

# The Journal of DementiaCare

For all who work with people with dementia

Vol 32 No 2 March/April 2024



## Music in Mind: celebrating ten years

**Also inside  
this issue:**

- A specialist dementia care role in homecare
- Ethnic elders in Leicester
- Winter Warmers



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



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# The Journal of DementiaCare

For all who work with people with dementia

Vol 32 No 2 March/April 2024

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Cover photographs: Sincere thanks Robyn Dowlen and all involved in the *Music in Mind* programme described on pp26-30.

**NEW FOR 2024**

# The Journal of DementiaCare WEBINARS



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

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

**11 March 2024**

## Cognitive Stimulation Therapy for Dementia

**Presenter:** **Emily Fisher**, Research Fellow and PhD Student, University College London

**Description:** Cognitive Stimulation Therapy (CST) is an intervention for people living with mild to moderate dementia. It involves themed activities, which stimulate and engage people with dementia in a social group environment through tasks such as physical activity, word association and discussion. This webinar will give an overview of CST and its history, cover the key principles of CST, and outline how and where CST can be delivered, drawing on international evidence from the last 20 years.

**26 March 2024**

## Equality, Diversity & Inclusion in dementia care: the person comes first

**Presenters:** **Karan Jutla**, University of Wolverhampton; **David Truswell**, Dementia Alliance for Culture and Ethnicity; **Jagdish Brar-Orgill**, activist and former carer

**Description:** In this webinar, Dr Karan Jutla, David Truswell and Jagdish Brar-Orgill will explain what equality, diversity and inclusion really mean and how they link to intersectionality. They will highlight how to recognise health inequalities in dementia care and consider how inclusive dementia care can be achieved with person-centred approaches. This webinar will be a fantastic introduction to understanding more about equality, diversity and inclusion and is highly recommended for everyone working in dementia care and support.

**22 April 2024**

## Thrive – Benefits of gardening and green spaces for people with dementia and how to provide year-round accessibility

**Presenter:** **Mark Emery**, Thrive

**Description:** In this talk we will explore the benefits of gardening and outdoor spaces and think about how they offer activity, social inclusion and restorative environments to those with dementia and their carers. We will also look at theories that enable us to realise how gardens provided value to those engaging in them. We can then think about activities themselves and adaptations that can be made to make sure they are accessible as possible, on a number of levels, for those taking part.

**7 May 2024**

## Take a Breath in the Great Outdoors

**Presenters:** **Gordon Malcom**, Programme Leader, Dementia Adventure; **Debbie Carroll**, Director, Step Change Design

**Description:** The science tells us that getting outside is good for us, and in particular for people living with dementia, yet this doesn't always feel easy. Gordon Malcom, Dementia Adventure, and Debbie Carroll, Step Change Design, come together to share how to overcome the often subtle barriers to getting outside so you can reap the rewards of enjoying nature and your gardens more.

**21 May 2024**

## Can lie telling be used to support personhood?

**Speaker:** **Dr Jane Murray** – Assistant Professor, Northumbria University

**Description:** Lie telling is an emotional subject that tends to evoke strong feelings. Yet people tell lies every day, both consciously and unconsciously. In this webinar, Dr Jane Murray will challenge current viewpoints and advocate that lie telling is an important social lubricant that can be a very useful tool for sustaining relationships and supporting personhood in people with moderate to severe dementia. She will share some of the results from her groundbreaking ethnography and question why the truth of carers should be prioritised over that of the person with dementia.

**25 June 2024**

## Digital life story work

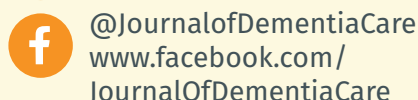
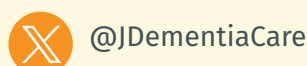
**Presenters:** **Aaron Smith** and **Natasha Lord**, Herefordshire and Worcestershire Health and Care Trust

**22 July 2024**

## Young Onset Dementia

**Presenters:** **Jan Oyeboode**, Professor of Dementia Care, University of Bradford and steering group member, Young Dementia Network; **Dr Jacqueline Hussey**, consultant old age psychiatrist and chair of Younger People with Dementia (Berkshire).





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**Ruth Eley**, Together in Dementia Everyday (tide)  
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**Toby Williamson**, independent consultant  
**Lucy Whitman**, former carer, writer, editor and trainer  
**Hilary Woodhead**, NAPA  
**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  
**Dr Nadia Wahid** – Dementia Primary Care Clinical Lead, Birmingham  
**Kate White** – former care partner, activist, writer & researcher

# People. People. People.

By Dr Richard Hawkins,  
 Editor-in-chief,  
*Journal of Dementia Care*



**P**eople are the rock upon which all organisations are built. The right people will enable almost every organisation, however badly structured, to succeed whereas however well structured an organisation is, without the right people it will struggle.

But who are the right people? The point which makes recruitment so interesting and challenging is that there is no one prototype 'person' who is right for every organisation nationwide. And when you think about it, it's not surprising there is this mismatch – organisations come in every size and shape – type of work, location, culture, size and clients for starters while workers are equally diverse – anything from hardworking to lazy, from respectful to rude, from caring to uncaring and so on.

Into this mix comes the whole question of retaining staff and teams and teamwork. I expect many will know the famous quote from Mother Theresa "None of us, including me, ever do great things. But we can all do small things, with great love, and together we can do something wonderful." Teamwork is clearly very important and sustaining for many people but it's not for everyone. I've known many successful relationships between client and worker, particularly in homecare, which have worked well, particularly suiting the worker who feels more comfortable working on their own. (See pp31-34, where Christina Newton and colleagues describe work on developing a specialist dementia care role in homecare.)

Over more than thirty years in the Journal of Dementia Care (JDC) we have published frequently on recruitment and its challenges. One thing we have learnt for sure is that recruiting and retaining dementia care staff is more difficult than in other social care fields. We know that in social care there is a 30-40% annual turnover of staff, and we know equally well that in dementia care the figure is likely to be closer to 40% and possibly even higher.

For all these reasons we have concluded that JDC, supported by its key events, the National Dementia Care Awards (now in its 14th year) and UK Dementia Congress (now in its 18th year) is well positioned to launch and run a focused Dementia Care Jobs and Opportunities Board. The board's USP will be that it will only focus on mid to senior dementia care jobs, initially in care homes and academia while we iron out any early niggles, and then moving to homecare, retirement housing and hospitals. In addition we will also include editorial content focused on highlighting the many advantages of working in dementia care and how to succeed, both as employer and worker. We are being assisted by our much appreciated partners, Barchester Healthcare, Care UK, Hallmark Healthcare, HC-One and MHA (see pp16-17).

We welcome all those interested in growing and developing dementia care recruitment and retention to contact us on 07947 640724. ■

**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](mailto:sue@dementiapublishing.community)

# News and resources round-up

*This is a brief round-up of the news and resources regularly posted and updated on our website.  
See more at: [www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)*

## **New dementia research sites to open across the UK**

The Dementia Translational Collaboration Trials Network, an initiative run by The National Institute for Health and Care Research (NIHR), has received £49.9 million in government funding to set up new dementia research sites across the UK to enable more people to take part in early phase clinical trials.

The Dementia Translational Collaboration Trials Network will have four key aims:

- Accelerate set up and regulatory processes for dementia trials.
- Increase industry engagement for early phase dementia trials.
- Enhance recruitment, support and diversity in dementia trials.
- Increase capacity and expertise for early phase dementia trials, thereby increasing the number of people with dementia in the UK who can participate.

Later this year there will be an open, transparent application process for selecting where and when the new research sites will open.

<https://www.alzheimersresearchuk.org/more-people-able-to-take-part-in-dementia-research-thanks-to-new-government-funding/>

To find out about participating in dementia research visit Join Dementia Research: <https://www.joindementiaresearch.nihr.ac.uk>

## **Alzheimer's Society research plans for 2024**

The Alzheimer's Society has shared information on its research plans for 2024. These include:

- More investment in dementia research
- Progress with the Blood Biomarker Challenge (find out more about the Blood Biomarker Challenge here: <https://journalofdementiacare.co.uk/blood-biomarker-challenge-for-dementia-diagnosis>)
- Work on new Alzheimer's disease drug approval
- A research nurses project
- Combating inequalities around dementia
- Progress with the Longitude Prize on Dementia (find out more about the Longitude Prize on Dementia here: <https://journalofdementiacare.co.uk/the-longitude-prize>)
- Progress with their Accelerator Programme that supports dementia innovation (an example of this is here: <https://journalofdementiacare.co.uk/vr-technology>)

You can find out more about Alzheimer's Society's research plans here: <https://www.alzheimers.org.uk/blog/2024-exciting-year-research-alzheimers-society>

## **Wellcome announces targeted funding to increase diversity in research**

Wellcome, a charitable foundation focused on health research, has announced a targeted funding programme for researchers of Black, Bangladeshi and Pakistani heritage in the UK to stay in research and advance their careers.

From their data and insight work Wellcome has identified these groups as under-represented. The funding will open in spring this year; find out more here:

<https://wellcome.org/news/targeted-funding-researchers-black-bangladeshi-pakistani-heritage-uk>

## **Call to reinstate speech and language therapy service**

The Royal College of Speech and Language Therapists, Rare Dementia Support and Dyscover have called on the government and NHS England to reinstate the National Hospital for Neurology and Neurosurgery (NHN) 's speech and language therapy (SLT) service, which closed in 2023. In their letter to the Secretary of State for Health and Social Care, Rt Hon Victoria Atkins MP, they said: "As organisations representing people with Primary Progressive Aphasia (PPA) and the professionals who work with, and support, them and their families, we are very concerned about the loss of the only national specialist speech and language therapy service in England and Wales. Given the rarity of these language-led dementias, we are particularly concerned about the significant risks people with them face if the only speech and language therapy service dedicated to supporting them is not restored as soon as possible."

<https://www.rcslt.org/news/our-joint-letter-to-government-over-fears-for-people-with-language-led-dementias/>

## **Labour unveils new life sciences sector strategy**

Labour has announced plans for a life sciences sector strategy, with an emphasis on clinical trial participation to help find new treatments for conditions including Alzheimer's disease. The plan would include establishing standing national registries for clinical trials, boosting public participation in clinical trials, and making better use of data. You can find out more here: <https://www.digitalhealth.net/2024/01/labour-unveils-new-life-sciences-sector-plan-in-a-bid-to-increase-growth/>

## **ADI announces launch of AD-RIDDLE project**

Alzheimer's Disease International (ADI) has announced its participation in and launch of the AD-RIDDLE project. The project is a collaboration between academics, healthcare providers, pharmaceutical and diagnostic companies, regulatory bodies and patient advocacy organisations. It aims to improve detection, diagnosis and prevention of Alzheimer's disease. Initially focused on European countries, it's hoped it will be translated worldwide in the future.

The project aims to produce resources including:

- A digital community engagement portal.
- Screening tools for risk detection and early diagnosis.



- A decision support toolkit for healthcare providers.
- Personalised therapies.

<https://www.alzint.org/news-events/news/adi-joins-ad-riddle-a-new-initiative-to-improve-detection-diagnosis-and-prevention-of-alzheimers-disease/>

### **Bob's Brainwaves goes live to help families**

Chris Suich, whose husband Bob has dementia, has created a kit to help carers and families affected by dementia. The kit, Bob's Brainwaves, includes ideas to support a person with dementia to live at home for longer, as well as important documents and forms. The local signposting that's included is focused on Louth, Lincolnshire, alongside information relevant to all parts of the UK. The free kits are available online here: <https://www.bobsbrainwaves.org.uk>. They will be officially launched during Dementia Action Week in May. Find out more about Chris and Bob's story here: <https://www.bbc.co.uk/news/uk-england-lincolnshire-68175607>

### **People with lived experience of dementia wanted for NIHR Policy Research Unit**

The National Institute for Health and Care Research (NIHR) Policy Research Unit is looking for people with dementia (of any type) to join their Policy Research Unit to help shape their work. Involvement opportunities are varied and participants are paid for their time.

Contact Rachael Litherland from Innovations in Dementia by email: [rachael@myid.org.uk](mailto:rachael@myid.org.uk) or phone: 07549 944796.

### **Study shows benefits of family intervention package to support independence**

A study published in The Lancet Healthy Longevity has shown that NIDUS-Family (New Interventions for Independence in Dementia Study) helps people with dementia and their family carers reach personal goals. Participants worked with a facilitator to set their personal goals to live independently at home for as long as possible, and these were then mapped to modules that the participants completed. These included information and strategies to address specific needs like exercise, activity and mobility; relaxation; and sleep, diet and healthy routines. Professor Claudia Cooper, Lead author, said: "Because NIDUS-Family can be delivered by people without clinical training, it has the potential to enable many

more people to access good quality post-diagnostic support. NIDUS-Family is the first readily scalable intervention for people with dementia that is proven to improve attainment on personalised goals, and can be remotely delivered, and it should be implemented in health and care services." Read the study here: [https://authors.elsevier.com/sd/article/S2666-7568\(23\)00262-3](https://authors.elsevier.com/sd/article/S2666-7568(23)00262-3). Read more about NIDUS-Family here: <https://www.ucl.ac.uk/psychiatry/research/mental-health-neuroscience-department/projects/nidus>

### **Research links singing or playing a musical instrument with better brain health**

New research from the University of Exeter has shown that people who join a choir or play a musical instrument have a better chance of retaining their memory and thinking skills as they age. The research is part of the PROTECT study, which aims to understand how the brain ages and how to reduce the risk of dementia and mental health issues in later life. Professor Anne Corbett, University of Exeter, said: "Our Protect study has given us a unique opportunity to explore the relationship between cognitive performance and music in a large cohort of older adults. Our findings indicate that promoting musical education would be a valuable part of public health initiatives to promote a protective lifestyle for brain health, as would encouraging older adults to return to music in later life. Overall, we think that being musical could be a way of harnessing the brain's agility and resilience, known as cognitive reserve." <https://www.sciencedaily.com/releases/2024/01/240129122415.htm> More about the PROTECT study here: <https://www.protectstudy.org.uk>

### **Lewy Body Society Call for Grants 2024**

The Lewy Body Society has opened its call for applications to the 2024 grant round. The society will fund PhD studentships, Junior Fellowships, Innovative awards and Project grants. Applications should increase understanding of Lewy body dementia as well as improving care for people living with this condition and their families and carers. It is anticipated that 3-5 projects will be funded. Applications close on 26 April 2024 at 12 noon. Funding decisions will be made by the end of October 2024. For more information and to apply, please visit: <https://www.lewybody.org/research/apply-for-a-grant/>



 **Alzheimer's Society**  
**Annual Conference**  
**Making dementia a priority for all**  
 14 May 2024  
 etc.venues, 155 Bishopsgate,  
 London and online

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## Dementia and End of Life Choices booklet

The Scottish Dementia Alumni, a group of campaigning friends in Scotland who each have a diagnosis of dementia, have published their latest booklet 'Dementia and End of Life Choices'. They say:

"This booklet was an emotional creation, as we all needed to confront challenging concepts and our own personal bereavements in order to make this publication. Nobody found it easy. We hope that the booklet is helpful and comforting to all who read it."

The booklet is available as a digital pdf download here: <https://scottishdementiaalumni.uk/2024/02/05/dementia-and-end-of-life-choices/>. Also available free on Apple Books and will have a short print run by the end of February 2024.

The group is also working on a **new peer-to-peer publication about dementia and continence**. They are looking for anyone willing to share resources or personal experiences (anonymously if preferred) to inform their publication. Contact the Scottish Dementia Alumni here: <https://scottishdementiaalumni.uk/contact/>

## New SCIE website

The Social Care Institute for Excellence (SCIE) has launched a new website. SCIE's work centres around co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in social care and social work. You can visit the new website here: <https://www.scie.org.uk/>. An abridged SCIE dementia resource can be found here: <https://www.scie.org.uk/dementia/>.

## Photobook Project Impact Report

The Photobook Project, a Community Interest Company that supports people living with dementia to document, share and celebrate their experiences and perspectives through the lens of a single-use camera, has published its 2-year Impact Report.

The report details the key achievements and approach of the Photobook Project and shows how it links to the Five Ways to Wellbeing.

Find out more about the Photobook Project here: <https://the-photobook-project.com>

See also: Robinson-Carter E (2024) The Photobook Project: Empowerment through creativity. *Journal of Dementia Care* 32(1) 23-25.

## ADI Attitudes to Dementia global survey

Alzheimer's Disease International (ADI) have launched their 2024 Attitudes Towards Dementia global survey. The survey is open to everyone and aims to build a picture about prevailing attitudes and stigma towards dementia. The survey is currently available in English and many

other languages, with more available soon.

Take the survey here: [https://lse.eu.qualtrics.com/jfe/form/SV\\_71FXXETjeLzzvzE](https://lse.eu.qualtrics.com/jfe/form/SV_71FXXETjeLzzvzE)

Find out more here: <https://www.alzint.org/resource/attitudes-to-dementia-world-alzheimer-report-2024-survey-information/>

## Carers UK launch phone service

Carers UK have responded to the needs of carers who don't use computers or the internet by launching a new information phone service.

Carers can call the freephone telephone service on 0800 888 6999 and follow the options provided.

## New extra care housing resources

The University of Worcester Association for Dementia Studies has published new resources to support its DemECH Project, which explored how Extra Care Housing can help people to live well with dementia.

The new resources, all available for free, are:

- Key insights booklets
- An infographic
- A series of short videos

<https://adsdementiablog.wordpress.com/2024/02/15/demech-new-resources-available/>.

## 'Living with dementia: Voices of Asia'

A new eBook has been published that aims to combat stigma by sharing real-life accounts from people living with dementia and care partners across 13 countries in Asia. The eBook Project, led by Emily Ong, has involved 20 contributors and was officially launched in December 2023 at the ADI Asia Pacific Conference in Taiwan.

You can read the eBook here: <https://online.fliphtml5.com/ndtu/calg/#p=1>

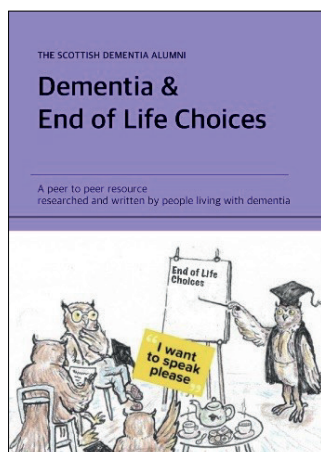
Find out more about this Project in Emily Ong's blog for Dementia Alliance International <https://dementiaallianceinternational.org/blog/together-we-are-stronger-emily-ong>

This work will be further consolidated in due course by the launch of the 'Voices of Asia Pacific' website.

## Survey shows caring responsibilities disproportionately affect women

A survey commissioned by Home Instead has shown that family carer responsibilities are disproportionately affecting women. Key stats from the research (conducted by Savanta, who spoke to 2000 people across the UK) include:

- There is greater expectation on women to meet caring responsibilities than men, according to 88% of females and 65% of men.
- Similarly, 84% of females think we need to rethink the role of women as default carers in society - a view shared by 66% of males.
- Some 62% of female and 42% of male carers believe men are not doing enough to help with ageing parents.





- And 77% of females and 62% of males believe women should demand the burden of care be shared more equally with men.

This survey forms part of Home Instead's 'Take Care' Campaign. Find out more about 'Take Care' here: <https://www.homeinstead.co.uk/south-cheshire/blog/take-care-campaign/>

### Initial delivery plan for Scottish Dementia Strategy published

Following the launch of Scotland's new dementia strategy, 'Dementia in Scotland: Everyone's Story', in May 2023, the Scottish Government and COSLA (The voice of local government in Scotland) have published a delivery plan for how they will work with people with lived experience and delivery partners to implement the strategy.

This delivery plan runs from 2024-2026 and is the first in a series of delivery plans. You can read it here: <https://www.gov.scot/publications/new-dementia-strategy-scotland-initial-2-year-delivery-plan-2024-2026/>  
Scotland's Dementia Strategy is here: <https://www.gov.scot/publications/new-dementia-strategy-scotland-everyones-story/>

### Opening Doors closure

Opening Doors, a charity launched in 2016 to support and advocate for LGBTQ+ individuals over 50, has announced its permanent closure on 29 February 2024.

For more information email [ceo@openingdoors.lgbt](mailto:ceo@openingdoors.lgbt).  
Opening Doors website can be found here: <https://www.openingdoors.lgbt>

### The Filo Project calls for an end to the 'Dementia Tax'

The Filo Project, a Community Interest Company who provide day care for people with dementia, has launched a campaign called 'End the Dementia Tax' to ask for a change in VAT rules. Currently, The Filo Project has to charge families who access their support the extra 20% VAT charge because they aren't a regulated business or charity. <https://www.thefiloproject.co.uk/post/help-us-end-the-dementia-tax>.

### 'Dare to Imagine' resource handbook for care homes

Magic Me, an intergenerational arts charity, have published 'DARE TO IMAGINE – A care home's guide to creativity'. This free resource builds on Magic Me's Artists' Residencies in Care Homes (ARCH) programme that saw arts companies team up with care homes to create new artworks with and for older care home residents. 'Dare to Imagine' is designed to encourage and build the confidence of care home staff, and includes ideas, prompts and guidance to bring everyday creativity into care homes. You can download it here: <https://magicme.co.uk/resource/dare-to-imagine-a-care-homes-guide-to-creativity/>

### Adopt a Grandparent launch webinar series

Adopt a Grandparent has launched a new series of webinars to share the impact it is making and encourage more care homes and volunteers to register with them. Adopt a Grandparent pair older, socially isolated care home residents (including people with dementia) with



**Creative Minds Devon recently ran an art afternoon at Sundial Care Home, Tipton St John, Devon. "It was a buzzing dining room full of artists" said Catherine from Creative Minds Exmouth, who combined their work into this community art piece for the lounge.**

volunteers worldwide to combat loneliness and encourage intergenerational relationships. Established as a socially-driven organisation in 2020, the charity now works with care settings and older persons residing across the UK – with almost 100,000 volunteers signed up to 'adopt'. Following their first webinar, more are being planned and information about these and the opportunities available to get involved with Adopt a Grandparent can be found here: <https://www.adoptagrandparent.org.uk>.

### Leeds Beckett University offers fully funded dementia research PhD

The Centre for Dementia Research at Leeds Beckett University is offering a fully funded PhD to research the experiences and support needs of social care staff in the management of long-term conditions alongside dementia. It is funded by the NIHR Three Schools Dementia Research programme, and is aimed at individuals looking to develop a career in dementia and social care research. The deadline for applications is 7 May 2024, with commencement of the PhD in October 2024. Find out more and apply here: <https://www.leedsbeckett.ac.uk/the-graduate-school/studentships/health/centre-for-dementia-research/>

### BBC Programme about clutter is looking for families or households affected by dementia

The BBC One series 'Sort Your Life Out' is looking for families or households affected by dementia to take part in a new series. The application deadline is 21st April 2024 and you can complete an application here: <https://www.optomen.com/sort-your-life-out>

More information from DEEP:

<https://www.dementiavoices.org.uk/deep-groups-news/take-part-in-sort-your-life-out-bbc-tv-programme-with-stacey-solomon/>

### New dementia design film for people living at home

The University of Stirling's Dementia Services Development Centre (DSDC) has launched a new film to share low-cost dementia design principles that can enable people with dementia to maintain their independence and <https://youtu.be/yvZRU44Nbyw?si=DzMqbidtWTkqhZ8e>

### Dragons' Den investment for safer finance

Sibstar, a debit card and mobile app for people living with dementia and their families has secured a £125K investment after appearing on the BBC Dragons' Den programme. More about Sibstar here: <https://www.sibstar.co.uk>

# Dementia Diaries

At the time of writing, it has been just over a week since we learned the sad news of Wendy Mitchell's death. An award-winning writer of books, blogs, a consummate adventurer in all senses, Wendy was a beacon for an enormous number of people.

So this edition of the Dementia Diaries column is dedicated to her, with a selection from her diaries over the years.

But let's start with a heartfelt tribute from fellow diarist and Amigo George:  
<https://dementiadiaries.org/entry/22263/george-pays-a-moving-tribute-to-wendy-mitchell-this-diary-will-resonate-for-so-many-people/>

Along with Gail and Dory, George and Wendy were the Four Amigos, a virtual group who together recorded some amazing conversations – which you can see more of here: <https://www.dementiavoices.org.uk/group/the-4-amigos/>

In one of Wendy's earliest diaries, she talks about the value of being with and learning from others with dementia.  
<https://dementiadiaries.org/entry/4401/there-is-nothing-more-comforting-than-for-someone-else-saying-that-they-are-experiencing-the-same-symptoms/>

Wendy was a huge advocate of peer support and of DEEP. Despite being one of the more high-profile advocates for dementia, when she took her place in the York Minds and Voices group, she describes how she could relax, and be just Wendy.

*Shelagh suddenly mentioned the value she'd found in her DEEP peer support group. How she can cry, speak of difficulties, share tips and share laughter without being judged.... There's so much expectation and pressure on you to deliver. But at Minds and Voices I'm normal and when I walk through the door and start putting out the chairs....I'm just ...Wendy.*  
<https://dementiadiaries.org/entry/9228/at-minds-and-voices-im-normal-and-when-i-walk-through-the-door-and-start-putting-out-the-chairsim-just-wendy/>

Wendy always had great insight into her dementia, and how it was affecting her, and it was this, in part, which lent her books such authority, and which were an inspiration to so many.  
<https://dementiadiaries.org/entry/8619/dear-dementia-we-have-to-sit-down-and-have-a-heart-to-heart-i-preferred-my-life-when-you-werent-apart-of-it-but-now-i-cant-live-witho/>

However, Wendy was always at pains to remind herself and others that this was *her* story, and that everyone is on their own path:  
<https://dementiadiaries.org/entry/6900/wendys-words-on-the-publication-date-of-somebody-i-used-to-know/>

In this diary Wendy reads from one of her favourite parts of her first book. She captures something that others with dementia have reported, that since the onset of dementia, they have found it easier to live in the here-and-now. This is something we talk about often with people with dementia, many of whom find it easier to be present in the monument than they do to remember the past, or consider the future. Wendy considered this a blessing, and all achieved without the help of years of meditation or mindfulness training:

<https://dementiadiaries.org/entry/9450/wendy-reads-her-favourite-bit-from-her-book-somebody-i-used-to-know-about-billy-the-cat/>

When we started work on the DEEP Symphony – titled 'I've got you' – I had a clip of Wendy using words and phrases from Great Expectations to express her feelings about the impact of dementia on her life. I knew from the first time I heard it that it would be at the heart. You can hear Wendy reading her poem from 1.50 here:  
<https://www.youtube.com/watch?v=H3EHg3JdOM0>

DEEP is often described as a family. The loss of Wendy has left many feeling bereft, conscious of an empty chair that will never be filled. But the fact is that Wendy, like those that have gone before her, lit the creative spark and inspired countless other people with dementia who have gone on to become campaigners, start their own groups, and share their stories and experiences. As a result, many, many more people around the world, are a little bit less afraid, and a little bit more hopeful that one can live well after a diagnosis, and have grasped the opportunity. What more can one ask of a life. ?

*Dementia has brought me many new opportunities.....  
....I've met the most amazing people who I would never have met if I hadn't been diagnosed with dementia.  
But most of all I have to thank my daughters who have been at my side and never left it. Enabled me rather than protected me. Without their love and support I'd be in a very different place.  
So on this bittersweet anniversary my one message would be....never give up on yourself. There will be so many others who will do that for you.....believe in yourself and live your life as best you can.*

<https://dementiadiaries.org/entry/12332/never-give-up-on-yourself-there-will-be-so-many-others-who-will-do-that-for-you-believe-in-yourself-and-live-your-life-as-best-you-can/>

Goodbye Wendy . And thank you.

*Steve Milton, Director, Innovations in Dementia*

**See pp12-13 of this issue, where her long-standing friend Philly Hare pays tribute to Wendy.**





## **Learning - Sharing - Inspiring**

### **Building a Dementia Community**

Dementia Community is delighted to announce that the 18th UK Dementia Congress (UKDC) will be held at **Coventry Building Society Arena, Coventry CV6 6GE on 26-27 November 2024**

We look forward to welcoming everyone to the largest annual multi-disciplinary dementia-focused event and exhibition in the UK. UKDC has a long history of bringing together everyone involved in dementia care to learn, share and inspire each other with fresh energy and enthusiasm for our work.

We welcome proposals for presentations on all aspects of dementia care in all settings and from all the diverse perspectives of everyone involved, including: people living with dementia, care partners and family carers, health and social care practitioners and professionals, people working in the housing field, and the voluntary, community and social enterprise sectors, researchers, innovators and entrepreneurs.

**CALL FOR PRESENTATIONS     Deadline 10 June 2024**

#### **Knowledge-based practice**

We prioritise papers that include not only a detailed description but also an element of evaluation of a project or service. Your proposal should consider the factors contributing to success or failure, identify barriers to progress, assess how these challenges were overcome, and draw conclusions with lessons learned.

#### **Equality, Diversity and Inclusion**

We are committed to integrating the principles and practice of Equality, Diversity and Inclusion (EDI) to enhance and personalise care and support for people living with dementia and their carers. Please provide details of how your service or project exemplifies how EDI values have been included and addressed. Please see last year's special issue of the *Journal of Dementia Care* for more information about EDI and dementia, still available free to download on our website [www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)

#### **Involving people living with dementia, care partners and family carers**

As in previous years, a strong theme running through the Congress will be the experience of people living with dementia, and their involvement, and that of their families and care partners, in care provision at every level. As appropriate, proposals should show that this important aspect has been addressed.

Please refer to these guidelines on making your presentation accessible to all:  
<https://www.dementiavoices.org.uk/deep-resources/making-things-more-accessible/>

#### **Options for contributions are:**

**Short paper presentations:** Presentations offered will usually be for 12 or (in selected cases) 18 minutes.

**Interactive workshops:** We hope to include a small number of interactive workshops of either 30 or 70 minutes.

**Poster presentations:** We welcome posters for display at the congress itself and inclusion in the congress app. Posters should describe a project or service with comment/evaluation, or report on research work.

#### **How to submit your proposal**

**Submit your proposal using the online form via our website [www.journalofdementiacare.co.uk](http://www.journalofdementiacare.co.uk)** making sure that you enter all the information requested in every field. Please check for an email acknowledgement that your proposal has been received. If not please contact us as below.

If you have any queries email Sue Benson ([sue@dementiapublishing.community](mailto:sue@dementiapublishing.community)) **Join the conversation #UKDC2024**

# Wendy Mitchell

31 January 1956 – 22 February 2024

Dr Wendy Mitchell BEM, campaigner, educator and best-selling author, has died aged 68, after living with dementia for almost a decade. Her long-standing friend **Philly Hare** pays tribute to an exceptional person whose writing and campaigning will have a wide and enduring influence

Born in Wakefield in 1956, Wendy loved school and excelled at many sports, including tennis and running. A quiet and very private person by her own description, she brought up her two daughters single-handedly in Milton Keynes, earning her living first as a cleaner and then as a non-clinical NHS team leader. She continued in this role for several months after her diagnosis with young-onset Alzheimer's disease and vascular dementia in July 2014, aged 58.

Initially thrown into depression by her diagnosis, Wendy's life took a new turn a few months later when she met Agnes Houston MBE at a Joseph Rowntree Foundation-funded 'Women and Dementia' event in York. Agnes had already been living with dementia for several years and was an active campaigner. "She showed me that there is life after a diagnosis and changed my thinking about having dementia," said Wendy, who soon became equally passionate about promoting this more positive message.

Having never previously used social media, she began to write a blog – Which Me Am I Today? – which now has thousands of subscribers worldwide. As she explains in the forward to her blog:

*It will hopefully convey the helplessness of those diagnosed with dementia, as there is no cure – the end is inevitable. However, I'm also hoping I can convey that, although we've been diagnosed, people like me still have a substantial contribution to make; we still have a sense of humour; we still have feelings. I'm hoping to show the reality of trying to cope on a day-to-day basis with the ever-changing environment that dementia throws at those diagnosed with the condition. Living as well as you can with dementia is all about adapting. Adapting to new ways to enable us to live better for longer with dementia.*

While Wendy lost the ability to write or use the phone, she continued to type away almost until her death. The details of her daily life and contacts would quickly vanish



from her memory, but recording everything she did, thought and felt in her blog, and posting on social media, enabled her to share her ups and downs with the wider world. Wendy was also an active member of *Dementia Diaries* (see p10). Her X (Twitter) account now has over 20,000 followers.

Wendy has co-written three books (published in 2018, 2019 and 2023) with Anna Wharton, all of which have become best-sellers and have been translated into many languages. In her books she explores with great honesty the many challenges that dementia brought her, and how she constantly tried to 'outmanoeuvre' it. But she also explains how dementia

helped her to live a new life, becoming much more outgoing and fearless.

One manifestation of this was the series of dare-devil activities she undertook to raise awareness and money – these included firewalking, wingwalking, paragliding, and a zip-wire walk.

Wendy lived alone by choice, though with loving and sensitive support from her two daughters and son-in-law. Together they ensured that her last house, in an East Yorkshire village, was easy to live in and navigate, sticking photos of contents on cupboard doors, using Amazon Alexa to turn lights on and off, paring down cutlery and crockery to two of each type, taping round light switches to make them easy to find, and reducing her entire wardrobe to several sets of exactly the same clothes.

Wendy soon got involved with her local DEEP peer support group in York, finding much pleasure and solidarity from her friendships with other people living with dementia, her 'playmates'. Through DEEP, the UK Network of Dementia Voices, she participated in many ground-breaking local and national projects. Wendy also took part in numerous research studies – not just as a research subject or participant, but often as an adviser, co-researcher or even researcher in her own right. Both Bradford and Hull Universities awarded her an honorary



doctorate. Wendy also advised Julianne Moore on her award-winning role in 'Still Alice' (2014), and featured on Woman's Hour and many other media programmes. In June 2023 she received a British Empire Medal for services to People Living with Dementia in the King's Birthday Honours.

As she got increasingly involved in public speaking, research, campaigning and writing, Wendy would travel all over the country (and sometimes overseas as well.) She wryly claimed that she cast a hex over any public transport she used, frequently having to cope with delays, cancellations and changes of plan which played havoc with her dementia. Wendy's favourite place in which to recharge her batteries was Keswick in the Lake District – she called it 'Paradise'. In the last few years she would spend a few days there every month, always at the same guest house and relishing the same walks and views.

The Covid pandemic put paid to much of Wendy's travelling, and could well have sent her on a downward spiral. But she started walking many miles a day round her village area, taking thousands of photos of the wildlife and sunrises with her Nikon camera. She would post these not only on social media and her blog, but also in the village newsletter, soon becoming known locally as 'the lady who takes photos' rather than 'the lady with dementia'.

In her final book, *One Last Thing*, she explored the issue of assisted dying, interviewing many proponents and adversaries of this controversial issue, and explaining her own carefully-thought-out views (in its favour) with great honesty. Following an accident in January 2024, she decided the time had come to stop eating and drinking. As she explains in her final posthumously-published blog:

*I wasn't depressed, I wasn't forced or cajoled in any way whatsoever, it was solely down to my choice. I was ready... dementia didn't play the winning card – I did.*

As a person, Wendy was positive, inspiring, kind, funny, brave, honest and endlessly generous with her time, energy and wisdom. She supported many other people with dementia to have their voices heard. Numerous professionals and family carers have testified as to the impact her words have had on their own understanding of dementia. She will be hugely missed by many.

*Wendy is survived by her daughters, Sarah and Gemma, and her son-in-law Stuart.*

*Philly Hare worked for the Joseph Rowntree Foundation and Innovations in Dementia (supporting DEEP, the UK Network of Dementia Voices) before her recent retirement.*

## Book review

### **LGBTQ+ People and Dementia: A Good Practice Guide**

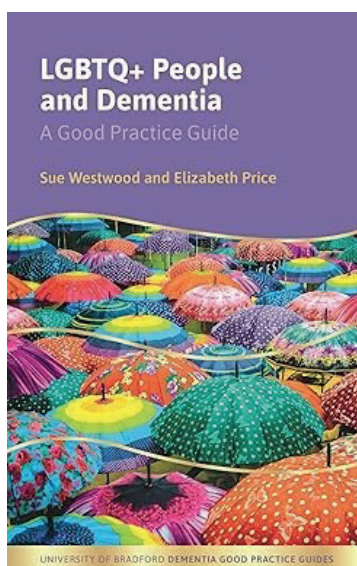
*Sue Westwood and Elizabeth Price,  
Jessica Kingsley Publishers,  
ISBN 9781839973307 £16.99*

This slim volume, one of the University of Bradford Dementia Good Practice Guides, is packed full of information, insights and helpful guidance.

The book explains the particular challenges for LGBTQ+ people who are affected by dementia and why a one-size-fits-all approach can never meet individual people's needs. It includes a succinct account of the oppressive laws and social attitudes – including within the medical profession – which have profoundly affected the lives of all older LGBTQ+ people in the UK and which deter some from engaging with health and care services. It provides plenty of ideas for creating an environment where LGBTQ+ people will feel safe to be themselves.

There are numerous case studies and quotes from practitioners, and some carers, in addition to quotes from older LGBTQ+ people, many of whom express their fear of becoming dependent on care services if they develop dementia in the future. There is a lack, however, of voices of LGBTQ+ people who already have a diagnosis of dementia, and this is a missed opportunity.

There are now several support groups for LGBTQ+ people with dementia and carers scattered across the UK, co-produced between people with lived experience of dementia and LGBTQ+ or dementia organisations.



For those who wish to develop their practice as a result of reading this book, the next step will be to engage directly with LGBTQ+ people with dementia and carers, as well as seeking information and support from organisations with experience in this field. The LGBTQ+ Dementia Advisory Group, <https://www.lgbtqdementiaadvisorygroup.net>, which is led by LGBTQ+ people with lived experience of dementia alongside practitioners and researchers, offers learning and networking opportunities for those with a shared passion for creating LGBTQ+-affirmative dementia care. It is also important to recognise the complexities of intersectionality, such as the additional challenges faced by

LGBTQ+ people affected by dementia who belong to minority ethnic communities. Again, seeking out, engaging with and co-producing services with people from diverse backgrounds is a vital part of good practice.

Overall, this book is an excellent primer for those who want to make their practice more LGBTQ+-inclusive. It is admirably concise, clearly written, and full of practical guidance, particularly about dealing with challenging situations arising from conscious or unconscious prejudice, or ignorance about LGBTQ+ people's lives and experiences. The authors do not shy away from the need for "difficult conversations", but their approach is always supportive and respectful of all concerned.

**Lucy Whitman**

*Lucy Whitman was previously Dementia Engagement Officer at Opening Doors <https://www.openingdoors.lgbt>*

# JDC asks:

**Recruitment and retention of staff is a burning issue in dementia care services. What are the best ways to find and keep exceptional staff working for your organisation?**



**L to R: Emma Hewat, Laura McEwan, Mitch Miller, Laura Steward**

## **Emma Hewat, Head of Dementia, KYN:**

There are an unprecedented five generations in the workforce today from Traditionalists and Baby Boomers through to Generations X, Y and Z. Each generation works differently and expects different things from us. With that in mind, we need to know what people want from us as their employer and conversely what we need from them to maintain a productive and effective workforce.

But why should it matter when someone is born? We are all a product of our time. Family dynamics and parenting, education, environment, politics, world events, cultural phenomena, media and technology all have a part to play in shaping us. They affect our values, motivations, behaviours, needs, attitudes to risk, social consciousness, and ways of working. There is no right or wrong way, we are just different.

Understanding the different generations can determine our recruitment strategies for example social media versus traditional marketing, engagement levels and enjoyment at work, leadership strategies, employee retention and leadership development. Ultimately it comes down to understanding and connecting with each generation to create an inspired, healthy workplace, which will in turn yield us outstanding results.

At KYN all generations are represented in the workforce. Understanding and responding to their diverse needs at every stage of their journey to becoming an employee and beyond, is crucial to ensure their wellbeing. As Kitwood taught us, a person cannot be expected to deliver person centred care that meets the psychological needs of people living with dementia if their own psychological needs are not being met. Values based recruitment, getting to know team members and creating a sense of belonging, a robust system of recognition and rewards, opportunities for continuous development and promotion, a strong employee wellbeing strategy, all help KYN to recruit and retain exceptional team members who are proud to work for us.

## **Laura McEwan, Director & Head of Quality and Compliance, Home Instead West, Mid, North Norfolk and Cambridge**

We all know that the continuity of care professionals in supporting clients living with dementia is key to success of the support. Life history work has been transformative to our service over the past 12 months, as we all know this information can become vital when supporting clients, especially those with communication difficulties. The way that the care professionals can tailor the support and really live in the client's reality becomes much easier if a relationship has been built with the client and there is trust and familiarity there. The way that we induct and introduce, support, and shadow a care professional with a client living with dementia has changed the way that the relationship has developed and thus the investment and longevity of the care professionals in supporting the client.

Continuity allows the care professional to be on the dementia journey with the client additionally, knowing the client well, understanding their routine and symptoms is crucial in being able to be responsive to changes, developments and declines in their health and abilities. We put a huge amount of time and resource into recruitment asking questions and presenting scenarios to ensure that we are finding exceptional care professionals who are passionate about providing outstanding support.

Once we find these special individuals it's important for us to nurture them, otherwise we wouldn't be able to sell a service that is based on continuity; support and engagement is key. As a company we shifted our focus within the last 2 years on the well-being of our care professionals, we now have a dedicated well-being group that supports the wellbeing of our clients and care professionals and focuses on their differing needs throughout the year. Caregiving is rewarding but it can also be a tiring and emotional job. Support, recognition, ongoing training, development, and engagement are key to good retention. ▷

▷ **Mitch Miller, Chief Executive, Astute Homecare:**

Recruiting and retaining exceptional staff in dementia care services presents a deeply personal challenge. Recognising the profound impact dedicated caregivers have on individuals with dementia underscores the critical importance of finding and retaining the right caregiver. Without a doubt, the best way to find a great dementia caregiver is through a robust word-of-mouth referral scheme. We place great value on recommendations from people who know good caregivers, offering up to £500 per referred care professional. Keeping the scheme simple and the payment timely ensures the best response, you want to make it easy for people to refer people.

Our advice to care providers is straightforward: prioritise creating a culture where staff feel valued, supported, respected, and included. This means adopting a supportive, proactive, and communicative approach from the initial interaction when recruiting staff. We set ourselves the ambitious yet achievable goal of responding to every recruitment application within 24 hours. We firmly believe in hiring based on intelligence, energy, and, above all, integrity, given the immense trust we place in our caregivers.

We often observe instances where care companies emphasise the importance of communication skills but fail to follow through with responsive actions. Consistency in behaviour is paramount; actions must align with words. Absolute conviction in company values and actions is imperative to attract and retain the best talent.

While staff benefits hold significance, we've learned that caregivers place greater value on feeling respected and appreciated. We express gratitude through consistent acts of kindness, from the outset of the recruitment process to becoming a full-fledged caregiver.

Investing in staff growth and development remains crucial. Providing ongoing, dementia-specific training instils confidence in caregivers and equips them with lifelong skills. Recognizing and celebrating staff achievements further cultivates motivation and dedication.

**Laura Steward, Head of Dementia Development  
Maria Mallaband Care Group**

Feeling valued and empowered is what our Dementia Ambassadors say drives them forward – they shared with me that they feel valued, they feel appreciated, and they feel at home in their care team settings, and this is what pulls them to stay with Maria Mallaband.

For me, supporting those who support the people who live with us is key to high recruitment and retention – we value each of them, and work closely supporting them, alongside the home management team and wider business, helping them to succeed.

Being in dementia care services is – as we all know – tough, but highly rewarding and uplifting. To see someone come to life again, with the right support, guidance and understanding in place, is just magical. They, along with the team that they have trained and supported get to see this magic on a daily basis.

Our learning programme - delivered by our Dementia Ambassadors - takes the home team on an emotional, thought-provoking journey, giving them the permission they need to be open to building relationships and connections with those they care for. To really see them for the person they are, and always have been - that is our mantra: see the person first before their diagnosis. Each one of our Dementia Ambassadors has a purpose and lives by this golden thread which joins them all.



**Dementia Community is delighted to announce that the  
14th National Dementia Care Awards will be held at Cutlers' Hall, Sheffield  
on Thursday 26 September 2024 (a lunchtime event).**

**Details of awards and how to enter will be on our website soon:**

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

**If you are interested in sponsoring an award please contact Isabella Barclay:  
[isabella@dementiapublishing.community](mailto:isabella@dementiapublishing.community)**



# Announcing our dedicated dementia care recruitment website

Our charity, Dementia Community, is delighted to announce the launch of a dedicated dementia care jobs and opportunities website. Initially our focus will be on the recruitment of middle to senior dementia care staff for the care home sector and academic markets. As we establish the site we will move on to the retirement housing, homecare, NHS and community charity sectors.

## Why dementia care?

While there are no specific figures for the turnover in dementia care staff, we know there is a 30-40% annual turnover of staff in social care and these figures are likely to be higher for dementia care staff. Recruitment and retention in dementia care is therefore challenging but we believe we are well-positioned to support a greater level of success in both recruitment and job seeking.

## Our partners

Any new venture benefits from having enthusiastic and knowledgeable partners so we are delighted that, for our launch, we have four partners who understand the challenges within dementia care and promote the values which will make dementia care a much more attractive place to work. In alphabetical order below, they introduce themselves:

### Barchester

At Barchester Healthcare, we'll ensure you are supported in your career, with ongoing opportunities to develop and expand your skills. You'll be rewarded for your hard work and the crucial part you play in the teams that keep our homes and hospitals thriving.



We have over 240 care homes and six independent hospitals nationwide. Join the Barchester family and you'll make sure our residents and patients get the outstanding quality of care, support, services and facilities they deserve. With a range of care, nursing, hospitality, leadership and support roles available, there are endless opportunities to flourish and progress in your career with us. We don't just want you to feel valued, we want you to truly love what you do.

### HC-One

HC-One is focused and committed to supporting, growing and developing our Colleagues, to reach their potential, Colleagues benefit from career progression opportunities, and enjoy a fulfilling career with us.



Person-centred care isn't easy – it takes highly skilled, kind and caring Colleagues who have the patience and knowledge to understand our Residents' needs and put a plan in place to support them to live their best possible life. Although not easy, it's incredibly rewarding.

Through our sector-leading, tiered Dementia Care Learning and Development programme, we equip our Colleagues with the skills and expertise needed to provide Residents with the best possible care. Delivered through both e-learning and face-to-face sessions, the programme covers topics such as communication, empathy, relationships and inclusion in dementia care, including caring for those with complex behaviours, enabling Colleagues to enjoy a rewarding career as an experienced specialist in dementia care.

### MHA

As the UK's largest charity care provider, we're searching for empathetic and committed individuals with diverse skills and experience to uphold our mission



of enabling older people and people living with dementia to live later life well. Discover a career that combines passion and purpose. Be part of an organisation that celebrates diversity and stands at the forefront of care and compassion. Whatever your role with MHA, it's more than just a job.

We believe that each and every one of our staff members deserve the best working environment and terms and conditions we can provide. That's why we offer: Excellent terms and conditions; a bright future; a great contribution to society; our values and reputation; equal opportunities; a substantial package of benefits and perks.

### Hallmark

At Hallmark, we set the standard for exceptional resident experiences. Here, we work together with residents and their loved ones, enabling them to live well with dementia. Across our 22 luxury homes, our expert teams in Dementia Care, Lifestyles, Hospitality, and Nursing are dedicated to supporting residents and families to thrive – no matter where they are on their journey. Our experienced regional and central dementia care teams provide innovative support, guidance, and award-winning training so that with us, you can fulfil your potential.



We seek talented, bighearted individuals and as a proud Real Living Wage Employer, we offer many benefits such as free life assurance, NMC Pin renewals, private healthcare, and more. On behalf of the Hallmark family, we would be excited to meet you.

## Why us?

The *Journal of Dementia Care* (JDC) was launched over 30 years ago and has been published successfully and continuously ever since. During that time the largest annual dementia-focused dementia care conference, UK Dementia Congress (now in its 18<sup>th</sup> year) and the popular National Dementia Care Awards (now in their 14<sup>th</sup> year) have been added to JDC making it the best known and respected dementia care portfolio in the UK. We believe we are uniquely placed to promote the importance and value of the dementia care sector and to attract the right sort of people. Because there are two challenges: one is attracting people into the sector in the first place (recruitment) and the second is ensuring, as best we can, they are the right people to stay within the sector (retention).

We look forward to involving as many of our readers as possible once the website is live. Thank you for your interest.  
Dr Richard Hawkins, Editor in Chief, Journal of Dementia Care. Tel: 07947 640724



## Jobs & Opportunities Dementia Community

Dementia Community is launching a dedicated job board focused on attracting the best talent into dementia care.

The new site will promote career opportunities throughout dementia care including mid to senior management, nursing and related roles in social care (primarily care homes initially), education and research, the NHS and charities.

**You can help our mission by getting - and staying - in touch, and spreading the word throughout your networks.**

PROUDLY SUPPORTED BY

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# Let's Be Clear

## New guidelines on better writing

**Steve Milton** introduces a new accessible writing guide from Innovations in Dementia

We've never had so much information. It's coming at us from all sides, from our handheld devices to our computer screens, and still occasionally through our letterboxes. It screams at us from billboards, from adverts on public transport and even from self-service tills as we buy our daily milk.

This is a good thing, right? Information is power and all that.

Except.....except when it *isn't*.

Too much of the information presented to us seems to make our life not easier, but more difficult. The drip, drip of small challenges that can soon mount to a cognitive load that can seem overwhelming.

"UNIDENTIFIED ITEM IN BAGGING AREA"!!!

Excuse me?

Aside from the merciless torturing of the English language, what on earth does it mean, and what I am meant to do about it?

Of course, most of the time we can work out what things mean. We just shouldn't *have to* anywhere near as much as we do. Why can't we just be clear?

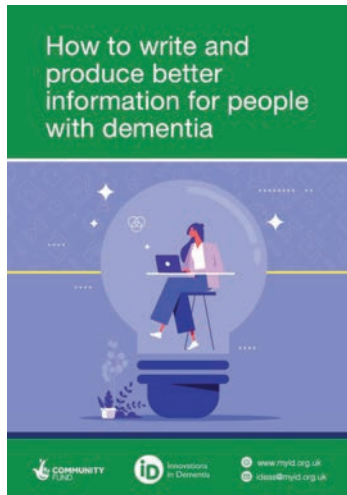
This overload of poorly written information is a challenge for all of us, but especially for people with dementia. The onset of dementia can make it even harder for people to translate bad information. This can make it harder to people to get out and about, and to do many of the things the rest of us take for granted.

These can be very real barriers for people:

- The badly designed bus timetable that meant someone got on the wrong bus and got lost, or went home having failed to work out what to do next.
- The self-service checkout whose instructions had neither meaning nor direction, and sent the would-be customer scurrying out of the shop, mission unaccomplished.

We know what can happen when we begin to struggle, or fail in certain tasks. It means we are less likely to risk failing again, so we stay at home where it is safe. We disengage.

Many people with dementia have told us that a single incident like this can send them into a tailspin and have a huge impact on their confidence in their ability to interact



with the world. They disengage.

How much easier would life be for all of us if things were just a little bit clearer?

This is why in 2013 we wrote some basic guidelines on writing better information for people with dementia.

Since then we have used them to produce dementia-friendly materials for lots of events and organisations, from conferences to lay summaries of academic papers.

What is very striking though is that not only do people with dementia find these versions easier, so does everyone else. We first realised this when we produced a dementia friendly timetable for a conference.

We had to go across the road to a photocopying shop for more copies as they had all been snaffled up in preference to the main conference timetable.

We can see the impact we can have by making things just a little easier for everyone.

A few years ago, we wanted to update our guidelines. So we started the process by looking around to see what else has been produced since our guidelines were published.

I discovered two things that were quite shocking. Firstly, not much else had been produced by way of guidelines for general consumption. Secondly, our own guidelines were being cited left right and centre as an authoritative guide. That was quite a strange feeling. While we were pleased with the guidelines, especially the fact that they had been co-produced with people with dementia, it was a relatively small group, and it was only ever our intention to provide a perspective, a contribution to the field, NOT the authoritative arbiter it seemed to have become.

It was at this point that we realised we needed to broaden the scope of the new guidelines. We needed to involve more people, and go into a lot more depth in our exploration of the issues.

So, with a grant from Awards for All, we set about producing new guidelines that we hoped would justify our newly-found and rather baffling status in the field.

We worked with the Dementia Diarists Zoom group (a member of the DEEP network) to scope out the issues. They identified areas where people with dementia struggled to read, what helped and what hindered the process.

We then built an online survey to test out and explore the issues identified by the group. 123 people responded, 18% of whom were people with dementia. 82% of those people

"My saving grace is I cling to the thought that I have enjoyed the book and that is what matters most even if I cannot remember anything from it."

(Survey participant with dementia)

"Usually it's the construction of the sentences that I find hard to get to grips with."

(Survey participant with dementia)



with dementia said their dementia had affected their ability to read.

There are a range of different skills and abilities involved in reading. Dementia can have an impact on all of them:

- The ability to navigate within a document
- The ability to orient oneself within a document (where am I?)
- The ability to understand what is being read
- The ability to read quickly
- The ability to concentrate
- The ability to remember what has been read.

Our new guidelines then, focus on three distinct, though overlapping areas:

**Layout** – which has a significant impact on the ability to navigate, orient, read and understand. This includes consideration of:

- maintaining a visual hierarchy
- contrast
- the use of images
- spacing
- alignment
- the use (and abuse) of bullet points.

A bullet point list can be difficult to understand as it relies on the reader keeping a leading phrase in mind and connecting it to each of the bullet points.

Each bullet point **MUST** work with the leading phrase.

If you have a dog, make sure that it:

- has clean water to drink
- gets regular exercise
- doesn't eat too much curry before the dog show
- has a chance for a nap after a walk

**EXAMPLE**

**General writing style** – has a significant impact on both understanding and *enjoyment* of reading, something which often seems to be overlooked. In this section of the guidelines we look at issues like flow and 'tone'.

**Content** – a real 'nuts and bolts' deep-dive into the content of what we write, in order to make it as accessible as possible. In this section we look at issues like:

- What to consider before you start writing
- The role of individual words
- Sentence construction
- Paragraph construction.

One of the interesting findings from the survey was that while 65% of people with dementia struggle with

Can you read it out aloud in a single breath? If not, it's probably too long.

Think about breaking things down into shorter sentences, or even separate paragraphs.

❌ If you come over we can take a walk down the river and maybe go for a drink, then go for something to eat, but we should be careful to take the right clothes because there's some rain forecast for later in the day, which is pretty typical of this lousy summer.

Or

✅ If you come over we can take a walk down the river and maybe go for a drink. Then we can go for something to eat.

We should be careful to take the right clothes because there's some rain forecast for later in the day.

This is pretty typical of this lousy summer.

understanding of individual words, a larger number, 88% struggle with sentences.

This underlines the importance of remembering that we are writing for people with dementia, most of who will be coming to the page with a rich and varied lifetime of reading, many of whom can still understand and employ a large vocabulary. They are not children.

We have written these guidelines predominantly for those writing information that people need to know.

However, we hope that there will be food for thought in here for writers of all kinds of material.

Remember though, these are just guidelines, and you shouldn't cramp your style in the pursuit of accessibility... so long as your style is working for you and your readers of course.

The clearest, most accessible writing in the world is of no use if it is so dull that no one wants to read it.

The written word and the English language are things of beauty, and nothing in this guide should deter you from expressing yourself in whichever way you want.

However it is our hope that everyone will find something to take away that can make their writing more accessible, more useful and more

pleasurable for everyone to read.

One important thing that we learned from the survey was that there was very little difference between the types of challenges faced by people with dementia, and those without.

The same goes for solutions.

This leads us to be able to say with confidence that good writing for people with dementia is good writing for everyone. Everyone benefits.

So it doesn't matter who your audience is... we hope that these guidelines will help you to get your message across more clearly to all your readers.

You can download a full copy of the guidelines here:

<http://www.innovationsindementia.org.uk/wp-content/uploads/2023/01/accessible-writing-guide.pdf>

# Positive Spin: the transformative power of cycling for everyone

Positive Spin is a cycling community of people with dementia, their families and friends. **Clare Morris** describes how it developed, the benefits it brings, and the inspiring launch event held in London last autumn



Participants gather for the pre-ride pep talk. Below: Councillor Coleman, deputy leader of Hammersmith and Fulham borough council

*Cycling is the glue which holds my memories together. I believe that cycling – or any exercise – is key to living well with dementia. When I cycle I have a great sense of achievement and it keeps me independent and healthy.* Peter Berry

## Why cycle?

Cycling is fun, can boost mood and improve quality of life. Cycling is also an excellent form of exercise that benefits both physical and mental health. It can help maintain muscle strength and cardiovascular health. Cycling also stimulates the brain, promoting mental alertness and wellbeing.

When the idea of cycling and dementia was mooted back in 2015, it was met with scepticism, and this may well have been justified, given the symptoms of impulsivity, poor planning and judgement that can accompany dementia. But cycling relies on procedural memory, an aspect of memory that is often unaffected in people with cognitive impairment, despite some of the very disabling movement disorders that often coexist.

Pilot projects were initiated to explore the value and any contraindications to encouraging people with dementia to try cycling. A dementia practitioner worked alongside professional cycling instructors to ensure risk was managed effectively and comprehensively. Our expectations were exceeded in terms of impact and everyone benefitted, people with both mild and severe

cognitive impairment, family carers, and practitioners, who revised their view of whether cycling is a suitable activity for people living with dementia. For some families it became the highlight of their week, and years later precious memories remain.

## Dynamic risk assessment

National Standard Outcomes for teaching cycling break down the skills required for cycling into very small steps. This framework is used across the board in teaching cycling skills, for children in schools, for experienced cyclists seeking training on-road, and for people with special needs. The same framework has enabled people living with dementia to develop and/or regain cycling skills safely, mitigating symptoms such as impulsivity, visual perceptual disorders, and disorders of movement. ▷



*Clare Morris is the founder and CEO of For Brian CIC and the Positive Spin cycling community*





**Judy says: "I didn't think at 77 I would be cycling again. I was dropped off at my door after a fun day out."**

### ▷ What is Positive Spin?

The concept behind Positive Spin is the transformative power of cycling for everyone, whatever their age or abilities, bringing joy and improved quality of life to people with dementia, their family and their friends.

Positive Spin enables access to beautiful spaces around London and the UK. To date, events have been held in London in the Olympic Park, Morden Hall Park, and green spaces in Hammersmith & Fulham. The cycles provide structure, and people living with dementia and their support networks build ongoing relationships with the team of instructors and other participants. Everyone experiences new things, learns new skills, and has quality family time.

Positive Spin is not just about cycling, it seeks to create a supportive and enjoyable environment where everyone can have fun in a scenic place. Varied types of cycles offer different cycling experiences; these have facilitated people unable to stand unaided to cycle independently, and families to enjoy riding side by side where abilities are equalised. The joy is shared, with "dementia monsters" dismissed for the duration. Some family members will take

the opportunity to cycle alone, other might choose to go for a walk, taking precious, mindful time for themselves. It has been a privilege to share such groundbreaking achievements with people whose life experiences are so constricted by disability.

The vision for a UK wide cycling club is now within reach due to the exciting partnership between For Brian CIC and Bikeworks CIC. Positive Spin is a unique and growing community of people from across the UK, who share an interest in riding together.

Positive Spin events are co-produced with this community to fit individual and collective needs. Events can be initiated by just one family, or an established group; events are built around that family or group, and the rest of the community is invited. Riders can try the wide range of cycles, take part in group leisurely rides in parks, and talk mechanics with the instructors. Everyone has a story about cycling. There will be marshalled rides between two destinations, and the opportunity to try out more challenging routes if they wish.

There is a cycling experience for everybody. ▷

## Positive Spin: For Brian and Bikeworks working together

### For Brian CIC ([www.forbrian.co](http://www.forbrian.co))

The name For Brian, for brain health, plays on the anagram of brain/Brian. It represents the need to think creatively in addressing the enormous challenges people with dementia and their families face in accessing activities, as well as the challenges for organisations in obtaining the continuity of funding that is so crucial for families living with dementia. The focus has been on dementia inclusivity, both in the activities in the local community it delivers, and enabling access to other activities, broadening the circle of support, and enabling the development of new friendship groups.

For Brian is concerned with finding the smallest thing that makes a significant difference to individuals and a

cost-effective way to make it happen. Positive Spin has a promising role to play in tackling the health inequalities that persist for people with dementia, their families, friends, and support networks.

### Bikeworks ([www.bikeworks.org.uk](http://www.bikeworks.org.uk))

Bikeworks is a cycling-centric social enterprise that promotes inclusivity and wellbeing through cycling. The organisation contributes extensive experience in enabling people with a wide range of disabilities to cycle. Working together, For Brian and Bikeworks develop and deliver Positive Spin. They share the vision of enabling more people to benefit from cycling, promoting the cycle as a mobility aid and transport option for people with disability.





### ▷ The launch of Positive Spin

Positive Spin launched on 11 September 2023. More than thirty people cycled around Ravenscourt Park in Hammersmith, followed by a group ride to and around Bishops Park in Fulham, and for some the return trip. Peter Berry, For Brian's patron, is well known for his books and campaigning, and for riding a penny farthing. He was there with the penny farthing community who rallied around the event; the cavalcade was led by Peter, Les and Daisy on their penny farthings. Many heads were turned, smiles galore, and interaction with the wider community on route. Andy Slaughter MP, Cllrs Coleman and Souslous with responsibilities for health and wellbeing and social inclusion in Hammersmith and Fulham, participated and experienced the impact. Transport for London supported the initiative by participating in the risk assessments, engaging the four different building contractors along the route who ensured our safe passage through their areas, and riding with the cavalcade.

### Outcomes

*Social benefits:* The social benefits are exceptional. Participants engage and make relationships with the instructors and other participants. Everyone has a story about cycling and the range of different cycles is an intriguing topic, making Positive Spin an ideal trigger for reminiscence, whether a person cycles or not. Family and formal carers have been surprised by increased communication and expressions of joy, often learning new things about both the person and their abilities.

### *Progression through National Standard Cycling*

*Outcomes:* the clear structure and small steps for teaching cycling provide a particularly useful framework to assess risk, as well as facilitate learning for participants. For those with a diagnosis of dementia the process has a significant role in validating existing skills, acquiring new ones, and developing confidence.

*Locus of control:* For those people with a diagnosis of dementia, a sense of freedom to move around independently and under their own control has a huge



**Dione, patron of For Brian CIC: "How the heck am I going to get up on to this saddle?"**

impact. The opportunity for carers to engage mindfully in cycling without worrying about their relative, and sharing a joyful experience on equal terms, contributes to the therapeutic value of this project.

*Mobility and cognition:* There is some evidence for improved cognition. Language and communication flow, participants remember and look forward to the sessions. Visual perceptual difficulties are very disabling for some people with dementia. To date this has not been a barrier to balance or navigation, and confidence soars by being able to cycle independently around the park. Dyspraxia is another rarely discussed symptom which causes difficulties for all activities of daily living. Very experienced cyclists have found their symptoms do not affect them whilst cycling, for others placing the feet on the pedals and passive cycling has led to developing the ability to cycle independently. Osteoporosis, chronic pain, reduced mobility when walking, stroke, wheelchair dependence, have not been a barrier to engaging in cycling. Quite the contrary, pain free, independent mobility has been facilitated.

Disorientation is common in dementia, and is associated with considerable anxiety, for the individual and caregivers. Cycling independently around a large space, ▷

▷ returning to base, and cycling in a group around the park, or group riding on quiet streets has been possible for many participants who experience disorientation and never go out alone. Trying out different cycles has led to greater confidence and the ability to generalise the skill and initiate pedalling on a bicycle. Due to unaffected procedural memory, skills are retained from week to week, or have been regained quickly.

*Increased use of cycling on road/transportation:* All ability cycling hubs help increase the riding abilities of many of the participants, from carers learning to cycle for the first time to those with dementia learning to ride on road. The Positive Spin cycling community will enable exploration of places of interest, but also enable dementia inclusive journeys by cycle.

### Join the Positive Spin community

The community (people with dementia, their families, formal carers and practitioners) can join Bikeworks' weekly all ability hubs in various London parks, as well as participating in Positive Spin's unique riding events. Taking part is to experience something special, to see people with disabilities functioning at their best, challenging beliefs about capacity and wellbeing. Several members of Positive Spin already access the hub in north Kensington regularly, and are now co-producing opportunities to cycle in different parts of London, and ultimately the UK, including journeys on road. You do not need to be an experienced cyclist, nor able to ride a standard bicycle, or even own a bike. Bikeworks provides all the necessary equipment, a suitable cycle (various models of trikes, tandems and side by side cycles) to enable everyone to participate. Whether you are living with dementia, a family member, or a friend, we welcome you to join us in our cycling outings and become part of our supportive and caring community. The next event is 3rd May 2024 in west London. Route to be confirmed but it will set off from Little Wormwood Scrubs in Dalgarno Gardens. Pre-booking is essential, and any barriers to taking part are addressed, such as travelling expenses (up to a point!)

### Get involved

If you are interested in supporting this initiative, there are many ways you can get involved. You could volunteer to help during our cycling outings, donate cycling equipment, or sponsor a cycling event. Your support is crucial in helping us continue our work and make a difference in the lives of people with dementia.

For Brian is actively fundraising to bring the joy, and benefits of Positive Spin to more people, fostering social connections for people living with dementia, their families, and their friends. Join us in making a positive difference in the lives of people with dementia. Email: [clare@forbrian.co](mailto:clare@forbrian.co)

### Testimonials:

Patrick: *"it reminded me of my childhood, cycling with my dad and being back home in Barbados. I always wanted to drive a car, but my bike was my car. It brought back all those memories. It's amazing to have the opportunity to cycle again, and with everyone else you feel safe and secure"*

Molly: *"Wonderful. I never knew this place. I didn't think I wanted to get on, and now I don't want to get off!"*

Donald's wife and primary carer, Pat: *"He really enjoyed the cycle ride. Cycling is a wonderful opportunity to meet new people. And gets us outside. And I get to ride and take a break for myself"*

Donald: *"The cycling keeps me fit, I am 90 you know. It's a great way to travel, he does all the work!"*

Jim Blakemore CEO Bikeworks: *"Positive Spin engages and activates those people that on many occasions wouldn't have access in the community to cycle on the road. For that, it's not rocket science but it is so so important and we should be doing it every day"*

Dione: *I am having a wonderful day by the Thames, wonderful. Thank you Clare, For Brian and Bikeworks"*

Judy came along to watch the spectacle, but could not resist joining in for the day. Initially resistant, *"My cycling days are over"*, she is now convinced about the benefits for mobility: *"This is just the way to see the Bridge"*.

Andy Slaughter MP: *"Fantastic, and exhausting!"*

For Brian's patron Peter Berry, his wife Teresa and Deb Bunt (co author of *Slow Puncture*) joined us. Regular cyclists in Suffolk, they had no experience of cycling in London: *"Brilliant, and I have never cycled around London on a penny farthing before. So this is a first for me. Absolutely wonderful. Very well organised. And a pleasurable place to be."*

Teresa *"It was a fabulous day, where I could forget about dementia, have fun, and make memories"*

Deb Bunt: *"It was a great day for all. I was particularly moved by the networking that went on prior to the event. This resulted in Peter being loaned a penny farthing AND being joined by two other penny farthingists. The joyful expressions on the faces of all involved, plus the support of the local community, elevated the ride into an event that encapsulated the ethos and principles of For Brian wonderfully"*.

Jacqui Nunn, Rare Dementia Support: *"Great pictures. Such a special event."*

### Videos

The history of Positive Spin <https://youtu.be/cO8N00IqB-w?si=cyJ7OeMhYeronErD>

Positive Spin Launch: <https://youtu.be/Alk8EINB9nQ?si=XIaHkax9xkphHIV4>

The original pilot was a day trip from Finsbury Park to Springfield Park for a picnic involving 12 people with dementia and their families: <https://www.youtube.com/watch?v=hxRSqBmJWaqn>

### Positive spin in the media:

Morris C (2017) Positive spin: the benefits cycling brings. *Journal of Dementia Care* 25(2) 14-15

<https://wcgl.london/casestudy/positive-spin-cycling-1>

<https://www.cycleboom.org/positive-spin>

<https://www.localdementiaguide.co.uk/positive-spin-brings-dementia-friendly-cycling-lambeth-hackney/>

<https://bikebiz.com/project-getting-people-with-dementia-cycling-is-hailed-a-success/>



# Winter Warmers: a project to address fuel poverty

Members of Trent Dementia ran a collaborative project to trial, source and provide items to help members and their families keep warm through the winter months.

**Jane Rowley** describes how the project was planned and implemented

Trent Dementia is a small charity based in Nottingham that provides support to people living with a diagnosis of dementia and family caregivers across the East Midlands. We have a small team of three part-time staff and a dedicated group of trustees. Our focus is on empowerment, co-production and collaboration with people affected by dementia. All the projects in our Empowerment Programme are developed through co-production with those directly affected by dementia. We refer to the people we support as members and consider them all as members of our team. We offer scaffolding and support to enable members to establish and facilitate their own peer groups, walking groups, drop-in sessions, craft sessions (both online and face to face), in addition to outings throughout the year. Unique to the members' activities is the way they contribute to planning, organisation and running of Trent Dementia's annual conference. Members decide upon the theme or the conference message and design its programme, also choosing whom to invite to 'hear' their message.



**Following trials, popular items were radiator foil, draught excluder tape, LED lightbulbs, fluffy gowns, blankets, and gloves, hats, and scarves in different styles and materials according to individual needs**

## Key points

- A collaborative project to develop winter warmer packs for families affected by dementia.
- Product testing by members to find the most helpful items
- Bespoke packs to meet individual needs
- Addressing fuel poverty by helping people to insulate their homes and keep warm when out and about
- Starting a conversation about other ways to stay warm.

Members have told us throughout the year of their angst about the rising costs of utility bills and worry about how they will keep warm through the winter months. They have told us about how people ride for hours on buses and use cafes and libraries to keep warm. We know that people often only heat one room at home and that they worry constantly about their bills or 'topping up the meter'.

We successfully applied for a grant from The National Grids Community Matters Fund to develop winter warmer packs. Our intention was to make these packs bespoke, so that they met real people's individual needs, rather than just supplying a kit of standard items. The first step was to discuss with our members about possible content for bespoke packs to meet the individual needs of our members. The grant aimed to help people in the coldest months, so we had three months to agree on the contents of the packs, buy the items and distribute them to members. Members were asked to consider what type of items they might find useful and, concurrently, staff members researched various options.

We first purchased a range of samples for home insulation items, for example radiator foil and draught excluder tape, bowl warmers, warm hats, diverse types of scarves and gloves. We invited some members to lunch and distributed these items for product testing. After a month of use they advised us which items were most helpful, and which were more difficult to use or were not

*Dr Jane Rowley is Empowerment Programme Manager, Trent Dementia*





### After a lot of testing and discussion, the group sourced a wide variety of useful items for the packs

helpful at all. For example, they told us the design of the bowl warmers (a quilted pad to hold bowls and maintain heat) was not popular and the radiator foil, although popular, was difficult to install. They told us that the neck warmer they trialed was too heavy, especially if the person was frail. So, we went away and investigated assorted designs for the bowl warmers and different tapes to install the foil pads behind radiators to make them easier to use.

### A simple survey

We then developed three categories of items with the members involved in product testing: 'Energy Savers', 'Out and About' and 'Keeping Toasty'. We developed a simple survey and distributed hard copies of these across our membership, with them nominating one person from each peer support group to collate and return the survey forms. This is a key learning point because, even when people are able to use online surveys, we know they prefer hard copies, so we distribute these and complete the online survey ourselves from their data to provide an analysis of what people have asked for. We asked people what they would find useful. However, we also indicated that we could not guarantee they would receive all of the items requested as we had to be guided by overall demand and the budget available.

Once we had a clear picture of the most popular items, we began to purchase them by bulk buying to gain the best value. Items purchased included draught excluders, draught excluder tape, radiator foil, LED lightbulbs, fluffy gowns, and blankets. In addition, we purchased distinct types of gloves, hats, and scarves. People with differing mobility often found lighter fleece scarves easier to use, whereas family carers supporting people with dementia found neck warmers to be more helpful as they are easy to help someone wear and do not easily drop off. We also asked people what other items they might find useful, and these included slow cookers, electric hot water bottles and hand warmers.

Our distribution started in early February 2024 and in March we will run a winter warmers workshop to seek feedback on what members have found useful and what



they think might help in future winters. We plan to create a resource of top tips for staying warm as well as their review of the items used this winter to distribute throughout the year. We are also partnering with another charity who provide energy saving advice to offer a further workshop.

### Direct consultation is vital

We understand that it is vitally important to consult directly with people affected by dementia. This level of collaboration can take time and be resource intensive. It would have been easier simply to send everyone a hat, scarf, and gloves from an online retailer, but, if the products are unsuitable or not used, then we have wasted money and potentially frustrated someone already facing multiple challenges. Creating bespoke winter warmer packs for people takes time. The logistics of purchasing and storage for hundreds of items has been a challenge, for example simply storing items awaiting distribution. However, we know that when each person receives their pack, bespoke for them, whether it's a soft scarf and neck warmer, thin gloves or insulated ones or bed socks in a colour they like, they will know that we have listened to them. Hopefully they will feel warmer too.

Trent Dementia is a charity established in 2004. Central to our work is collaboration with people affected by dementia.  
[www.trentdementia.org.uk](http://www.trentdementia.org.uk) Tel: 0115 74 84220

# Music in Mind: celebrating ten years of growth

**Robyn Dowlen** and colleagues describe the partnership between Manchester Camerata's *Music in Mind* programme for people living with dementia and the University of Manchester. Over ten years it has grown to encompass live improvised music-making sessions, interdisciplinary research and training for care staff

*Music in Mind makes you stand taller; makes you feel prouder. It feels good to have a bit of attention, you know, rather than saying 'Oh he's over there, he's got dementia, leave him to it'. (Keith, person living with dementia)*

*It's not copying but responding, which shows a sense of independence and musicality and courage and imagination. (Music in Mind practitioner)*

This article celebrates the ongoing partnership between Manchester Camerata's *Music in Mind* – a 20-week, improvised, live, music-making programme for people living with dementia – and a variety of interdisciplinary research, teaching, and practice staff at the University of Manchester. Since starting in 2012, it is a partnership that continues to grow and flourish, and has led to a better understanding about the 'in the moment' experiences, creativity and well-being of people living with dementia when they engage with the programme. It has also illuminated the wider 'ripple effects', or the continuing or spreading action outwards from the programme, for people living with dementia, care staff, family members, musicians, members of the public, and researchers who have experienced *Music in Mind*. For us, it has been, and still is, an unfolding performance and a story of discovery informed by sensory connections.

## Why is music important?

It might be an obvious thing to say, but creating sounds and music together is a different type of communication to that which is led by word-finding and/or remembering/recalling the symbolic meaning of words in the correct

## Summary

There is growing recognition of the positive role that music can play in the lives of people living with dementia. Making music together with others, whether this is with family members or those supporting from a professional capacity, has been shown to create moments of connection, to enable creative self-expression, and facilitate feelings of joy. This article celebrates the ongoing partnership between Manchester Camerata's '*Music in Mind*' – a 20-week, improvised, live, music-making programme for people living with dementia – and a variety of interdisciplinary research, teaching, and practice staff at the University of Manchester. We explore the components of the programme and the expertise of Manchester Camerata and their associated musicians and music therapists, as well as sharing how the programme has impacted on the lives of people with dementia who have taken part, and the ripple effects of music into their everyday lives.

sequence and in the correct order. Making music by tapping out a rhythm with your fingers or feet, clapping your hands together, shaking a tambourine, or using your vocal cords to hum along to a tune, is something we can all do, in some form, no matter what our age or verbal communication abilities. As an article by Pia Kontos and her colleagues in 2017 suggests, for people living with

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**Music in Mind sessions in progress: a collaborative approach with every contribution viewed as valid, and each person viewed as a musician rather than separated by role or diagnosis. Photos above and on the following pages are shared with the permission of Manchester Camerata**

### What is *Music in Mind*?

First piloted in Greater Manchester in 2012 in collaboration with music therapist John Habron-James and Manchester Camerata's then Head of Community/Outreach, Nick Ponsillo, *Music in Mind* is a 20-week, improvised, live, music-making programme for people living with dementia and their family carers, or those supporting them in a social or professional capacity. The *Music in Mind* programme can take place in a care home or community setting, such as an accessible community hall, and can accommodate up to 30 participants. Each session is co-facilitated by a certified music therapist and a Manchester Camerata orchestral musician who has had additional training in working with people living with dementia. This principle of co-facilitation and co-creation is at the heart of the *Music in Mind* approach, so that the music-making space is defined by creativity rather than by specific therapeutic outcomes alone.

Each *Music in Mind* session follows the same structure. The room, or space within a room which is intended for the programme, is set up so that a circle of chairs is placed around a central table which contains an array of handheld percussion instruments, such as small shakers, tambourines, chime bars or bells, and so on. *Music in Mind* practitioners position themselves within the circle of chairs rather than in a position that would suggest it is a traditional

performance which separates 'audience' and 'performer'. This in itself is a non-verbal indication of a collaborative music-making approach, with every contribution in the circle viewed as valid, and each person viewed as a musician rather than separated by role or diagnosis. People living with dementia often use the centre, or outskirts of the circle, as spaces for dance and performance.

The practitioners typically start the *Music in Mind* sessions with a 'Welcome Song'. This song is kept consistent across the duration of the programme, as a non-verbal signal that the music-making is beginning and to acknowledge each group member's presence.

The 'Welcome Song' is followed by the creative music-making part of the session, which provides an extended time usually lasting between 30 and 60 minutes for people living with dementia and those involved in the group to explore the different percussion instruments on offer to

dementia, taking part in music-making is an embodied action which allows a person to feel a sense of 'connectedness' and 'presence' due to the interaction with other people's musical bodies and with the surrounding sensory world. Appreciating these processes is important as the creative and expressive sounds that emerge from such momentary connections and interactions deserve to be celebrated and seen as a sense of achievement for all concerned. However, in this age of evidence-based practice, how to position and authentically represent such 'in the moment' musical creativity from people living with dementia and then somehow 'measure' the longer-term benefits for those taking part, especially when the event itself may no longer be remembered, is a challenge. Nevertheless, it is a challenge that has been taken up by Manchester Camerata, their *Music in Mind* programme and staff at the University of Manchester, as we will now further outline.





Watch our short, award-winning film 'Untold: Keith' - <https://www.youtube.com/watch?v=iTLalcliecQ&t=1s>. Read about Music in Mind Remote Ltd, Manchester Camerata's new enterprise helping care staff to use music to benefit the people they look after: <https://manchestercamerata.co.uk/music-in-mind-remote-ltd/> Read more about Manchester Camerata's Music and Dementia work: <https://manchestercamerata.co.uk/community/music-and-dementia/>

### Key points

- Making music with other people can facilitate feelings of connection for people with dementia.
- Improvised music making presents opportunities for creative self-expression 'in the moment'
- Manchester Camerata's Music in Mind programme uses improvised music making to support the wellbeing, quality of life, and agency of people with dementia
- The research partnership between Manchester Camerata and the University of Manchester has allowed the programme to develop over time and has nurtured new researchers entering the field.
- 'In the moment' musical experiences can enable a sense of joy, fun, and hope for both people living with dementia and their family members.

them, creating new music through supported improvisation and musical games, as well as singing and improvising around familiar music. Sessions are ended by the practitioners through a 'Goodbye Song', which is again consistent across the duration of the programme. Group members are encouraged to attend each week to ensure space for musical exposure and opportunities to develop connections with other group members. The principles of *Music in Mind* afford a context whereby the person living with dementia is given choice and the opportunity to be creative within the sessions. Musical improvisations, using tuned and un-tuned percussion instruments, as well as the person's own vocalizations or physical movements and gestures, are supported by the session practitioners. This

enables the person living with dementia to situate themselves in a supportive music-making environment where their musical contributions and whole being are heard, responded to, and valued.

As well as *Music in Mind* sessions for those living in care homes, Manchester Camerata now runs free community 'Music Cafés' across Greater Manchester and the North West of England for people whose lives are directly and indirectly affected by dementia, such as home carers or close family members. Its flagship Music Café is at the orchestra's base in the Monastery at Gorton, a now deconsecrated Grade 2-listed building, which serves as a local landmark to many of the participants who grew up in the nearby area. The Monastery is shown as a backdrop in most of the photographs in this article. Like *Music in Mind*, these Music Cafés generate new music at every session, using musical improvisation techniques to help people connect with others in similar situations to them. The sessions also aim to reduce loneliness and isolation for family members, which can often be brought about by the everyday demands of caring for people living with dementia at home.

So far, the *Music in Mind* programme has reached over 11,000 people, mainly living in the North West of England, and the programme is also developing links overseas in Japan, Taiwan and Sweden, with hopes for places further afield. *Music in Mind* has also been the subject of a BBC One 'We Are England' documentary, 'Music, Dementia and Us', which was first shown in November 2022 - and generated both local and national interest in the *Music in Mind* approach. Some of the resources available about *Music in Mind* are shown in the box above.

### Our research partnership

Manchester Camerata has an ongoing commitment to evidencing the impact of *Music in Mind* to improve their practices and develop the programme over time. In 2012, they actively sought the involvement of social researchers



in dementia care at the University of Manchester to help them answer questions that had arisen from their practice, and they have remained the drivers of many research studies, designs, and questions over the years. The University of Manchester also has an ongoing commitment to working with industry, which has been evidenced through the forming of *Creative Manchester*, a university-wide interdisciplinary platform focussed on supporting research with the creative and cultural sectors.

Over the duration of collaboration between Manchester Camerata/*Music in Mind* and the University of Manchester, we have undertaken and developed several research methods and approaches to practice which have been embedded into Manchester Camerata's work with people living with dementia. Facilitating and actively participating in academic research is a vital part of *Music in Mind*. It allows us to stay at the cutting edge of music and therapy-based programming aimed at supporting people with dementia living at home, or in other community-based settings, such as a care home. For example, over the last 10 years, two competitively won PhD studentships involving Manchester Camerata/*Music in Mind* have been awarded by the Economic and Social Research Council (ESRC) as part of its CASE programme available through the ESRC North West Social Science Doctoral Training Partnership (NWSSDTP). John Keady at the University of Manchester has been the main supervisor of the two awarded ESRC CASE PhD studentships, but it is very much an interdisciplinary and team approach where the PhD students (one completed, one in progress) use innovative and creative research methods to support their studies..

Across our programme of work together, we have sought to capture data that centres the experiences of people living with dementia as they engage in creative music-making. This is because in the broader music and dementia literature, the voices of people living with dementia are not frequently drawn upon in shaping, developing, and understanding musical experiences. To further showcase the specific ways in which improvised, live, music-making is important for this sense of connection, we will briefly highlight three examples from our work together.

### Connections 'in the moment'

This first example is taken from Robyn Dowlen's ESRC CASE PhD studentship (2015-2019), with Manchester Camerata as the industry partner. The research followed a community-based *Music in Mind* group and used a participatory case study methodology (Williams & Keady 2021) alongside video-based methods, such as video observation and video-elicitation interviews, to explore the creative and 'in the moment' experiences of people living with dementia who were taking part. In the research design, people living with dementia were positioned as an individual case study to allow a detailed picture of the person's musical contribution, abilities and preferences for certain rhythms, harmonies, and songs to be mapped.

Similarly, the role that imagination and playfulness had in the creative, improvisatory process was also documented, as well as how this moved and changed over time. The sense of connection felt and experienced by people living with dementia in this community-based *Music in Mind* programme was palpable. A sense of belonging was also built over the duration of the programme, with group members greeting each other with hugs or shaking hands, bringing and sharing food, such as apple cakes and jollof rice, and extending invitations to meet outside of the group to experience gallery exhibitions or church activities.

The deep sense of connection between the group members was driven by their 'in the moment' musical experiences which engendered a sense of joy, fun, and hope for both people living with dementia and their family members. Everyone who took part held a sense of anticipation to attend the sessions each week, and the group developed a shared musical repertoire that held emotional significance between them. This was to the extent that tears were shed by members of the group, and by Robyn herself, during the last session.

At the end of Robyn's PhD studentship, Professor Gabe Mythen, Director of the ESRC NWSSDTP, had this to say about our partnership and Robyn's completed study:

*CASE collaborations such as this demonstrate the clear value of social science research undertaken in partnership with external agencies and are a testament to both the dedication of the researcher and the expertise and efforts*



of colleagues at the partner agency, Manchester Camerata. This innovative and highly impactful project involved exploring the embodied and sensory experiences of people living with dementia. The findings serve to highlight the creativity and musical abilities of people living with dementia and illustrate the value of music in connecting people living with dementia to individuals and meaningful communities of belonging.

A more detailed overview of Robyn's PhD work, and the methods used during its conduct, can be found in an academic paper published in the journal *Ageing & Society* (Dowlen *et al* 2021), as well as in the PhD thesis itself (Dowlen 2019).

### Training for staff in care homes

The global Covid-19 pandemic resulted in *Music in Mind* having to temporarily cease live, in-person music-making in care homes. The consequences of the pandemic propelled Camerata's vision to train care home staff in the *Music in Mind* approach so that music-making activities could be more widely engaged with outside of formal live sessions delivered by *Music in Mind* practitioners. Manchester Camerata wanted to provide a programme that developed care staff's confidence to use music, as well as to provide them with meaningful training that could support their own personal development and wellbeing. Out of these circumstances, *Music in Mind Training* was born. Manchester Camerata then collaborated with colleagues at the University of Manchester to secure funding through the NIHR School for Social Care Research to evaluate the training programme's impacts on carer wellbeing and understanding of music-making practices.

This study started in the summer of 2022 and will end early in 2024. However, so far (October 2023), we have observed the ways in which training, led by professional musicians and music therapists at Manchester Camerata, can support person-centred dementia care, establish and embed a creative and meaningful programme of music-making into a care home, and develop care staff confidence. In particular, the training has facilitated the development of individual 'musical profiles' for residents which lists preferred musical styles, songs of significance, and their interactions with musical instruments. Care home staff have discussed the 'happy atmosphere' that is created through music-making and show a real enthusiasm for sustaining music-making opportunities in the long term for their residents.

### Building musical communities

Grounded in the work of *Music in Mind Training*, Manchester Camerata have developed a focus on sustaining music-making opportunities in the community through a new role of 'Music Champions'. In 2022, following a grant from UK Research and Innovation [UKRI] as part of their Design for Ageing Healthy Ageing Challenge, Manchester Camerata combined forces with the University of Manchester to start a new company, *Music in Mind Remote Ltd*, which aims to train a network of Music Champions to use *Music in Mind*-based skills to help improve the lives of those living with dementia.

Other local organisations advising on the project are the Greater Manchester Care Record, Greater Manchester Combined Authority and Manchester City Council as well

as Dementia United and Nordoff & Robbins. Warren Heppollette, Executive Lead for Strategy and System Development for Greater Manchester Health and Social Care Partnership, has said of this work:

*Music in Mind Remote Ltd is typical of the ingenuity and 'can-do' spirit in Greater Manchester, and I am delighted that the Greater Manchester Health and Social Care Partnership will be a partner in this new and innovative product.*

At present, nine care homes across Greater Manchester and five community dementia groups are taking part in the Music Champions scheme. As well as being provided with a box of instruments, over 25 carers and volunteers are being trained in core *Music in Mind* values and techniques with the aim of independently running their own *Music in Mind* and Music Cafe groups. This is being achieved by delivering bespoke, online resources and instructions put together by Manchester Camerata's *Music in Mind* musicians and therapists. This work continues until spring 2024 and further information will be shared on its completion. In the meantime, it is hoped that this work will provide a sustainable funding model to enable Manchester Camerata, as a registered charity, to continue to provide work for its musicians and music therapists to extend its reach in the field of music and dementia across the UK and internationally.

### Our future ambitions together

*Music in Mind* is an ambitious programme which continues to break new ground in the music and dementia space. Our collaborative research relationship has allowed for the development of creative research methods which centre the voices and lived experiences of people living with dementia. Looking back over the last ten years or so has allowed us to reflect on the strengths of our partnership, and to identify areas of practice that need to be explored further. At the University of Manchester, we are continuing to build a network of researchers from different disciplines and backgrounds who are interested in exploring the role and meaning of music in the lives of people living with dementia and developing new methods for capturing these experiences. This partnership could not happen without the vision of the Chief Executive Officer of Manchester Camerata, Bob Riley, and the dedication of Manchester Camerata staff and musicians to evidencing, reflecting, and developing their *Music in Mind* programme to meet the musical and creative needs of people living with dementia.

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# Using science illustration to aid co-production in developing a specialist dementia care role in homecare

In this first of two articles on their social research study, **Christina Newton** and colleagues describe a co-production workshop where all involved—people living with dementia, family carers, homecare managers, workers from services and those who plan and co-ordinate homecare—contributed to build up a picture of a specialist dementia care role in homecare

Many people living with dementia prefer to continue living at home for as long as possible and many will need the support of homecare professionals (Lakey *et al* 2012). This also enables people to maintain comfort and independence at home, and contact with their community. However, workforce challenges around recruitment and retention, training and development, career progression and low pay, can make finding good quality homecare difficult.

In this study we aimed to define, refine and evolve the role of Dementia Champions in Homecare, as a potential solution to tackle some of the sector's challenges.

The study was funded by the National Institute for Health and Care Research School for Social Care Research (NIHR SSCR) and carried out by four social care researchers from Kings College London, supported by two advisory groups and partners.

In this work, we use the term 'Dementia Champion' to describe a specialist dementia staff role. Of course, the term 'Dementia Champion' can mean different things to different people. The original study proposal referred to this role as *a Dementia Champion, continuing on from other research programmes in hospitals and care homes that had used the same term*, and so it was set. However, Alzheimer's Society had its own voluntary Dementia Friends and Champion roles at the time (now re-branded as 'Dementia Ambassadors') and others used the term too, in different ways. Terminology was a challenge we had to continually consider and overcome when communicating with different people and this was an important lesson to learn. We discussed the name of the role with our co-production workshop members (discussed below) but no agreement was reached so we stuck with Dementia Champions. We hope to continue developing this work and find a suitable name for the role through further co-production in a meaningful fashion.

In the context of health and social care the Dementia Champion role has already been tried with varying degrees of success. However, it isn't widely used in a formal or structured way in homecare. We really wanted to find out whether it is something that people affected by dementia would value and benefit from, as well as helping to support aspirational care workers who want to deliver good quality dementia care with opportunities for career development. It must also be a realistic option for home care providers, considering the pressures that so many face.

## Summary

Many people living with dementia prefer to continue living at home for as long as possible often with the support of homecare professionals. Though sometimes seen in healthcare and other social care environments, the role of a Dementia Champion in homecare is not well understood.

We held a co-production workshop, and invited a Science Illustrator, aiming to create a model of what a Dementia Champion in homecare should look like, from the perspectives of people living with dementia, family carers and people working in the home care sector. As the illustrator drew their discussions in the group they could immediately see what was drawn on a big screen and question anything that didn't accurately reflect what they had said.

Activities in the session stimulated a great deal of discussion and feedback at the end of the session was very positive. Many people felt that it had been a vibrant and lively activity, fuelling participation, and the science illustrator's presence had been a novel way to engage people and have their voices heard.

This workshop was phase 3 of a study that also involved interviews with people working in homecare (with and without dementia champions in their organisations, in both health and social care settings) as well as people affected by dementia.

At a pivotal stage of the 18-month study, taking what we'd learned at earlier phases about Dementia Champion roles already existing in health and social care settings, we held a co-production workshop. We wanted to see whether what we'd learned about the role in those environments could be brought to home care. ▷

*Christina Newton is Research Involvement Lead for the Dementia Champions in Homecare Study, Dr Monica Leverton is Research Fellow and Project Lead, Dr Kritika Samsi is Senior Research Fellow and Dr Tiffeny James is Research Associate, all at National Institute for Health Care Research (NIHR), Health & Social Care Workforce Research Unit, King's College London.*





**Above: Some of the group consider important values and skills. Right: The group's thoughts on what a Dementia Champion in Homecare might be.**

▷ The study was shaped by previous work with homecare staff who discussed wanting to develop and specialise in dementia care and to progress in their career (Leverton *et al* 2021). We aimed to address their reports of feeling 'unheard' throughout this study and the inclusion of a Science Illustrator in the workshop meant that their perspectives could inform the Dementia Champion in Homecare role, alongside people affected by dementia, in an accessible format.

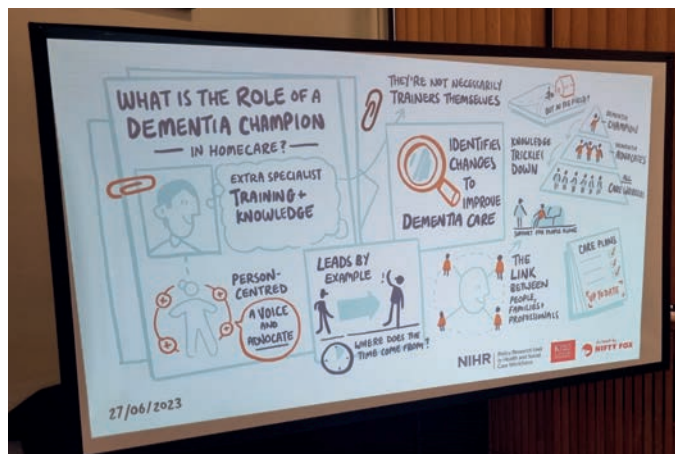
### **Enabling people affected by dementia to be heard: a co-production workshop**

While people living with dementia are sometimes excluded from research, we found that thinking creatively and using visual methods (in addition to other important practical considerations) was an effective way to plan, run, and learn from *everyone* in a co-production workshop. Illustration was a key part of this, and an exciting new way for us all to support inclusivity and engagement with research.

In attendance there were people living with dementia, family carers, homecare managers and workers from services with and without Dementia Champions and others involved in planning and co-ordinating homecare.

## **Key points**

- In this study with four phases, we aimed to define, refine, and evolve the role of Dementia Champions in Homecare.
- Here we discuss phase three of the study where we held a co-production workshop with a science illustrator who 'drew' the group's discussions.
- We looked at tasks and responsibilities as well as values and skills for the Dementia Champion in Homecare role.
- The science illustrator produced an image of what a Dementia Champion in Homecare looks like from the perspective of people affected by dementia, as well as that of people with various roles, working in homecare.
- People who attended the workshop and engaged with this novel approach to co-production reported that they found it a very positive experience.



Importantly, they were all working in or receiving home care services. The workshop was facilitated by the research team, but discussions were very much driven by the workshop members.

It was of course crucial that we supported everyone to attend. There was a lot of practical support. Some just didn't feel terribly confident when travelling, others needed help with travel arrangements or extra support because of mobility issues. People were called the day before to ensure that they were still happy to attend and that it was appropriate and safe for them to do so.

### **Science Illustration—visually scribing the discussion**

Instead of taking written notes or minutes, we invited a Science Illustrator who 'visually scribed' the discussion. He produced a number of drawings that reflected the group's discussions on various topics and they were projected onto a large screen in real time for all to see. Ultimately, from these discussions and drawings an illustrated model of a Dementia Champion in Homecare would be produced.

At the start of the workshop, we introduced the illustrator and explained why he was with us. We asked the





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group to engage with the illustration and they were asked:

*If you feel what is drawn doesn't represent what you've said, in the way that you meant it, please tell us. This will help to make sure that everyone's views are captured and the illustrator will go away and create a model of what you have decided a Dementia Champion should look like.*

We explained that the image would be shared after the workshop.

This vibrant and lively activity meant that members were able to follow the discussion by watching the development of the illustration on the screen and they could feed back if any elements were missing or didn't accurately reflect their perspective. The illustrator was able to change or revise these elements on the spot. We provided everyone with a yellow 'I want to speak' card to encourage participation in a respectful environment.

One example of a group activity in the workshop involved taking potential Roles and Responsibilities of a Dementia Champion, identified in an earlier phase of the study. We put them in a grid on large A3 laminated sheets and asked people to work in pairs to choose five things on the grid that they felt were important for the role and circle them in pen. The lamination enabled people to visualise their thoughts and erase things if they changed their mind throughout their discussion, and afterwards the grid was shown on the screen and the group's choices were added in real time.

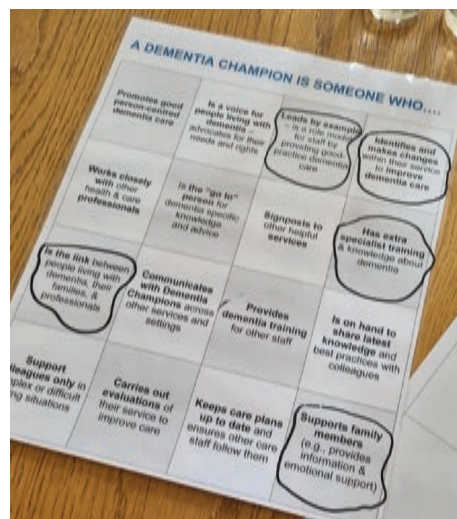
As well as defining the Roles and Responsibilities, the workshop focused on best practices for recruiting the 'right' people to become a Dementia Champion, including motivations and skills, the training and support required to implement and sustain the role, and the practical considerations of the role including scheduling, management and pay.

After the workshop, the resultant illustrated model of a Dementia Champion in Homecare (see previous page) was sent to all workshop members for their feedback and reflections before being finalised. In the next and final phase of the study it was used to facilitate qualitative interviews with homecare staff and people affected by dementia.

The whole workshop was very visual and interactive. It encouraged people to discuss the group's findings because they were immediately accessible to everyone. Some people find it is easier to work with a visual representation of something rather than written or spoken information.

Involving an Illustrator in a co-production workshop was a new experience for all involved, including the research team. We took away considerable knowledge of the practical and ethical considerations important for involving people affected by dementia in co-production research. We categorised these into five key learnings:

- 1) Building rapport and engagement ahead of time;
- 2) Accessibility;
- 3) Creating a comfortable and nurturing environment;



**In this activity, people worked in pairs choosing five tasks and responsibilities that they felt were important for the role.**

- 4) Workshop tasks and activities;
- 5) The use of visuals to increase inclusivity and engagement.

### Feedback

We asked workshop members for honest feedback to allow us to improve on anything that didn't quite work. Feeding back during and at the end of the session, when asked about the impact of the science illustration, all members responded positively. Some reported it as an 'enjoyable' and 'novel' experience, that 'fuelled participation' by seeing the discussion 'come to life'. For people living with dementia, the live scribe made the discussion 'easy to follow'. We had also projected interactive tasks and activities onto a large screen which was described in feedback as 'a huge improvement on the flip chart that was a lot easier to follow'.

Reflecting on the success of the workshop, one person living with dementia said 'and to think, there are people who still believe people like me can't be part of these things'.

It should be noted that we only invited people living with dementia who had capacity to agree to be involved and who were able to travel to the workshop. Although innovative methods such as science illustration may be suitable for people with more severe symptoms of dementia, further research is needed to explore this. We will look more closely at the implications for practice and the opportunities and challenges for embedding, supporting and developing this role in homecare in the next issue of *JDC* (May/June 2024).

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b) This study/project is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

### Acknowledgements

a) This article summarises independent research funded by the National Institute for Health and Care Research School for Social Care Research. The views expressed are those of the author(s) and not necessarily those of the NIHR SSCR, the NIHR or the Department of Health and Social Care.

# Access to dementia health care by ethnic elders in Leicester

It is commonly accepted that access to dementia care services by minority ethnic populations in the UK is poor. In Leicester however, ethnic populations are significant and growing, and studies show that clinical services see the same levels of access as for other ethnic groups, as **Hari Subramaniam** reports

It is well established that in most high-income countries including the UK, ethnic-minority communities have different dementia aetiologies, prognosis, treatment, patterns of help-seeking and care practices; further they experience marginalization and systemic racism (Babulal *et al* 2019; Low *et al* 2011; Mukadam, Cooper & Livingston 2013; Menezes, 2016; Farina *et al* 2020; Knepper & McLeod 2018). Collectively, these contribute to multiple systemic disadvantages often manifesting clinically as reduced access by these ethnic elders to health services.

In the UK, dementia in people from ethnic minority backgrounds is expected to rise by nearly 600 per cent in just 40 years, doubling from current levels to 50,000 by 2026 and to over 172,000 by 2051 (Runnymede Trust 2018; Livesey 2010; All party Parliamentary Group on Dementia 2013). This is a seven-fold increase in 40 years compared to the two-fold increase in the majority population (Rees *et al* 2012).

Service delivery to ethnic elders faces systemic disadvantages. Evidence of this can be seen at all the three main stages: access, assessment and outcomes. While prevalence is similar to the indigenous population, in ethnic elders reduced awareness and stigma may reduce access to diagnosis. Assessments may be fraught with additional challenges; varying treatment responses and outcomes may be different. Increased awareness of these disadvantages may help in designing different support systems appropriate to the needs of this group.

Literature in the area of service provision within dementia care to ethnic minority elders is patchy, conflicting and with several gaps. Previous reviews (Beattie *et al* 2002) identified that the main challenge is the under-utilization of services by minority ethnic groups; differing prevalences of dementia within different ethnic groups who also experience differing care giving experiences. Further language barriers are a factor in cognitive assessment. The instruments used to assess cognitive function suffer cultural biases towards Western populations. Published evidence would seem to suggest that the fundamental issue is language ability, rather than minority group membership in itself. Studies into care



## Summary

Access to health care services is often the manifestation of systemic disadvantages within dementia assessment and treatment services of elders from ethnic minority backgrounds. Access may be affected by several prejudices, lack of cultural appropriateness of interventions provided and care that is not suited to cultural norms and expectations. Ethnic elders face many disadvantages in access to their treatment and care. When they do present for treatment, cognitive assessments and tools are unable to capture the language and cultural complexities that are needed to adapt and provide care that is culturally appropriate to their needs. Here, I review the existing evidence in the access to services within dementia health care in the UK making local comparisons to establish if the accepted norm of reduced access by ethnic elders still applies in Leicester, an area where the ethnic population is no longer in the minority.

giving experience among different ethnic or racial groups suffer from theoretical and methodological weaknesses. Studies of help-seeking amongst ethnic groups find that many do not prioritise dementia as a health problem in the face of more pressing concerns. There is little consensus about whether services should be provided specifically for different ethnic groups, and a lack of evidence concerning the efficacy of different models of service provision.

## Access to dementia care services in the UK

Access is the final common pathway by which these systemic disadvantages influence health care utilisation in this group. It is commonly accepted that access to health care by this group is poor. Studies have consistently demonstrated that access to memory assessment services and dementia care by ethnic groups is poor. Factors include issues such as awareness and stigma (Mackenzie J

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## Key points

- Access to health care including dementia care by ethnic elders may be affected by several systemic disadvantages.
- Reduced health care access within dementia care services by ethnic groups in the UK and elsewhere is well recognized.
- In areas and regions where, ethnic groups are in a small minority, reduced access is a consistent finding.
- However, our studies in Leicester demonstrate that in regions where ethnic groups are a significant portion of the population, reduced access by these groups may no longer be the case; ethnic groups here have similar access as indigenous population in other regions.
- Such findings may be subject to variations over time and intergenerational effects, and may need further scrutiny.

2003; Mukadam *et al* 2011) (Mackenzie J 2006) that deter people from accessing formal support for their memory and cognitive symptoms. Cultural perceptions particularly around health, caregiving, or dementia itself affect willingness of individuals and families to seek support. Further, there are issues in defining the problem group, ethnic elders are not a homogenous group. They are also subject to intergenerational effects. Literature review reveals lack of adequate data, and when present, data is of variable quality. Lack of awareness of dementia as an illness may be an issue with no equivalence of the term dementia in some languages and cultures; the condition being synonymous with aging (Lindesay 1998; Shah Lindesay & Jagger 1998; Dennis *et al* 1998) thus preventing help seeking (Braun & Browne 1998). Many Asian service users do not see terms such as dementia or Alzheimer's as applying to them (Lawrence *et al* 2008). Stigma (Seabrooke & Milne 2004; Sara Turner 2005) and taboo may affect access to services with some seeing dementia as due to lack of family care (La Fontaine *et al* 2007). Those from Asian communities may fear dementia in the family as damaging their prospects of arranged marriage (Mackenzie J 2006).

Studies on prevalence data are limited and there is conflicting evidence on whether or not there is under representation. Some small district level memory clinic and outpatient-based services find under representation (Mukadam *et al* 2011; Tuerk & Sauer 2015), while others find paradoxical over-representation (Banerjee *et al* 2007). Most of these are primary care studies (eg Mukadam *et al* 2014). UK research suggests that many from Asian communities often try to hide problems (Seabrooke & Milne 2004), and only come to the attention of services when symptoms are severe (Cooper *et al* 2010), or when people in the community comment, or carers can no longer cope (Low *et al* 2011; Bowes & Wilkinson 2003), hence it is harder for preventive interventions to be employed (Alisoun 2009).

Dementia screening by general practitioners (GPs) is affected by lack of specific cognitive assessment tools for ethnic population. This may be due to low literacy levels, language barriers and a lack of appropriately translated and culturally adapted screening and diagnostic tools for this group (Kenning *et al* 2017). Currently, there is a lack of both culturally appropriate services and accurately translated neuropsychological assessments for UK South Asians (Regan 2014). How dementia is identified by GPs, as well as how it is judged to be clinically appropriate for referral to secondary care, also affects the extent to which communities access a diagnosis. In a study of referrals to one memory service, only 44 per cent of South Asian patients were likely to access dementia diagnostic services in a timely way, in contrast to White British patients (62 per cent) (Ogliari *et al* 2020). It is suggested that GPs often use a 'watch and wait' strategy for patients suspected with dementia, to ensure that enough information is collected to support a referral to secondary care (Iliffe *et al* 2009). Difficulties in cognitive screening or language and cultural issues may be more common when assessing these elders. This can result in people from these communities accessing a diagnosis later (Philp 2004).

### Access to services in Leicester

So, is access an issue in Leicester? Our clinicians in Leicester do not clinically encounter reduced access by ethnic elders within memory assessment or dementia care services. Further they are constantly subject to service pressures and growing waiting lists. Experience in clinical practice seemed at odds to established norms of reduced access by ethnic groups, so we examined this systematically. Demographics of Leicester show that increase in those aged over 65 will be much greater in South Asian than other groups and that overall, the proportion of over 65s from black and ethnic minority communities will rise from 31% at present to 40% in 2026. It is timely to establish whether underutilization remains a significant clinical issue in Leicester.

We re-examine the findings of our recent work through memory clinic services in Leicester; we have ongoing work on service utilisation by ethnic minority groups and this is a project update. These are secondary care studies, and while we are unable to establish prevalence rates of dementias or cognitive disorders, we attempt to provide clarity on whether or not underutilization of services by ethnic elders is a significant issue; the studies have been published elsewhere and have been conducted through NIHR grants (PBPG-0416-20019) and approved by University of Leicester Ethics Sub-Committee for Medicine and Biological Sciences, (13597-sa144-healthsciences).

Our first study (Wilson *et al* 2020) examined referrals between 2010 and 2017 to the local memory clinic services comparing Asian, Black and White British referrals. Severity of dementia was assessed by record review. Odds ratios were adjusted for general practice, age, gender and year of referral. A diagnosis of dementia was recorded in 74.5% White British, 73.3% Black and 61.5% Asian referrals. Compared with Asians, White British had twice the adjusted odds of a dementia diagnosis. Of those with dementia, Alzheimer's disease was more common in

White British than in Asian and Black referrals. The proportion with moderate/severe disease was highest in White British (66.8%), compared with 61.9% in Asian and 45.8% in Black groups. Differences in confirmed dementia suggests that GPs had a lower threshold for referral for possible dementia in ethnic groups, this is different from findings from other studies and other regions of the UK. Unlike other centres, we found no evidence of greater severity at presentation in Asian and Black groups.

In our other study (Subramaniam *et al* 2020), there was a significant underrepresentation of referrals from the ethnic elderly population as compared with the White population in 2011, 2012 and 2013, when compared with population estimates of those aged  $\geq 60$  years from the 2011 UK Census Leicester city data. While the data for the Black population were too small for comparisons, the likelihood of being referred to a memory clinic for the White group was double that of the Asian group in 2011 and nearly 1.5 times in 2012. This difference did not persist after 2014. However, this differential change to referral rates disappears when the age difference between the groups is accounted for. After adjusting for age, there were no differences between the two groups in their odds of referral to the memory clinic from 2011 to 2013, but from 2014 to 2017, members of the Asian group had higher odds of being referred. The higher proportion of non-dementia diagnoses in Asian and Black groups suggest that GPs may respond to difficulties in assessment of cognition by a lower threshold of referral. Higher proportion of unclassified dementia in these groups may suggest a complex assessment. Again there was no evidence of greater severity at presentation in ethnic groups in comparison with White British group.

### No major issues with access

So, taken together, what do the two studies mean? We did not find major issues with access; we found that ethnic communities have a lower threshold for accessing diagnostic services than other groups do, a finding repeated elsewhere too (Cook *et al* 2019). However, these studies including ours in Leicester have been undertaken within memory services in areas with high ethnic minority populations, so clinicians involved in diagnosis are likely to be well-versed in identifying, referring, and diagnosing dementia in those groups. Similarly, GPs from primary care may be familiar with the clinical presentations manifested by ethnic elders and may not be pursuing the approach of 'wait and watch' as reported by other studies. So it appears to be the case that access issues remain in regions where ethnic minority populations are restricted to small pockets, but in regions like Leicester with significant minority populations, issues of problems with access may no longer be the case.

The study's strength is the large number of referrals to memory clinic in an ethnically diverse city over several years and the ability to assess not only severity but also the type of dementia and the prevalence of other diagnoses and outcomes, as described elsewhere (Chithiramohan *et al* 2023). However, the study has limitations. Definition of ethnicity was as per NHS records; it is subjective, perception-dependent and self-identified. Ethnic groups

were broad to allow quantitative comparisons, which may mask differences within groups, and the study does not capture intergenerational effects or changes over time. We were unable to control for deprivation or other confounding factors. However, this is a clinical study of clinical populations, and despite limitations it is of direct relevance to clinicians. Results cannot be generalised to places where the composition of the ethnic population is different from Leicester, explaining why our findings differ from studies in London for example, where composition of ethnic groups may differ.

In conclusion, access and health care utilisation within dementia services is complex, multifactorial, reflects several underlying systemic disadvantages and may vary with time. While underutilisation is well described in regions where ethnic populations are in minority, with changing demographics this may no longer be the case in regions such as Leicester where the ethnic populations are significant and clinical services see the same levels of access by ethnic minority groups.

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# Evidence for practice/Research news

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

We welcome contributions such as:

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

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

## Detecting dementia: comparison of tools

Involving 706 participants with mild cognitive impairment or probable mild Alzheimer's disease, this study identified that the Digital Clock and Recall method (DCR™) was superior on average to the Mini-Mental State Examination (MMSE) in classifying mild cognitive impairment and early dementia. DCR administration was also significantly faster (completed in less than three minutes regardless of cognitive status and age). The authors conclude that DCR outperforms the MMSE in detecting and classifying cognitive impairment - in a fraction of the time - while being not influenced by a patient's ethnicity. The results support the utility of DCR as a sensitive and efficient cognitive assessment in primary care settings.

Jannati A, Toro-Serey C, Gomes-Osman J *et al.* Digital Clock and Recall is superior to the Mini-Mental State Examination for the detection of mild cognitive impairment and mild dementia. *Alzheimer's Research and Therapy* 16, 2. Published Jan 2 2024. <https://doi.org/10.1186/s13195-023-01367-7>. Open access.

## Living well: Minority ethnic comparison

This study explored 'living well' for people with dementia (quality of life, life satisfaction, wellbeing, loneliness, social isolation) and for carers (stress, relationship quality, role captivity and caring competence) from minority ethnic and white groups. It found that people with dementia from minority ethnic groups had poorer quality of life and higher loneliness whilst minority ethnic carers had higher stress and role captivity with lower relationship quality than their white peers. The authors suggest that confirmatory research with larger samples is required to facilitate analysis of the experiences of specific minority ethnic groups and examine the factors contributing to these disadvantages.

Victor CR, Gamble LD, Pentecost C *et al.* Living well with dementia: An exploratory matched analysis of minority ethnic and white people with dementia and carers participating in the IDEAL programme. *International Journal of Geriatric Psychiatry*, 39, 1 e6048. Published Jan 5 2024. <https://doi.org/10.1002/gps.6048>. Open access.

## Support in young onset dementia (YOD)

Through interviews with people living with YOD, this study identified that online peer support can be an important source of post-diagnostic support. To make this work well, it is key to have a trained and skilled facilitator who listens, gives everyone a chance to speak, ensures the group is a safe space for everyone, and gets to know the members well. Additionally, this study recommends that facilitators of online peer support groups provide a detailed description of their group so that people can better assess whether the group would suit them. The insights obtained from this study will be used to develop a Best Practice Guidance on online peer support for people with YOD. Gerritzen EV, Orrell M, McDermott O. Optimising Online Peer Support for People with Young Onset Dementia. *International Journal of Environ. Res. Public Health*, 21(1) 60. Published Jan 2 2024. <https://doi.org/10.3390/ijerph21010060>. Open access.

## Learning disability

The life expectancy of people with a learning disability is increasing and with this comes a greater risk of developing dementia. This qualitative systematic review explores the evidence base of family and formal carers' experiences and needs of caring for someone with both a learning disability and dementia. Four themes were identified following analysis: Knowledge and skills, Accessing support, Repercussions of dementia for carers, and Influences of continuity of caring role. There are significant training and educational needs for all carers who support the dual diagnosis of dementia and learning disability. Parity across services combined with sufficiently trained carers may support dementia diagnosis and improve quality of care provided.

Hughes M, Hanna K, Giebel C *et al.* The experience of caring for someone with dementia and a learning disability: A qualitative systematic review. *Dementia*. Published Jan 3 2024. <https://doi.org/10.1177/14713012231225797>. Open access



## Life story templates

The use of life stories in dementia care has been described as a way of seeing every person as an individual, looking beyond their dementia, but life stories are often standardised and generated by a family member answering predetermined questions in a template. This study aimed to chart what versions of a person's life story the templates produce, and establish the intended purpose of such life stories, as communicated by the templates. The life story templates were found to generate two very different versions of the individual: (1) a person before symptoms of dementia or (2) a patient *with* dementia. The researchers also found contradictions about what information should be included, whose life story it was, and the intended use. Despite strong pressure on dementia care providers to collect life stories from residents, these authors highlight that the life story templates being used are without clear direction, ideology, or purpose. They also highlight the need to develop ethical guidelines for life story template design, matched with guidelines for their intended use. Möllergren G, Harnett T. Life story templates in dementia care: Ambiguous direction and purpose. *Dementia*. Published Jan 4 2024. <https://doi.org/10.1177/14713012231224545>. Open access.

## Lewy body dementia (LBD): cost of care

LBD is a prevalent yet frequently underdiagnosed form of dementia, accounting for up to 15% of all dementia cases. This systematic review of literature involved participants with LBD or Parkinson's disease dementia; it aimed to increase awareness and advocacy for LBD by gathering and critically assessing the economic evidence, including the cost of illness and cost-effectiveness of interventions for managing LBD. It concluded that the cost of LBD tends to be higher than that of other forms of dementia and these costs escalate more steeply as the disease progresses. Cost-effectiveness of potential interventions for LBD is limited. The authors conclude that, despite numerous drug trials and other interventions for dementia, very few have targeted LBD, let alone explored the cost-effectiveness of such therapies for LBD. This disparity highlights the urgent need for cost-effective strategies and interventions targeting LBD.

Boland E, Fitzpatrick R, Ryan D et al. The high cost of care and limited evidence on cost-effective strategies for Lewy body dementia: systematic review of evidence. *BJPsych Open* 10(1) e20. Published Jan 5 2024. <https://doi.org/10.1192/bjo.2023.626>. Open access

## Therapeutic songwriting

This study aimed to explore the experiences of people living with dementia and their informal and formal care partners following participation in a 10-week online therapeutic songwriting program facilitated by a music therapist. Participants highlighted songwriting as a unique opportunity to connect with music, experience welcomed challenges, and spend 'real time' together. The program drew on participants' lived experience and promoted connection with others, resulting in feelings of enjoyment, enhanced mood, and achievement. Participants valued both the songwriting process and song product, emphasising the

importance of sensitive and skilful facilitation. The authors suggest that these distinct benefits were not available through other support services. Further, online songwriting is a viable option for people living with dementia and their care partners where in-person sessions are not available or accessible.

Clark I, Christopher N, Lawson *et al*. The experiences of people living with dementia and their care partners participating in an online therapeutic songwriting program. *Dementia*. Published Dec 22 2023. <https://doi.org/10.1177/14713012231224069>. Open access

## End-of-life care in hospital and other settings

This retrospective clinical audit aimed to establish evidence related to end-of-life care for people dying with dementia in hospital compared to other settings. It identified that people who died in hospital were more likely to be living at home and to not have a spouse. Less than one in five people had advance care directives or plans. Many were still being actively treated at the time of death; almost half of people who died in hospital had an investigation in their final 72 hours; less than half of people were coded as receiving palliative care at death, and more than two thirds did not get access to specialist palliative care. This study provides novel insights for those providing end-of-life care to people with dementia; it highlights the need for more support to prepare advance care documentation and timely consideration for palliative care.

Triandafilidis Z, Carr S, Davis D *et al*. What care do people with dementia receive at the end of life? Lessons from a retrospective clinical audit of deaths in hospital and other settings. *BMC Geriatrics* 24, 40, Published Jan 9 2024. <https://doi.org/10.1186/s12877-023-04449-1>. Open access

## Dementia support worker (DSW) roles

To inform future role development, this evaluation sought to understand the perspectives and experiences of DSWs and related healthcare practitioners. Through semi-structured interviews and focus groups, they described inconsistencies in the understanding and delivery of the DSW role. Overall, this paper offers insights into challenges experienced by DSWs and addresses factors that could help improve and support the DSW role, and potentially the experience of other staff, and patients/people living with dementia.

Prendergast LM, Davies CT, Williamson T et al. 'A lot of people think it's just a Mickey Mouse role': Role ambiguity among dementia support workers within secondary care and community hospital settings. *Dementia*. Published Dec 15 2023. <https://doi.org/10.1177/14713012231220461>. Open access

## Hearing, hearing aids and dementia

The results of this cohort study suggest that hearing loss is associated with increased dementia risk, especially among people not using hearing aids, and that hearing aids might prevent or delay the onset and progression of dementia.

Cantuaria ML, Pedersen ER, Waldorff FB et al. Hearing Loss, Hearing Aid Use, and Risk of Dementia in Older Adults. *JAMA Otolaryngol Head Neck Surg*. Published online January 04, 2024. doi:10.1001/jamaoto.2023.3509. Abstract available.

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