the musical reaction of the three people with dementia to the charge:

We need a plan
We need a plan
We need a plan
To fight the man in the suit

And the system
The rigid system
She's in cahoots
With the man in the suit ▷

Ron Coleman gives this account of how the show came about:

It did not start its life as a musical, but as a play about James, Nancy and Agnes. Very early on in the writing of the play I gave the title of 'The Ballad of the Dementia Activists', and it was at this point it moved away from being a play towards being a musical. It promises to celebrate not just the activism of James. Nancy and Agnes but of every person with a diagnosis of dementia to change the dominant perception of dementia and show the world we are much more than people think we are.

Magdalena Schamberger, director of the show, writes:

I became involved in 'Dementia the Musical' in 2022, following its first reading on the Island of Lewis. Ron was in search of a director with experience of working with people with dementia. He was aware of my passion and commitment to working creatively with people living with dementia for the past 25 years, initially by creating Hearts and Minds' Elderflowers programme (see Killick 2003) and more recently by creating collaborative performances for people living with dementia, namely Curious Shoes, In the Light of Day and Framed, the third part of my dementia-responsive trilogy which is currently in development.

My performance projects are tailored for high quality engagement with small audience numbers. With support from the Creative Scotland Touring Fund, Dementia the Musical was able to embark on a National Tour to larger theatre venues, achieving higher audience numbers and overall reach. This has played an important part in spreading the word and encouraging activism and change.

I guess you could say that Dementia the Musical chose me. I realised from the outset that the play had an important story to tell. I have known and worked independently with James, Agnes and Nancy. the three activists at the centre of the story, as well as Willy Gilder, the reporter, for a number of years. This was particularly useful when directing the filmed segments incorporated in this production.

In terms of challenges – the project was unsuccessful the first time we applied for funding and we had to wait an entire year to resubmit our application. Overall, I felt a huge responsibility to do justice to Ron's script, while at the same time incorporating contributions from all collaborators and drawing on my directing experience to enhance the theatricality of the piece, without losing its intention. As with staging any new play, there was a lot to balance – the juxtaposition of dementia activism with the theme, with a musical as the chosen style for the piece; keeping the political message clear, while incorporating a strong sense of fun and humour and letting the beauty of the music by Sophie Bancroft and the life stories of James, Agnes and Nancy unfold. I hope that we have achieved this celebration of lives, creativity and political activism, whilst not shying away from the challenges a diagnosis of dementia brings.

▷ Must be quick
 Can't miss a trick
 They're devious in the way
 That they do things

Steal our rights
 In the middle of the night
 And put us on the back foot
 We're the enemy
 Of the high backed vinyl office chair.

The kernel of the show is the three songs given to the three protagonists. Nancy lives in a cottage on the Black Isle and hers is a rural life style:

I plant flowers, sow some seeds
 Prune roses, remove the weeds
 Find ways to make my garden bloom
 People always ask, people always ask me
 Nancy, how does your garden grow?

Verdict

This is very much a musical with designs on the audience. Does it succeed? The answer I would give is: triumphantly! It is very much a company effort. The actors and the technical staff are at one in putting the message across. Sophie Bancroft the composer, Magdalena Schamberger the Director, and Gemma Greig-Kicks the producer, are at one in maintaining consistency. And sound and lighting (Tom Lyne and Colin Grenfell) contribute massively to the overall effect. The show is always on the move with sharp projections underlining the meaning at all times. You cannot avoid absorbing the ethos of this production. I also think that because the show started out as a play and not a musical this has given it a focus and a tension which it might otherwise have lacked. The four professional actors – Ross Allen, Pauline Lockhart, Kirsty Malone and Fiona Wood – are fully in command of their acting and singing roles. There is a fifth actor in Willy Gilder, who actually has dementia, and plays the part of



Above, left to right: Pauline Lockhart, Kirsty Malone, Fiona Wood, Ross Allan. Below, left to right: Fiona Wood, Ross Allan, Kirsty Malone.

Reporter; he appears mid-set on a tv screen linking scenes and giving historical information.

Ron Coleman as the instigator of all that we see and hear is clearly a force to be reckoned with. Since his diagnosis in 2017, he has established Deepness Ltd, an organisation run by people with dementia with opportunities for workshops and performances. He has thrown himself into writing of all kinds, and has been helped in this endeavour by his association with the arts centre 'San Lanntain' in Stornoway where he lives.

Conclusion

The clear trajectory of the musical is that the three individuals on which it is based both solely and communally earn a positive verdict from the audience, which will carry away an impression of the achievements of the SDWG movement, but be in no doubt that there is far more to be done: we all need to remain vigilant in our dealings with institutions (care homes, day centres and hospitals), and the staff who run our NHS (specialists, doctors and nurses) and the administrators of those services, that the personhood of their clients must be maintained and enhanced at all times. It is a shame that this production has only been seen in Scotland. Its message is relevant to the population of the whole of the British Isles, and I have no doubt that an artistic experience of this quality is the best way to influence hearts and minds.

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Improving access to social farms for people with dementia, including people from India, Bangladesh, and Pakistan

Ruth Bartlett and colleagues report on a study that aimed to find out how accessible social farms in England are for people living with dementia, including people from India, Bangladesh, and Pakistan. They found health and social care professionals were largely unaware of this kind of service and its many benefits

Traditional support services, such as day care and support groups, are under pressure and may not always be appropriate for a person with dementia. Such services are often indoors, and activities are sedentary, which may not suit everyone. Many people with dementia like to be outside in nature and enjoy being active, as work by Mapes (2017) and others has shown (e.g. Evans *et al* 2019). Hence, care professionals are encouraged to consider a wider range of community options, to promote quality of life and a chance to engage in meaningful activities with others.

One such option is social farming. Social farms (also known as care farms and farm-based services) are a relatively new and rapidly expanding form of social care in the UK. Social farming is defined as the use of commercial farms or agricultural landscapes to provide health (both physical and mental) and social benefits through farming, following a facilitated or structured programme on a regular basis (Bragg 2021). Over the last decade, it is estimated that the number of social farms in the UK has increased from 180 to just over 400. Around 20% of social farms support people living with dementia (Bragg 2021). Research shows that people living with dementia value being on a social farm because it provides a chance to be in nature, enjoy familiar and traditional activities (such as feeding animals and tending to plants) and experience an everyday (rather than a care) setting (Pedersen *et al* 2022). While social farming has grown in the last decade, the full potential of this service is not currently being realised within the UK (Bragg 2021). As one expert notes: there is a 'latent potential for care farming to expand as an option in health, social and educational care' (Bragg 2021, p4).

One potential reason for the lack of uptake is because some people are not aware of or signposted to this service. Studies conducted in Norway and the Netherlands (the front runners in this form of social care) have found that attendees tend to be younger, married men; older widowed women were more likely to use day care (De Bruin *et al* 2021; De Bruin *et al* 2020; Ibsen & Eriksen 2021). This

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Summary

This article reports on a recently completed mixed methods project (January 2023 to April 2024) funded by the National Institute for Health and Care Research Three Schools Dementia Programme

Background and context for the project

Social farms (also known as care farms and farm-based services) are a relatively new and rapidly expanding form of social care in England. Social farming is defined as the use of commercial farms or agricultural landscapes to provide health (both physical and mental) and social benefits through farming, following a facilitated or structured programme on a regular basis. Research suggests that some people living with dementia value the opportunity to visit a social farm, but work to date has mainly involved younger, married white men. Therefore, we conducted a study that aimed to find out how accessible social farms in England are for people living with dementia, including people from India, Bangladesh, and Pakistan.

Research design and methods used

We used a concurrent transformative mixed-methods design. This meant that data were collected at the same time using a combination of methods (survey and interviews). We used Levesque's conceptual framework for access to healthcare to guide activities.

Key findings

We found a wide variation in access to social farms by people living with dementia. This was due to a range of factors, including a general lack of awareness about social farming amongst health and social care professionals, as well as people living with dementia and their carers. Cultural considerations and socioeconomic factors were found to shape perceived acceptability of the service.

Implications for practice

More consideration needs to be given to the acceptability of social farms for people with dementia from India, Bangladesh, and Pakistan, as many people of this heritage have a farming background, and certain animals have positive meanings.

Key points

- Participating in farm-based activities can have physical and mental health benefits for people living with dementia and reduce social isolation.
- There is a wide variation in access to social farms by people living with dementia.
- More consideration needs to be given to the acceptability of social farms for people with dementia from India, Bangladesh, and Pakistan, as many people of this heritage have a farming background, and certain animals have positive meanings.
- Levesque's conceptual framework for access is a useful tool for social care researchers, as it examines access from both a system/provider and client perspective, and it can easily be changed into lay terms for public contributors.
- Building into a project the opportunity for people to try a service for the first time, has the potential to improve access to that service in the longer term.
- Health and social care professionals have limited awareness of social farms and how people living with dementia may benefit physically, mentally, and socially.

suggests that some bias, or misperceptions might exist about who social farms are for, and who might want to go. Another study conducted in the UK found that most social farms are in rural areas, and so people living in deprived urban areas are unable to benefit (Mitchell *et al* 2021). Data on ethnicity is not available, as it is neither reported in studies nor collected by social farm managers. It is important that newly expanding services like social farms are accessible, otherwise there is a risk that the structural inequalities related to people with dementia recently identified by the Office of Health Economics are exacerbated (Hodgson *et al* 2024).

Therefore, we conducted a study that aimed to find out how accessible social farms in England are for people living with dementia, including people from India, Bangladesh, and Pakistan.

People involved

The project was co-led by Ruth Bartlett based at the School of Health Sciences, University of Southampton, and Alex Kaley from the School of Health and Social Care at the University of Essex. Other members of the project team included Sara Mckelvie (Primary Care) University of Southampton, Denise Tanner (Social Care), University of Birmingham; Faraz Ahmed, Lancaster University. A full-time research fellow – Mohammed 'Naz' Hussain – was employed to manage the project. Hussain's background and cultural competencies enabled us to recruit people with

dementia from India, Bangladesh, and Pakistan, to the project relatively easily. Three undergraduate interns, one of whom could speak a south Asian language, joined the team on a part-time basis for ten weeks. Gordon Malcolm (Dementia Adventure) was a partner on the project; they were tasked with ensuring the comprehensive involvement of individuals with dementia, their carers and social farm staff in the project. They leveraged their expertise in supporting people with dementia and family carers in areas such as co-production and the development of dementia support services.

Research design and methods used

The project was a concurrent transformative mixed-methods design (Tashakkori & Terrel 2003). Data were collected at the same time using a combination of methods (survey and interviews). This design was the best way of addressing an exploratory research question within the 15 months' timeframe. Access was a key concept informing the study, hence the transformative [theory-driven] element in the design.

We used Levesque's conceptual framework for access to healthcare to guide activities. With this framework, access is defined as 'the opportunity to reach and obtain appropriate health care services in situations of perceived need for care' (Levesque *et al* 2013, p4). It incorporates five dimensions of accessibility with a corresponding ability of people to interact with them. These five dimensions are:

- (1) **approachability** - people with care needs can identify that some form of services exists, they can be reached, and will have an impact on the health of the individual
- (2) **acceptability** – the service is likely to be acceptable to client groups from diverse social and cultural backgrounds
- (3) **availability and accommodation** – service can be reached in both a physical and timely manner
- (4) **affordability** – the economic capacity for people to spend resources and time on the service
- (5) **appropriateness** – the service meets the clients need and is adequate in terms of the way it is provided. The corresponding abilities are (1a) ability to perceive (2a) ability to seek (3a) ability to reach (4a) ability to pay and (5a) ability to engage.

To address the research aim and to gain a broad understanding of access to social farms, we developed a survey using Qualtrics based on Levesque's conceptual framework for access in collaboration with public contributors. The survey was administered electronically to approximately 100 social farm managers in England. We achieved a response rate of 32% (32 responses). To supplement survey data, additional data about individual farms (e.g. postcode, opening times, services provided etc) were extracted from the Social Farms Gardens website from about 139 social farms.

To examine access to social farms in more depth, we recruited and conducted interviews with 46 people. Fourteen interviews (two individual, 12 dyad) were with people with dementia and their family carer or a



Women potting plants during a visit to Beetle Bank Social Farm

volunteer. Eight of these interviewees (all white British) used a social farm and this is where interviews were conducted. Six interviewees (from India, Bangladesh, or Pakistan) did not use a farm. We made a short video about social farms to show participants who had not used this service before. This helped to spark conversations about what people think and feel about this form of support. We conducted four online focus groups (two with care professionals and two with farm managers) with 19 people in total. Including different perspectives in the study meant that we found out how differently people think and feel about social farms regarding access.

Towards the end of the project, we organised a knowledge exchange event at Beetle Bank Open Farm – a service run by the organisation Partners in Dementia – where Bartlett, Hussain and Gordon from Dementia Adventure presented findings from the research project and invited discussion about access to social farms for people with dementia. A total of 15 people with dementia and their care partners attended the event, along with members from a volunteer organisation, Touchstone. The event involved a tour of the farm followed by indoor activities (potting plants, painting wooden posts, chopping vegetables for the animals) and lunch. We asked a local amateur photographer who also attends the farm to take photos of the event (see above). Participants gave written consent for their images to be used.

Financial considerations

We offered all non-salaried participants a £25 gift voucher for taking part in the study. A budget was available for Dementia Adventure to collaborate with us on public engagement work. They helped us to establish a lay

advisory group made up of people with dementia and family carers, and to organise and run the knowledge exchange event at Beetle Bank Farm.

Key findings and examples of the project

Key findings and examples of project work are presented according to the corresponding dimensions of access proposed by Levesque *et al* (2013).

Approachability (ability to perceive)

Under the Levesque framework, care services are considered *approachable* when populations with a care need can identify that some form of service exists and can be reached. Overall, our study found there to be a general lack of awareness about social farming amongst health and social care professionals, as well as people living with dementia and their carers. People living with dementia in our project were commonly referred to the service via informal routes, i.e. local advertisements, word of mouth and through family carers. Whether or not care professionals were aware of this service was perceived as down to luck or largely dependent on where a social farm was based in the country (postcode lottery). Our focus group findings suggest that care professionals are keen to learn about the service but need more evidence about the potential benefits and ways of mitigating risk.

Acceptability (ability to seek)

Access to care varies by *acceptability* in the Levesque framework according to the social and cultural factors which underpin provider and patients' attitudes to the service. In our project, cultural considerations were found to shape perceived acceptability of the service. For example, for participants living with dementia from India, Bangladesh, Pakistan, language barriers, religious practices and dietary needs were highlighted as crucial factors influencing the accessibility of social farming for these communities. Another factor was people's perceptions about animals. A person's background and experience also play a role in shaping perceptions of acceptability. For example, previous experiences of racial discrimination within rural settings might dissuade people from minoritised ethnic backgrounds from using this service. Participants reflected on the current lack of diversity in the social farm workforce, which might add to the misconception that this service is predominately aimed at white men.

Availability and accommodation (ability to reach)

Availability in terms of access refers to the physical existence and location of social farms across the country, and whether these services can be reached in a timely manner. In terms of hours of operation, it was felt that it was important to consider flexibility to accommodate diverse needs. Participants discussed the importance of offering morning and afternoon sessions to cater for individual preferences and a range of health conditions. We found that opening hours vary and depend on resources and the season. Survey results show that 7% of farms are open once a week, 22% are open two to three times a week, 26% are open four to five times a week, 7% are open more than five times a week, and 19% are open seasonally or at specific times. Social farms are generally

located in the least deprived areas of England and the most common mode of transport was a car (79%). Service provider shortages and issues to do with staffing and capacity were perceived to act as a potential barrier to access for marginalised groups.

We found that socio-economic status had a role in determining whether this service was financially feasible for people living with dementia, and that some communities might find this service more affordable than others depending on their economic circumstances and access to financial support, such as direct payments. For example, one focus group participant said:

If they have had a financial assessment through the local authority, it can usually be commissioned as part of their care package. So, it is one option for people, especially those with a lower income.

Survey results show that 76% of people with dementia had to pay for the service, but for 24% of people living with dementia the service was free (this is because the farm has secured a grant). Of those who pay for the service, costs varied considerably from £7 to £125 a day, or from £20 to £50 an hour. Additional charges were sometimes applied for food and assistance.

Appropriateness

Participants described how social farming offers a different approach to other forms of social care, emphasising the importance of purposeful activities, engagement with nature and the opportunity for people living with dementia to spend time away from home, and contribute to the running of a farm in meaningful ways. To this end, social farming was observed as having the potential to provide people living with dementia with a sense of purpose within a supportive environment, and opportunities for social connection. Additionally, participants described the therapeutic benefits of being on a farm, through being able to engage in hands-on activities such as gardening or cooking.

Implications for practice

The project has implications for dementia care practice. Social farm managers need to consider the acceptability of social farms for people with dementia from India, Bangladesh, and Pakistan for whom certain animals have certain meanings. For example, Hindu and Sikh people admire cows as sacred beings, often considering them as deities, whereas for people of Islamic faith, there may be apprehension or fear associated with dogs and pigs. In addition, formal care providers, including social prescribers, must be aware of community-based services such as social farms to signpost people with dementia and their family carers to the service. As people from India, Bangladesh, and Pakistan communities are less likely to be in touch with professional services, additional methods for informing these groups about social farms are needed, such as word and mouth and flyers at community events (Blackmore *et al* 2018).

Lessons learned

Organising the knowledge exchange event on a social farm meant that a group of people (mainly women) with dementia from India, Bangladesh, Pakistan, had the chance to visit a social farm for the first time. This meant that not only did a group of people learn about the project and value of social farms, but we also witnessed for ourselves the challenges people might face getting around a farm, as well as the benefit of indoor activities. For example, three of the visitors used a mobility aid and were not able to walk easily across the field to reach the animals. We found this could be managed by carrying chairs so people could sit down when they needed to. Further, involving people with dementia from India, Bangladesh, and Pakistan in the project provided important insights about the meaning of animals, not previously reported in farm-based studies.

Future plans

Going forward, we plan to maintain and develop the links we have made with charitable/community-based organisations including Dementia Adventure and Touchstones. We would like to work with members of these organisations to develop new research questions and create plans for future research. We also want to continue to use and develop the *Levesque's conceptual framework for access to healthcare* in relation to social care. We know from previous work that access is a key factor to the utilisation of a dementia care service, and the framework provides a useful guide for investigating this.

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Cognitive Rehabilitation in the community

Justin Mazzotta reports on a Cognitive Rehabilitation pilot project in the community. Six participants — Billie, Brenda, Mike and Lynne, Chris and Lorraine — also describe their experiences of CR and the varied ways it helped them

Partners in Dementia worked with 18 people with dementia and their care partners to deliver a Cognitive Rehabilitation (CR) pilot project. In this article, six participants have written about their experiences and CR advanced practitioner (Justin) also shares some learnings from the project. Partners in Dementia are known locally for a social farming service for people with dementia. CR training enabled us to help establish CR in York by providing an accessible toolkit to support its delivery. CR is typically delivered by occupational therapists from clinical settings, and up to the time of writing there was no known delivery of CR from a community organisation.

CR Research

Great CR is an evidence-based approach that supports people with mild to moderate dementia to function at the highest possible level in relation to specific meaningful (SMART) goals, and is recommended in the NICE guidelines for people with dementia. Great CR built on over two decades of research at the University of Exeter and other leading dementia research centres, culminating in the GREAT trial in 2018: <https://sites.google.com/exeter.ac.uk/great-cr/research-evidence/great-trial?authuser=0>; and followed by the GREAT into Practice implementation project: <https://sites.google.com/exeter.ac.uk/great-cr/research-evidence/great-ip-an-implementation-project?authuser=0>

CR Pilot Project in York

We were awarded a small (£8k) grant from the National Lottery to deliver 18 CR interventions and three CR-based 'My Life, My Goals' exploratory group sessions (not

Justin Mazzotta is a CR advanced practitioner with York-based social enterprise Partners in Dementia

Summary

Great Cognitive Rehabilitation (CR) is an evidence-based approach, recommended by NICE guidelines for people with mild to moderate dementia to help them to function at the highest possible level in relation to their own specific meaningful goals. However, CR provision is sparse in the UK.

York-based social enterprise Partners in Dementia (www.partnersindementia.org), ran a CR pilot project with 18 participants with dementia and their care partners. This article describes the project and explores the potential for community organisations to increase CR provision.

Our results demonstrated that participants' goal attainment in relation to specific goals significantly improved after CR interventions. Participants started with an average (mean) goal attainment of 2.67 / 10 and ended with a goal attainment averaging 7.58 / 10.

The article focuses on four case studies written in collaboration with pilot project participants, which reflect the wide range of positive goals participants chose for themselves to work towards: Billie explains what worked for her and what did not as she tries to cope with word finding difficulties; Brenda writes about how CR impacted on her life beyond her goals; Mike and Lynne describe how CR was sometimes a challenging process to go through although with useful results; and Chris and Lorraine explain how CR formed part of a jigsaw of support which promoted greater independence and wellbeing.

We share learnings from the project and highlight some of the potential benefits and challenges to participants, staff and organisations who engage in CR work, including the difficulty of progressing this work beyond the project.

Examples of goals chosen by participants during the CR pilot project:

I will be able to....

- know what plans I have on any given day.
- go to the Sporting Memories club once a week by bus with a companion.
- play memory games and other games I enjoy twice a week with my husband.
- take my medication independently without the help of my husband.
- look after my flowers and plants at least once a week.
- be able to use my mobile phone to make and receive calls.
- make a photo album to pass on to my granddaughter.
- learn strategies to communicate with my family, friends and others.

Below and on the following page are four case studies written in collaboration with the CR participants, to help understand their experience of CR.

Billie's story

Billie lives alone in a sheltered housing complex in York

My mother

They put her away. That was the phrase. My father was embarrassed. She was trying to find her way. Nobody would do that now. You don't tell anybody about that. We didn't have the phrase [dementia].

Dementia

I'd also be having trouble with speaking for quite a long, maybe three years or so, and then it hots up. It's obviously more difficult to report on yourself. I didn't know, but I was looking for it [dementia] because of my mother. I don't think the actual evidence is before 50 [years old] except from time to time.

Cognitive Rehabilitation

[Below are the goals I decided to work towards]

I will learn strategies to help when speaking and reduce anxiety:

I didn't use it very much because I was too busy going down and I really needed to go up if you know what I mean *[speaking strategies are things like describing things in a different way when stuck finding a word]*. I found *[breathing practices]* were very useful. It was easy to do it and just stop what you're doing. It helps you to step away from what you're doing now. I find it fairly easy to adapt at that stage. It's something that you go to quite normally.

I will be able to locate my important items whenever I need them:

That was good. If things are good I go *[picks keys up from safe place]*; when I get home I do this *[puts keys down in safe place]*.

People I'm with

And also I think the kind of people I'm with mostly are willing to encourage me to do what I can do. If I say "can you pass me the sugar" and I can't say it, I can say "Oh dear, we'll try again". They are very supportive. Better than I thought it would be.

Brenda's story

Brenda lives alone in a village near York

A life-changing experience

The day my GP told me she thought I had dementia was interesting - no more than that and I'm still interested to experience its development. My recollection of the start of my new life was when I had a car accident - not my fault! The insurance company paid up. I was admitted to hospital overnight to find I had no injuries and was sent home. I went to play bridge the following Monday (as usual) and I found it meant nothing to me. I collapsed on the bridge table and others brought me home. That was the end of my bridge and the end of an era. Good friends and family kept me going. I was frightened to go outside alone and have been brought home by strangers more than once (thank heaven I live in a little village where everyone knows me).

Cognitive Rehabilitation and my goals

I will be able to:

- catch the bus independently to my nearby village to attend an exercise class once a week.
- know where my important items are any time I need them (keys, purse, phone etc.).

Justin from Partners in Dementia was introduced to me and we embarked together on a Cognitive Rehabilitation journey. One difficulty for me was travelling alone on the bus using the timetable. Without the car I can't leave the village. So we started working towards that. Before I could get the bus Justin reminded me what I needed to take, e.g. purse, mobile, diary, keys. We practised this exercise with Vicki, my carer, when Justin wasn't there. We walked to the local bus stop, checking for landmarks on the way to remind me how to get there. We repeated the exercises over 6-8 weeks until I didn't need the reminders. That was a good exercise when broken down into little bits.

How I felt during Cognitive Rehabilitation

I felt listened to, excited by being independent - the repetition made me aware of what was to come next. Justin's rehabilitation therapy awakened my memory on how to use public transport. It gave me the confidence to leave the house safely with items necessary for me and walk to the bus stop feeling confident. It also gave me confidence in walking in my village as I recognised landmarks and a set routine for walking. This has also helped me to use the village shop - again with confidence, feeling safe to leave the house and be able to get home safely. I wasn't prepared to get on the bus on my own. I was frightened of it. I was scared to go and then to get on the bus. And that was what we overcame really. I walked through the hot coals! There is a name for it - facing up to your demons.

I have to say that it's the very fact that you're there. I know that you weren't always with me. It's like when the doctor visits and you feel, oh thank goodness. It's a bit like that really. But then you're OK. Meeting you was opening a window really to show me through the window. There was so much there I needed but didn't know I needed it. But it was there and it was wonderful and I wanted it. It became available to me.

The future

My aim was to go to keep fit class on the bus but then I discovered I couldn't keep fit. There were too many people in the class so I couldn't get the help I needed. It was embarrassing as I couldn't balance, therefore was not able to join in. I think if the keep fit class was tailored for all I'd still be using the bus. I intend to go to the singing group. I'll do anything that makes my brain come back and makes the fog go away. I've started knitting a sweater so lets see what happens now!!

Our story: Chris and Lorraine

Chris and Lorraine live in a village outside York

Childhood sweethearts, we both took early retirement after years of committed hard work in two very different professions. Since then, we have experienced five life-changing events followed by Chris's diagnosis of early onset dementia.

Cognitive Rehabilitation

It was a complete fluke that we found out about this service. The relationship between us and Justin was important. It has been positive from day one. It offered us a level of service that we ourselves always delivered. "We had a television which our son brought us for our Ruby wedding anniversary, and I couldn't use it. I were really frightened. I thought I'd break it. He spent so much money on it," (Chris).

Chris's goal: I will learn how to turn the TV on and off and choose my favourite channels.

It was a very personal adaptation to the television control. For example, working together on how to make that "home button" easier- we added glitter! Working with Justin has been part of a jigsaw of services that has helped Chris to move forward over the past few months. It also fits into family life. It's all been such a positive experience. One day I came home and Chris was chuffed because he had turned the television on. He excitedly said "I did it". He was so happy to tell our son, Ross, that the gift he had given us, Chris could now use. "I couldn't do it and now I know it doesn't break. Well, it's still here and it's working!" (Chris)

discussed here). The project was delivered by Justin with supervisions by CR researcher Jackie Pool. We aimed for a six month delivery time frame, but this was increased to one year after referrals were initially very slow. Referrals eventually came from the Memory Service, Social Services and internally via our social farm. A wide range of goals were chosen by the participants with dementia, reflecting what is important to them.

The CR Process is explained at this link:

<https://sites.google.com/exeter.ac.uk/great-cr/cognitive-rehabilitation/process?authuser=0>

Results of the CR Pilot Project

The person with dementias goal attainment was assessed by all stakeholders using the Bangor Goal-Setting Interview (short version) before and after the CR intervention. Overall the participants' goal attainment showed significant improvement after the CR interventions, very similar to the improvements shown in the GREAT into Practice implementation project. In our CR pilot project, participants started with an average (mean) goal attainment of 2.67 / 10 and ended with a goal attainment averaging 7.58 / 10. ▷

Our story: Mike and Lynne

Mike and Lynne were initially referred into the My Life, My Goals workshops

My husband, Mike, was diagnosed with Alzheimer's last year. Whilst attending a 'My Life, My Goals' workshop Justin offered us 8 home based sessions of Cognitive Rehabilitation. The aim was to choose relevant and achievable goals and identify small steps needed to work towards their completion. Initially Mike found the selection of goals quite overwhelming, causing him some anxiety: "I thought it would be easy but I struggled with the openness of the questions. I found it difficult to choose appropriate goals" (Mike). After discussing what he wanted to achieve we narrowed the choice and found goals with which he felt comfortable. His recovery from a knee operation led to an exercise based first goal:

- I will be able to walk independently to the local nature reserve or village and back at least twice weekly.

The second goal was safety based, as Mike would be walking alone:

- I will be able to make and receive calls on my mobile phone.

Each session consisted of a goals recap, walks of gradually increasing length or some practice using his phone. Justin suggested using a mnemonic to enable Mike to remember everything needed to go walking. One of Mike's weekly tasks on the farm (another service he attends) is feeding the pigs, hence the mnemonic 'We Keep Spotty Pigs' (weather-clothing, keys, sticks and phone). At first Mike found this difficult to grasp, but the constant repetition each time he left the house led to knowing it needed to be used, even if he could not always remember all items. Mike reflected: "[It was] fine, [I] got to grips with mnemonic. Quite successful - took everything I needed for my walks".

Every week the walking distance improved and both destinations were eventually reached. Mike also phoned home as he reached the turning point to indicate starting the return trip. Mike reflected "It has improved my confidence when walking, knowing that I am able to contact home if needed. It has made me more secure and prepared when going for a walk ... more motivated and I have met people whilst walking".

Overall, we would both recommend Cognitive Rehabilitation to other people living with dementia. Although the process was stressful at times and elements difficult, the drip feed and patient process proved to be successful for both of Mike's goals and he continues to strive for further improvement.



Mike practising walks to his local nature reserve

was a consensus that CR should be available free of charge so that it is equally available to all who could benefit. We are looking into applying for another fund to deliver CR on a larger scale.

Implications for practice
How viable CR is to other community organisations depends largely on funding and a commitment to a rehabilitation approach for people with dementia. CR practitioners also require supervision, especially when new to CR and a structure for this does not currently exist.

▷ Discussion

The project participants chose a variety of goals and were motivated to increase independence, keep physically active, manage difficulties and remain socially connected. These case studies highlight some of the potential benefits and challenges for participants and staff who engage in CR work. The benefits to participants sometimes expanded beyond the goal itself. For instance, Brenda spoke of the confidence that the work instilled in her, helping her to do more in her community, while keeping safe. In some cases participants have been initiating more than they were before CR, e.g. deciding to go for a walk. CR was also seen as a useful service to incorporate alongside other services, such as for Chris and Lorraine, all working together in a sense to increase independence and maintain wellbeing. Care partners also learnt skills during the CR process and felt able to use these to problem solve on other goals.

There were various challenges when delivering CR. Some goals were not able to continue easily after the intervention ended. For example, there was a six month waiting list for a respite service to enable a participant to continue to go to a social group. This showed that there is sometimes a need for staff to do more research before goals are committed to. Furthermore, some families were not able to engage in taking on more “work”, so some referrals did not lead to ongoing engagement. Some participants with dementia also found the CR concepts difficult to understand and that made it hard for them to be fully involved.

Following on

Funding for CR provision is not available in many parts of the UK, including York, even though it is recommended for people with dementia in the NICE guidelines. We set up a steering group which included participants and other stakeholders. Although some private care providers from this group committed to training their staff in CR, there

Current CR Training Requirements (NHS portal / Exeter University):

There are two options to access CR E-learning training: For anyone in the UK with an NHS or University email address who registers for a free account:

<https://learninghub.nhs.uk/>

For other users via the GREAT website <https://sites.google.com/exeter.ac.uk/great-cr/for-practitioners/elearning-course?authuser=0>

Suitable for health and social care practitioners, assistants and trainees involved in the direct care of people with dementia, including occupational therapists, nurses, psychologists and senior support workers. Managers who support practitioners may also find the course useful.

Key Points

- Community organisations can support the delivery of CR, with similar standards to clinical teams. Supervisions are an important factor in this outcome.
- Goals are sometimes difficult to come up with and can cause stress. Care partners can help.
- Participants’ confidence often grows throughout the process as improvements are experienced.
- CR can enhance and enable physical rehabilitation, e.g. post operation, as it did with Mike.
- CR works as a component of a range of services which together promote greater independence as well as wellbeing, as in Chris and Lorraine’s case study.

Reducing labelling and promoting person-centred language in dementia care case notes

Ian Davies-Abbott and **Emma Roberts** describe a ten-month quality improvement project in which they reviewed and analysed the language used by healthcare staff in case notes. They then developed guidance that staff were keen to embrace, and which led to more insightful, less stigmatising entries

The challenge to replace stigmatising terms about dementia with person-centred language has been championed by people living with dementia over the previous ten years through the creation of dementia friendly language guidelines (Alzheimer's Australia 2015; Care Council for Wales 2016; DEEP 2014; Global Brain Health Institute 2022). These guidelines have been invaluable for journalists and academics, with the need to embrace person-centred language more recognised than ever. However, an area which remains underexplored and underdeveloped is the language of healthcare workers, particularly when writing accounts of people living with dementia in medical/case notes.



The writing of daily case notes is typically completed without the oversight of the person living with dementia or their caregivers but creates a narrative about the person which is then shared with other health and social care workers throughout the person's life. Studies have indicated that medical professionals do express both positive and negative feelings towards patients through their note writing (Glassberg *et al* 2013; Park *et al* 2021), and that stigmatising terms used to describe patients may negatively inform treatment decisions (Goddu *et al* 2018).

In the United Kingdom, while access to personal medical records can be requested through General Data Protection Regulation (GDPR) (2016) they are generally invisible to the person they describe. It is perhaps this invisibility which has led to the meagre number of studies concerned with stigmatising language in healthcare case notes. Perhaps understandably, research studies and healthcare trainers have focused more on the delivery of person-centred care than the description of care. However, the

Summary

The documentation of daily case notes about people living with dementia is a routine practice in health and social care settings. However, there have been few studies which have explored whether the language used in these case notes aligns to person-centred principles. Accounts of people living with dementia as 'non-compliant', 'resistive' or 'aggressive' provide a negative portrait of the individual if presented without context or an understanding of the person themselves.

We delivered a ten-month quality improvement project across three specialist dementia assessment units to review the language currently used by healthcare staff in documentation about people living with dementia. The case notes were analysed by adopting Dementia Care Mapping (DCM) which also informed the development of person-centred language guidance. This guidance was provided to staff and their documentation was reviewed to assess whether this informed more person-centred language over the period of the quality improvement.

More insightful and person-centred entries were observed in all three wards following the introduction of the guidance. Some aspects of language were more difficult to influence, although this appeared to be due to the different approaches to case note writing across the wards. It was evident that staff had not previously had the opportunity to critically consider the language they used in documentation, and that they were enthusiastic to embrace more person-centred approaches.

The project revealed that better person-centred documentation can be informed by a relatively simple and cost-effective intervention. To develop this work further, the voice of people living with dementia and the consideration of non-English language documentation need to be included in future projects.

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absence of interest in case note writing is perplexing when considering the potential impact these narratives may have on the delivery of care and the sheer number of hours healthcare workers spend completing documentation.

Most studies have focused on physicians, nurses and midwives, with the total amount of reported time healthcare workers spend on documentation ranging from 20.9% to 41% (Cooper *et al* 2021; Haw *et al* 2016; Joukes *et al* 2018; Schenk *et al* 2017). While clinical settings, working schedules and professional status mean that the exact amount of time varies, it does appear that around 25% of healthcare time is spent on documentation. The lack of investigations into healthcare documentation is therefore a major oversight.

Our quality improvement project looked to understand the language currently used about people living with dementia in case notes written by healthcare workers on three dementia specialist mental health wards in Wales. As currently available language guidance does not address healthcare case note writing, we adapted the indicators for enhancing and detracting behaviours in Dementia Care Mapping (DCM) to analyse the case notes and develop guidance. DCM was also considered an appropriate tool for this location due to its presence in the *All Wales Dementia Care Pathway of Standards* (Improvement Cymru and Welsh Government 2021).

We wanted to test whether the provision of simple language guidance could reduce stigmatising language in healthcare case notes. The project was led on-site by the DCM team (ER and team) whilst the analysis of the case notes was conducted by the team and an external researcher (IDA). The study was approved as a quality improvement project by the health board. No patient identifying data was shared with the external researcher, whose involvement was approved by the Research Ethics Committee of Bangor University. The project was funded by Improvement Cymru, Bangor University and the Centre for Ageing and Dementia Research (CADR).

Method

DCM is an observational tool which supports the development of person-centred practice in health and social care settings. It was developed in the 1990s by Tom Kitwood and Kathleen Bredin and is now in its 8th edition (Bradford Dementia Group 2005) and practised globally. The process includes the observation of 34 staff behaviours of which 17 personally enhance (PE) and 17 personally detract (PD) from the well-being of people living with dementia. PD behaviours are indicated when the personal perspective of the individual is ignored or unrealised, often leading to care which may fulfil a physical need but fails to address the person's psychological needs.

The occurrence of PD behaviours by staff is not indicative of neglectful care but rather a culture of care which is focused on tasks rather than people or a lack of training and supervision regarding person-centred practices. For this reason, DCM mappers do not indicate which members of staff have engaged in PE or PD behaviours but rather share their observations for staff to develop action plans to realise person-centred cultures (rather than blame individuals). The PE and PD

Key points

- The language used by health and social care staff in documentation must be person-centred if it is to have a positive impact on care.
- There are very few studies which explore the language used about people living with dementia in healthcare documentation despite documentation accounting for around 25% of healthcare staff time.
- The provision of simple guidance to care staff is a successful first step in addressing the use of labels about people living with dementia in documentation.
- Non-person-centred documentation occurs due to the lack of discussion about case note writing practices and long-held traditions concerning case notes.
- The language guidance developed in this project could be applied to documentation writing in any setting where people living with dementia receive care.

observations were adopted for the analysis of case notes applying the same ethos as DCM with the assumption that incidents of PD case note entries were attributable to the lack of discourse concerning person-centred healthcare writing, rather than malicious, and that individual staff should not be identified when findings were shared.

The case note entries analysed for the project were taken from two-week periods every three months on each ward. One ward was analysed per month with the full project taking place over 10 months. Across the project, the case notes of 117 people living with dementia were analysed, encompassing 4,522 case note entries.

Following the first period of analysis, the ward staff were provided with simple person-centred language guidance based on the DCM PD behaviours most observed. The guidance was displayed over two sides of A4 paper, with the knowledge that the content had to be accessible for care staff who did not have time to read in-depth instructions. The second analysis of each ward provided an insight into whether the guidance had informed more person-centred writing in case note entries. Following the second analysis, the language guidance was revised in response to what had been observed and shared again. A final analysis of each ward was conducted to assess whether language had changed, and a final revision of the language guidance was designed.

The project

From the first analysis it quickly became evident that the full range of PE and PD behaviours were not observed in the case notes. Instead, it was the PD behaviour 'Labelling' which was by far the most common observation across the notes, followed by the PD 'Invalidation' and to a lesser extent, the PD 'Objectification' and the PE 'Acknowledgement'. ▷

Labelling	Why is this wrong?
Describing the person as or by a behaviour.	Labelling creates stigma which threatens the delivery of person-centred care. Labels are the antithesis of person-centred care as they recognise the behaviour but not the person.
Labelling	Acceptance
<p>Wanderer/Wandering/Wandersome <i>This suggests that the person's behaviour has no purpose</i></p> <p>Compliant/Non-compliant Resistive/ Not resistive <i>These suggest the person should 'comply' without considering their perspective.</i></p> <p>Aggressive Hostile Irritable Shouting Bad tempered Bizarre Stubborn Argumentative Difficult Interfering - <i>Include what the person is trying to do (e.g. help, engage) and add that this attention was not accepted by the other person involved. Without this context, 'interfering' appears malicious and does not help us understand how we can help the person.</i></p> <p>No management problems</p>	<p>The person is walking. Is this an expression of an unmet need? <i>Has the person been separated from someone/something? Is the person looking for someone/something or lost?</i></p> <p>The person chose not to.... The person did not want.... Language should not be custodial or suggest that you have authority over the person. Does the person understand what is being offered?</p> <p>Consider the behaviour from the perspective of the person. An expression of unmet need. <i>What are they trying to achieve?</i> Be descriptive. <i>What was happening before? What caused the change in how the person was feeling?</i> <i>Be specific about what actually happened.</i> <i>What support was given?</i></p> <p>There is no alternative to this term. It SHOULD NOT be used. It suggests an expectation that the person will present as a problem and other than labelling the person as a problem is otherwise meaningless and adds nothing to the care of that person.</p>

Figure 1: Labelling guidance shared with care staff across the three wards.

Labelling (when describing the person as or by a behaviour) was primarily observed in four ways:

- The description of behaviours without context. Examples of this included 'feisty and punchy', 'stropky with staff', 'aggressive behaviour' and 'interfering'. The guidance prompted staff to consider the context of the person's behaviour.
- Describing behaviour as having no purpose, most commonly through the terms 'wandering', 'wandersome' (sic) and, 'aimlessly wandering around the unit'. The guidance suggested that 'wandering' implied a lack of purpose, which 'walking' does not, and that if further context could be added, even better.
- The use of terms such as 'compliant' and 'resistive', which suggested that the person was expected to 'comply' regardless of their own viewpoint. The most common example of this language was the entry, 'non-compliant with medication'. The language guidance asked staff to consider the viewpoint of the person rather than suggesting that their role is to comply.

- The term 'no management issue' or 'no management problem' provided no insight into the person's experience but did suggest an expectation that the person would be a 'problem' (therefore saying more about the staff's experience than the person's). Due to the lack of insight this term provided, the guidance suggested that it should not be used.

Figure 1 (above) illustrates how guidance regarding 'Labelling' was shared with staff.

Invalidation (when the reality of the person living with dementia is not recognised or dismissed) was most observed when the person was described as 'confused and disorientated' without any further explanation. While confusion and disorientation may appear to be appropriate terms when describing the cognitive effects of dementia (particularly for people who require care in a dementia assessment unit) the term was highlighted in the language guidance because: ▷

Invalidation	Why is this wrong?
Not recognising the reality of the individual.	The ability to stand in the person's shoes and try to see the world as they do is imperative in person centred care. To deny the person's reality is to deny the lived experience of the person with dementia.
Invalidation	Validation
Describing someone as only 'Confused and disorientated'. <i>What does this tell us about the person?</i> <i>Are confusion and disorientation different?</i>	Focus on what the person can do and what they have achieved. Think about time, place and person. What are they orientated to? e.g., Disorientated to time and place. Able to recognise wife/family/staff members etc e.g., Disorientated to place and person. Dining area environment supported him to be oriented to lunchtime. e.g., Disorientated to time and person. Able to locate and use the toilet independently.

Figure 2 (above): Invalidation guidance shared with care staff across the three wards.

Objectification	Why is this wrong?
Describing the person in a non-human manner.	This suggests that people with dementia are unequal to others in regard to their human rights.
Objectification	Collaboration
When the person is referred to in a manner which may be used for an object rather than a person. e.g., Person was moved to..., taken to...	How did the person move? <i>Did they walk with staff to...?</i> <i>Assisted in a wheelchair to...?</i> This makes it clear that the entry is about a person and tells us something about how they move. Think about this for any action e.g., eating, washing, dressing etc.

Figure 3: Objectification guidance shared with care staff across the three wards.

- The description invalidates the person's perception and potentially results in valid perceptions being dismissed.
- There is lack of clarity regarding the terms. What is the difference between 'confusion' and 'disorientation'? The guidance asked the staff to focus on the cognitive strengths of the person rather than applying blanket terms. When considering disorientation, the guidance suggested that concepts of time, place and person should be used to provide a better understanding of the person, e.g. 'Disorientated to place but recognised his wife when she visited the ward'.

Figure 2 illustrates how guidance regarding 'Invalidation' was shared with staff.

Objectification (the description of a person in a non-human manner) was typically observed when the person living with dementia was involved in an action, but their involvement was invisible in the case notes. Examples included 'moved to bed', 'taken into the dining room' and 'toileted'. Although what had happened was described, the entry did not indicate the person living with dementia. The

guidance asked staff to consider how the person collaborated with the action e.g. did they walk? use a wheelchair? The guidance suggested that this approach should be considered for other areas, e.g. eating and dressing. Figure 3 illustrates how guidance regarding 'Objectification' was shared with staff.

Acknowledgement (the recognition and acceptance of a person's individuality) was the most observed PE. Examples of this included 'enjoys reminiscing about his work as a geography teacher' and 'likes to be around others and hold their hand when walking'. The language guidance did not specifically suggest how to increase Acknowledgement, as it was felt that reducing PD entries would encourage more person-centred entries and it was important that the language guidance document did not become onerous for staff to use. Following the provision of language guidance, an overall decline in PD entries was observed, with 59% of all case note entries across the three wards including PD language at baseline reduced to 28% at the final analysis.

Labelling dominated the PD entries, with 43% of all entries attributed to this category at baseline. However, occurrences of Labelling were also observed to

significantly reduce, with only 16% of entries belonging to this category at the final analysis.

The results were more varied across the three wards when observing entries concerning Invalidation. While two wards observed a reduction between baseline and the final analysis (8% to 5%, 2% to 1%), the remaining ward observed no change (remaining at 20%). This ward had a higher occurrence of Invalidation than other wards and evidently did not respond to the language guidance regarding this category, despite clearly responding to recommendations regarding Labelling. However, this ward also took a different approach to note writing, with strict headings for staff to adhere to (while other wards provided a blank canvas). One heading concerned 'cognition' which led to the shorthand of 'confused and disorientated' being used more regularly than on other wards. We do believe that the recommendations in the language guidance apply equally to this structured approach to case note writing, but also acknowledge that providing guidance alone (without further teaching and supervision) was insufficient to address this embedded practice.

Both Objectification and Acknowledgement were observed in much smaller numbers than Labelling and Invalidation. No significant change was observed in language regarding Objectification between baseline and the final analysis and only a small overall improvement was observed concerning Acknowledgement (2% to 3%).

Discussion

Whilst the occurrence of PD and PE entries could be aligned to previous studies suggesting that professionals do express positive and negative feelings about patients in their documentation (Glassberg *et al* 2013; Park *et al* 2021), the discussions with care staff in these wards indicated that the language used in case notes was informed more by cultural norms and rote learning. The care staff acknowledged that they had never critically discussed the language they used in case notes, and they embraced the opportunity to change and improve practice.

In DCM, care staff are asked to challenge PD behaviours in their own and others' practice, rather than defensively deny their existence once they are made aware of them. Similarly, the care staff in these wards had not previously considered how the language they used in case notes could negatively position the person living with dementia, but they were enthusiastic to make positive changes.

This enthusiasm was an important driver in the changes observed over ten months. Our intervention only involved the provision of short language guidance (two sides of A4 paper) and a brief discussion of what had been observed every 3 months (during the routine DCM feedback sessions with staff). While this intervention was not wholly successful (e.g. the lack of change in PD Invalidation entries in one ward), the project had a considerable positive impact overall.

There are clear implications for practice. While this project was undertaken on three specialist dementia assessment units, the language guidance developed during the project should be equally applicable to any area which involves the care of people living with dementia. As our project's main driver was the provision of the language guidance, other health and social care teams could take the guidance we created and provide it to their staff. The

financial implications are minimal, with only printing costs a potential barrier. The long-term financial implications are unknown. If the language used about people living with dementia in care documentation is more person-centred, this may result in different outcomes when other professionals make decisions based on case note entries.

Despite the significant amount of time healthcare professionals spend completing documentation, this is a research area in its infancy. There is much more to explore, including the longer-term impact of language change. The guidance was created using an existing tool and the next stage of its development must include the voice of people living with dementia. It is also important to consider the differences in case note writing traditions and person-centred language across international borders (what is considered person-centred in the United Kingdom and in the English language may have a different meaning in other languages). While more needs to be done, we hope that the simple guidance we have already developed can be adopted by health and social care staff to start to address this under-explored area of practice.

References

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Evidence for practice/Research news

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

We welcome contributions such as:

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

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

Person-centred support in daily living

Family carers were interviewed about providing support with activities of daily living to a spouse or partner with dementia and some of the challenges involved. The findings indicate a need for family carers to receive more support in providing good quality care. Although there were many examples given of support that aligned with the principles of person-centred dementia care, there were a substantial number that did not, or where principles of person-centred care were in conflict with one another or other considerations such as personal safety or carer wellbeing. The authors argue that there is a need for practical guidance and interventions that reflect the challenges and complexity of the issues faced by family carers.

Carporelli C, Oyeboode JR, Riley GA. Family carers and the provision of person-centred dementia care for activities of daily living. *Dementia*. Published online Jan 6 2025. <https://doi.org/10.1177/14713012241312266> Open access.

Caregiving and empathy loss in Frontotemporal Dementia

This literature review aimed to understand how the loss of empathy in a person living with Frontotemporal Dementia (FTD) impacts on the wellbeing of informal caregivers. Sixteen studies (eight qualitative and eight quantitative) were included and three main themes are discussed:

1) caregiver emotional reactions to empathy loss in the person living with FTD; 2) caregiver psychological distress; 3) changes in the relationship. The article suggests that loss of empathy in the person living with FTD changes caregivers' emotional reactions, increases caregivers' psychological distress and changes their relationship with the person living with FTD. Emphasised in these studies is that caregiver psychological distress is related to behavioural symptoms such as empathy loss, rather than cognitive abilities and dementia severity. The authors conclude that identifying these underexplored consequences is critical in understanding the wellbeing of caregivers. It recommends that understanding how to cultivate positive

emotion-based experiences in the context of empathy loss may be beneficial to overall wellbeing for caregivers.

Fisher L, Munsterman E *et al*. Caregiving in the face of empathy loss in Frontotemporal Dementia: an integrative review. *Age and Ageing*. Published August 16 2024. <https://doi.org/10.1080/13607863.2024.2390603>. Restricted access.

Dementia care pathways in prison

To identify good practice, this scoping review examined the literature on care and supervision of people living in prison with dementia, and on transitioning into the community. The literature indicated that there were difficulties across the prison system for people with dementia, along the pathway from reception to release and resettlement. Difficulties related to all aspects of prison life and environment, including health and social care. A lack of resources and policies were identified as barriers, however solutions were also identified in the literature, including locally tailored policies and increased collaboration with the voluntary sector.

Treacy S, Martin S, Samarutlake N *et al*. Dementia care pathways in prisons – a comprehensive scoping review. *Health Justice*. Published online Jan 20 2024. <https://doi.org/10.1186/s40352-023-00252-7> Open access.

Co-produced self- management tool

This study explored the potential of a co-produced self-management tool, My Life Today (MLT), to help people with dementia identify, plan and monitor aspects of their lives that are important to them and that help to maintain or improve well-being. The tool was found to be helpful by people with dementia using it themselves or with support, and could also be used by health or care workers to stimulate conversations or as part of a support package. The My Life Today tool can be found on the [IDEAL](#) website.

Pentecost C, Hunt A, Litherland R, *et al*. Qualitative evaluation of my life today - A co-produced personal tool from the IDEAL programme to help people with dementia monitor valued aspects of their lives. *Dementia*. Published online Jan 6 2025. <https://doi.org/10.1177/14713012241306506> Open access.



Music in care homes

This paper focuses on the implementation of music-based interventions in care home settings, drawing on evidence from a trial comparing music therapy to choir singing in residential care homes. The Music Interventions for Depression and Dementia in ELderly care (MIDDEL) trial in 16 care homes is used as a case study to highlight key issues which appear to affect the successful implementation and evaluation of music-based interventions. Based on data from the study and the literature about implementing psychosocial interventions in care homes, the authors recommend a checklist of guidelines developed to facilitate the take up of music in residential settings and to support interventional research in care homes.

Schneider J, Ablewhite J. *et al.* Music in Care Home Settings: Guidelines for Implementation and Evaluation Based on the Music Interventions for Depression and Dementia in ELderly Care (MIDDEL) Study in the UK. *Journal of Long-Term Care*. Published June 7 2024. <https://doi.org/10.31389/jltc.294> (Open access).

Social robots in dementia care

This article discusses a study on the use of robotic animals in dementia care, exploring how residents and staff in care homes for older people establish activities and a shared understanding of the situation in interactions involving robot animals. Using interviews, observations and filming in six Swedish nursing homes, conversation analysis and ethnography were utilised to analyse embodied and verbal interactions between staff and people with mild to moderate dementia. The authors argue that the findings show interactions characterised by playfulness and that, along with how the robots are introduced, allowed people to differ in their approaches to the robots but still interact together and achieve a shared understanding. The authors also discuss ethical considerations and implications for practice.

Iverson C, Persson M, Redmalm D. Playful framings of social robots in dementia care: reconsidering the principle of transparency in interactions with robot animals. *Ageing and Society*. Published November 14 2024. <https://doi.org/10.1017/S0144686X24000539>. Open access.

Pain assessment

Symptoms of dementia, including difficulties with language and communication, may hinder accurate assessment and management of pain for people with dementia living in nursing homes, as their ability to self-report their pain may be compromised. This scoping review aimed to identify and summarise research literature on pain assessment for people with dementia living in nursing homes, and how the residents' expressions of pain are integrated into clinical practice. Thirty-nine studies were included and the authors describe three 'patterns' in the analysis, constituting a process of pain assessment: (1) pain awareness; (2) suspected pain and (3) pain mapping. In discussing the findings, the authors found that the phenomenon of self-reporting in people with dementia is insufficiently explored. The results underpin the importance of pain assessment approaches that have sufficient flexibility to meet individual residents' varying and potentially fluctuating ways of communicating pain.

Overen CK, Larsson M, *et al.* The process of pain assessment in people with dementia living in nursing homes: a scoping review. *Palliative Care and Social Practice*. Published January 6 2025. [doi:10.1177/26323524241308589](https://doi.org/10.1177/26323524241308589). Open access.

Minority ethnic family carers

Acknowledging that much of the evidence base documenting the experiences of family caregivers is largely drawn from studies undertaken with white European, North American and Australasian populations, this exploratory qualitative study investigates the experiences of caregivers of people with dementia from key minority ethnic populations in the UK: Black Caribbean, Black African and South Asian communities. Emerging themes included: motivation to care, positive and negative consequences of caregiving, and the cultural context of caregiving. The findings and analysis develop the existing literature by identifying (a) the importance of spending time with the person they care for, (b) the absence of faith as a caregiving driver, and (c) the challenge of watching the declining health of a parent. The article explores how different motivations to care are intertwined and dynamic, illustrated by the linking of obligation and reciprocity in the same caregiving narrative. The authors highlight the importance of generational and intersectional perspectives as a challenging but necessary research agenda.

Victor C, van den Heuvel E, *et al.* Perspectives of Minority Ethnic Caregivers of People with Dementia Interviewed as Part of the IDEAL Programme. *Health & Social Care in the Community*. Published July 15 2024 <https://doi.org/10.1155/2024/8732644> Open access.

Healthcare support workers in hospital wards

This review analysed and thematically structured the literature on the everyday care practices of healthcare support workers supporting patients with dementia in hospital wards. The nature of working with patients with complex needs is discussed, including recognition of the complexity of support with personal care and the interactional skills required when supporting daily activities in the context of behaviour change. The article highlights that more work is needed to support the specific training and development needs of HCSWs, alongside recognition of the flexible and responsive skills used within dementia care practice, and the need to explore ethical and emotional issues through reflection and supervision structures.

Kindell JA, Harman K, *et al.* Exploring the everyday care practices of healthcare support workers when working with people with dementia admitted to National Health Service hospital wards in the United Kingdom: a qualitative systematic review of the literature. *Ageing & Mental Health*. Published online January 7 2025. <https://doi.org/10.1080/13607863.2024.2447319> Open access.

Dementia and the Deaf community

Deaf people face complex challenges in accessing health care, and this study explores health care issues in relation to dementia for older Deaf individuals. People in the Deaf community have higher rates of dementia risk factors (eg obesity, hypertension, diabetes, and depression). Practical changes are needed to tailor dementia assessments and services for Deaf people. The authors report that Deaf awareness training, health-care information in sign language, and accessible dementia services are crucial for improving healthcare access and outcomes for Deaf people, alongside highlighting the need for co-production with the Deaf community in future research and initiatives.

Flower I, Heffernan E, & Dening T. Dementia and the Deaf community: prevalence, assessment and management in people with hearing loss since childhood. *Ageing & Mental Health*. Published November 2024. <https://doi.org/10.1080/13607863.2024.2430533>. Open access.

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