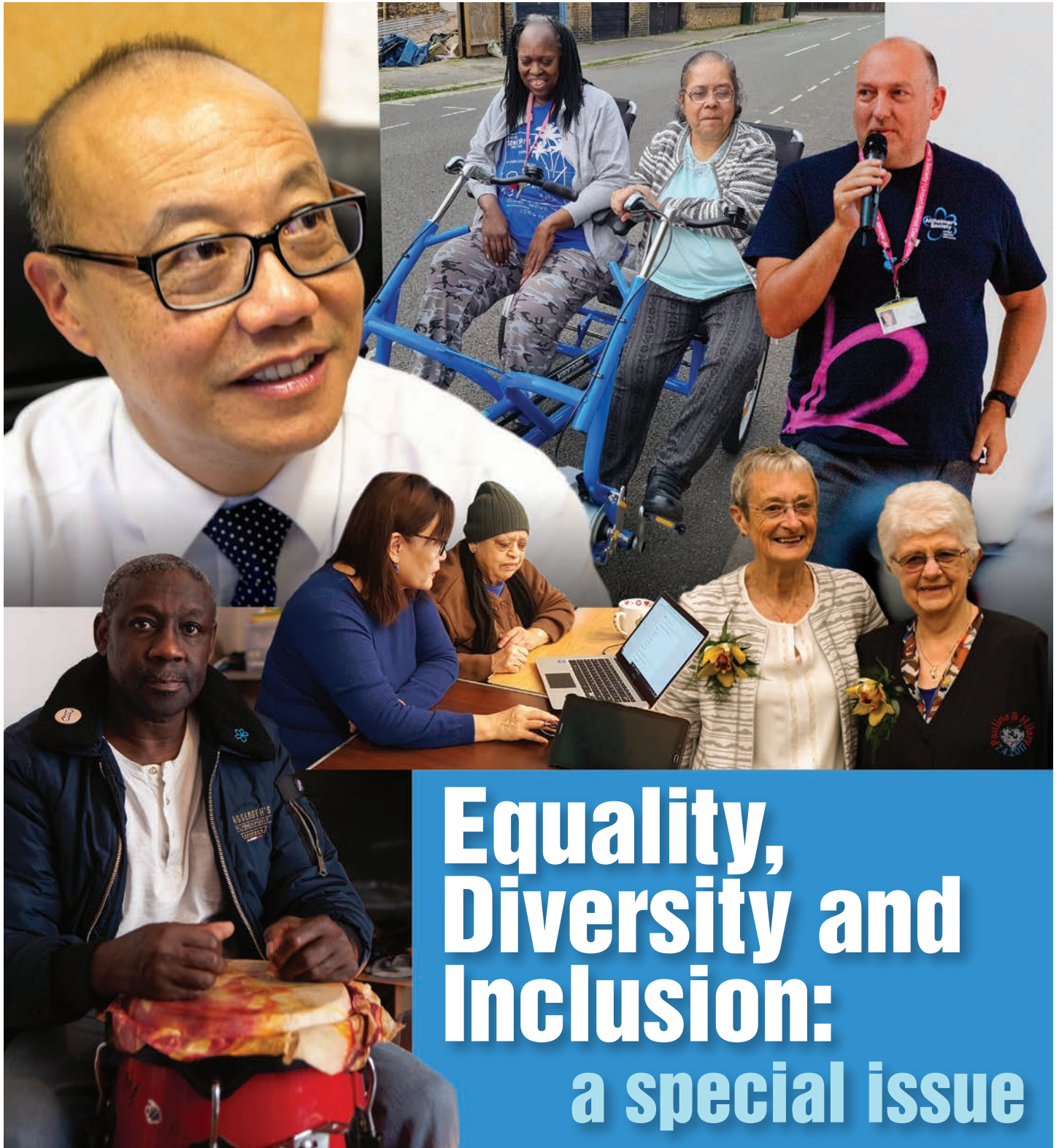


The Journal of DementiaCare

For all who work with people with dementia

Vol 31 No 5 September/October 2023



Equality, Diversity and Inclusion: a special issue

- EDI principles and practice
- Personal stories
- Effective co-production
- Inspiring projects and services



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:



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

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Who we are

Our Founder



Dr Richard Hawkins

Having worked for more than thirty years in the dementia care world, I have learned that simply wanting to provide the best possible dementia care is not enough for those providing care to people living with dementia. You need much more. You need to learn from trusted sources of information and guidance, you need to share your knowledge and enthusiasm, and you need to feel inspired yourself and want to inspire others.

Our Dementia Community provides you with the means to make a difference, by learning, sharing and inspiring. Our acclaimed publication, the *Journal of Dementia Care*, makes research understandable and offers practical solutions. Our website keeps you up to date and our webinars, conferences and events enable you to celebrate your achievements and excel.

Our Staff



Isabella Barclay

Bringing people together and working towards positive change are key motivators for me, and 'Dementia Community' achieves both of these things within dementia care.



Melanie Blake

I am proud to be part of 'Dementia Community', making a difference to how people living with dementia are regarded, respected and supported.



Beth Britton

'Dementia Community' is a fantastic way for everyone living with, working in, or connected in any way with dementia, to come together. I look forward to some great collaborations.



Mark Ivory

I'm thrilled to be part of 'Dementia Community' and its commitment to sharing knowledge and learning from one another, the lifeblood of all strong communities.



Beth Lang

I take pride in being a member of the 'Dementia Community' as I aspire for knowledge and understanding to reach as many individuals as it can.

Our Board



Sue Benson

I've been deeply touched by the terrific work and inspiring ideas described in so many wonderful articles, presentations and awards entries over the years. I hope to nurture that inspiration and support to continue, to grow and widen into an all-embracing dementia community: learning, sharing, inspiring into the future, into a world of exciting new possibilities through digital media and networks.



Suzanne Mumford

The *Journal of Dementia Care* and the UK Dementia Congress have embraced professionals working in academia and health and social care together with people with lived experience in an inspiring community of practice. The evolution of "Dementia Community" offers a unique opportunity to build on this achievement with the genuine intention of improving care through dialogue, publications and events.



Jude Sweeting

The *Journal of Dementia Care* and the UK Dementia Congress have motivated and inspired me for 25 years. I am genuinely excited by the next step we have taken in becoming a Dementia Community (Benefit Society) enabling us to expand our learning and networks together. Everyone has a voice in our new 'cooperative' structure which calls for us to form a unique and powerful collective.



Jane Ward

As my mother's full-time carer, I experienced first-hand how difficult it is to support someone without knowledge and understanding of how dementia affects every aspect of life. The *Journal of Dementia Care* is a crucial source of up-to-date information about gold-standard dementia care, vital for all people involved in caring for a person with dementia. I am proud to be part of 'Dementia Community' and to support its work going forward.



Karen Harrison Denning

The sharing of expertise and knowledge that comes with being part of this particular community has been a great enabler throughout my career. Whatever your own relationship to dementia, whether you have a diagnosis of dementia, are caring for someone with dementia, or working as a professional with families, this 'Dementia Community' will provide you with a sense of being an important part of the larger whole.



Maria Parsons

In a world full of challenges, we can easily lose heart. By being part of this community, we will be stronger. We will be empowered to bring about change with and for people living with dementia, here and now. We can, together, learn and share, build and connect through our website, the *Journal of Dementia Care*, national events, seminars, discussion groups, networks, and other means of relating to each other, both face-to-face and virtually.



David Truswell

Inclusion is an important part of the dementia experience we must all keep pushing for, especially when it seems – increasingly – that the voices in favour of exclusion, across a whole raft of everyday social experiences, become more and more amplified. 'Dementia Community' is an opportunity to press forward collectively and support each other in a spirit of hope and inclusion.



Barbara Stephens

As Society Secretary and co-founder of Dementia Publishing Community Benefit Society, it is very rewarding to reach this milestone. I am delighted to be serving the team that is launching 'Dementia Community' providing a unique opportunity for us to unite, make our voices heard and become a powerful force for change.

Equality, Diversity and Inclusion:

A special issue of *JDC*

This special issue of the Journal of Dementia Care has been planned and edited by members of the *Journal of Dementia Care's* Equality, Diversity and Inclusion working group, led by **Lucy Whitman** and **David Truswell**

Welcome to this special, unique issue of the *Journal of Dementia Care*, focusing on Equality, Diversity and Inclusion (EDI).

Why do we need a special issue?

Since 2013, when the landmark report of the All Party Parliamentary Group on Dementia, *Dementia does not discriminate*, was published, numerous further reports have been written, demonstrating that people from certain minority communities have a higher risk of developing dementia at a younger age than their peers, that they often present later to services, and tend to die sooner after diagnosis. For complex reasons, people from these communities often miss out on the support and care they are entitled to.

Yet despite the tireless work of committed practitioners and researchers over many years – much of it highlighted in the *Journal of Dementia Care* and at the UK Dementia Congress – it seems that this abundant information has failed to create traction across the country amongst commissioners, funders and service providers. Serious inequities in dementia care remain. Innovative projects are often funded briefly, and then left to fade away, rather than being replicated on a national scale, with the result that all too often, individuals from minority communities who have dementia or are caring for someone with dementia still do not receive culturally appropriate support.

We live in an unequal society, with stark and widening inequalities in health outcomes and life expectancy, which inevitably leads to differences in how people from different communities experience dementia and dementia services. One size does not fit all. Intersectionality, whereby people identify with more than one group which experiences discrimination and disadvantage – such as being black and gay – adds further complexity, but is also a positive reflection of diverse but interconnecting communities, and offers opportunities for more inclusive practice. Genuine person-centred care, to which we all aspire, has to take into account the social and cultural background of each person with dementia, as well as their individual story.

What's in this issue?

This special issue starts with an article setting out the principles and practice of dementia care from an EDI perspective, highlighting the importance for everyone of a rights-based, values-based approach, with inclusion at its heart. This is followed by articles exploring the social and political context in which dementia care takes place in the UK, interviews and personal accounts by people who are living with dementia or caring for someone with dementia,

and impressive examples of inclusive projects and services which are making a real difference to the lives of people with dementia and their families from many different backgrounds. One of the threads which comes through most clearly is the vital importance of genuine community engagement. It is helpful to see all these articles in relation to each other. To take just one example: perhaps the experience of Jagdish Brar-Orgill, who struggled to support her mother with dementia without culturally appropriate support, would have been different if her mother had lived in a part of the country where dementia services have been designed in an integrated way, in response to local needs, as described in the article about the Bristol Dementia Wellbeing Service.

We hope that by bringing these ideas and this information together in one place we will inspire everyone within the dementia community to do everything in their power to ensure that every person with dementia, and every carer, whatever their background and personal history, receives timely, competent, compassionate, culturally appropriate care.

The diversity of diversity

Our definition of diversity within the dementia community is wide-ranging, and we have tried to be as inclusive as possible. We invited contributions representing many different perspectives, both in terms of different communities and in terms of the role of individual contributors or the sector they operate in: people living with dementia, unpaid carers, volunteers, clinicians, researchers and practitioners in a range of settings, including small community-based organisations. (And of course, for many contributors these different identities and roles overlap – another example of intersectionality.)

Needless to say, it has not been possible to represent all communities and all dementia care settings in this one issue. We are confident that articles exploring the experience of people from other communities, and from those striving to apply the principles of EDI in other settings will appear in future issues of *JDC*.

Please do respond to this special issue. Let us know what you are doing in your community or your service. Take up the “*JDC Asks Challenge*” (page 11). Send in your ideas for further articles, or better still, offer to write an article yourself, sharing your experience of dementia care from an EDI perspective.

The printing of this special issue has been kindly sponsored by



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Cover photos:

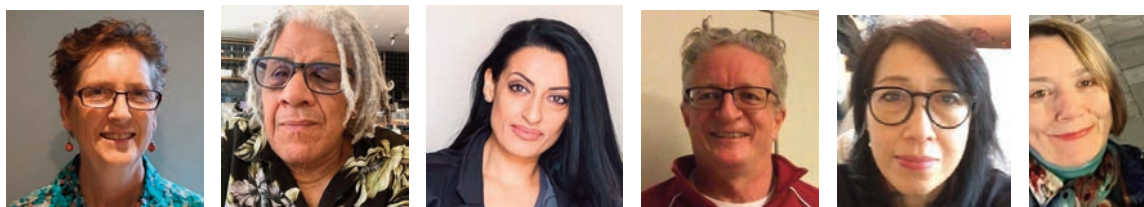
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Who put this special issue of JDC together?



Left to right: Lucy Whitman, David Truswell, Karan Jutlla, Toby Williamson, Jennifer Lim, Jude Sweeting

This issue of the *Journal of Dementia Care* was edited by Lucy Whitman and David Truswell with support from Karan Jutlla, Toby Williamson, Jennifer Lim and Jude Sweeting. All of us are members of the Dementia Community** EDI working group (a sub-group of the Dementia Community Advisory group with a special interest in EDI). The idea of creating a special EDI issue of *JDC* was proposed at an open workshop which we hosted at UK Dementia Congress 2022.

We are very grateful for the support of Mark Ivory and Sue Benson, editor and managing editor respectively, of the *Journal of Dementia Care*, who agreed to let us “guest edit” this special issue. When we found we had collected more material than would fit into a regular edition, they kindly agreed that this could be an extended issue, with a more generous word count, giving contributors enough space to avoid oversimplifying complex matters. We also greatly appreciate the decision to produce this special issue in print, in addition to the standard online version, to maximise its impact. Please do share and promote this issue to everyone in your network!

Lucy Whitman is a writer and editor and former carer for her mother with dementia. Her two anthologies, *People with Dementia Speak Out*, and *Telling Tales About Dementia: Experiences of Caring* are published by JKP. Lucy worked in the voluntary sector for 15 years, supporting people with dementia and carers, most recently at Opening Doors (<https://www.openingdoors.lgbt>) where she developed services for LGBTQ+ people affected by dementia.

David Truswell worked in community based mental health services for over 30 years, developing services for people with complex care needs and enduring mental health problems. He is an independent writer who contributes regularly to journals and practice handbooks, and is a Board member of Dementia Community. His book *Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities* is published by JKP.

Dr Karan Jutlla is head of the Health Research Centre and Dementia Lead at the University of Wolverhampton. Karan’s interest in the challenge of dementia care in South Asian communities is fuelled by both her personal and professional experiences. Her work includes projects supporting policy makers and service providers to deliver superb outcomes for a neglected but growing part of the community. See www.drjutlla.com

Toby Williamson is an independent consultant conducting research, evaluation and service and policy development work in adult and older people’s mental health, dementia,

and mental capacity. Working in both statutory and non-statutory organisations, he has developed and managed frontline services, as well as projects at strategic and national levels. Much of his work focuses on lived experience, rights, values and EDI. He is the co-author of *The Dementia Manifesto*, CUP, 2019.

Dr Jennifer NW Lim is a senior lecturer in public health at the University of Wolverhampton. Jennifer has over 20 years research experience working with minority ethnic communities in the UK to better understand their health needs, and co-produce culturally appropriate interventions to improve their quality of life. She is the creator of the first major project to build knowledge of dementia and brain health amongst Chinese communities in the UK.

Jude Sweeting has worked for over 30 years with statutory and independent sector organisations to improve dementia services. As a manager, leadership coach, facilitator, and consultant she has enjoyed the challenge of developing creative climates for problem solving and team wellbeing. She is currently a director of Dementia Pathfinders, Dementia Community and Resonate Arts.

Welcome from Mark Ivory, Sue Benson and the JDC team

We are delighted to bring you this special issue of the *Journal of Dementia Care* looking at equality, diversity and inclusion (EDI) in dementia care. Inequality and discrimination are regrettably still commonplace in the care system, both in access to services and health outcomes. To help address this, prompted by Lucy Whitman and other members of the Dementia Community Advisory Group,* we set up an EDI Working Group, to help us ensure that we put improvements in equality and inclusion at the heart of *JDC* and in all our events and activities, including the UK Dementia Congress.

The group has used its extensive expertise to plan, write and source all the articles. It has been a major and innovative undertaking and we hope we’ve produced a treasure trove of enlightenment and inspiration for you to make your own changes at work.

**As Dementia Publishing Community Benefit Society we have consulted widely with our stakeholders about our purpose and values, and have just announced our change of name to Dementia Community, along with a new membership structure. See pp2-3 of this issue and www.journalofdementiacare.co.uk*



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Karan Jutla – University of Wolverhampton

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Dr Nadia Wahid – Dementia Primary Care Clinical Lead, Birmingham

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

Be alert to this assault on dementia care

by Professor Sube Banerjee

Sube Banerjee is professor of dementia and executive dean at the University of Plymouth. He has worked in national and international health policy and is an applied health researcher focusing on quality of life and quality of care in dementia.



The amazing work of the past two decades moving dementia from obscurity into the light was powered by the need to address deep injustices and inequalities in health and care faced by people with dementia and their family carers. The papers in this issue of JDC chart emerging recognition of the diversity in dementia and provide hope and positive ideas about the value of inclusive dementia services.

However, there remains profound inequity in how those with dementia are treated relative to other major disorders. The disproportionate death rates of people with dementia during the Covid-19 pandemic laid bare the discriminatory nature of health and care systems worldwide which systematically undervalue their lives and wellbeing.

Until recently there has been the possibility that things were moving in the right direction, that we were on a path to acknowledging the breadth and depth of the impacts of dementia on society and working to change things for the better. That may no longer be the case. Dementia in the UK appears, in effect, to be being “disappeared” as a balanced health and care priority.

This assault has two fronts. First, government has abandoned its commitment to a 10-year comprehensive dementia strategy. Instead there is to be an ill-defined, non-specific “Major Conditions Strategy” including cardiovascular disease, chronic respiratory disease, mental health conditions, and cancer as well as dementia. Any such approach is likely to entrench and even broaden inequity since the evidence base and systems of service provision for those other conditions are much further developed than those that exist for dementia. The generality implicit in such approaches provides licence for the government to avoid meaningful and operationally achievable targets and actions.

And, second of the two fronts I have identified, there is a potential unintended consequence of the emerging first generation of disease modifying treatments for Alzheimer's disease. This is a powerful proof of concept that drug treatment can help. But, in a quest to find simple answers to complex problems, we face the real prospect of a narrowing of policy focus onto drug treatment alone.

There is understandable enthusiasm from the pharmaceutical industry and some researchers to see diagnosis and care pathways simply from the viewpoint of the delivery of disease modifying treatments. This, however, neglects the fact that current systems of dementia diagnosis and care are almost universally patchy, of poor quality, and thinly resourced. Actions to re-engineer systems to deliver these drugs may diminish already poor services for the very large majority of those with dementia who will not be eligible for drug treatment.

Our problem is not that we do not have treatments that work: this journal is full of powerful positive changes that can be made that would allow people with dementia to live well. With will, we could already provide great dementia care. Instead we must be alert to a narrowing of the definition of “success” to slowing the progress of cognitive impairment. This runs the risk of creating exclusively drug-focused dementia services which would fail the majority and miss delivering so much good that could be done. ■

Writing for JDC:

Do you have a project or survey to report, or a change in practice organisation or structure which has worked well (or not), and would you like to share this experience with others? Do you have a strong opinion you would like to express? We welcome letters and contributions that promote discussion and debate about dementia care. Contact the editor, Mark Ivory: mark@dementiapublishing.community

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.

News round-up

News and Resources are regularly updated on our website
www.journalofdementiacare.co.uk

Major Conditions Strategy

An initial “strategic framework” has been published by the government as a prelude to its forthcoming Major Conditions Strategy (MCS) for England, which will set out plans for tackling six health conditions including dementia over the next five years. In his foreword to the framework, which is the “interim report” he promised when announcing the combined strategy in January, health secretary Steve Barclay said the government had undertaken a “wide ranging engagement” which had shown that people can find it hard to navigate a fragmented system that is not always well placed to support people with more than one condition.

Apart from dementia the MCS will cover the five other major conditions which the government says account in total for 60% of the years lost to early death or living with ill-health – cancer, cardiovascular disease, mental ill-health, respiratory disease and muscular-skeletal disorders. Justifying the combined strategy, the new framework forecasts that by 2035 two-thirds of adults aged over 65 will have two or more conditions and 17% will have four or more.

The framework flags up a focus on early diagnosis, prompt care delivery, long-term care and treatment, and prevention including halting the progression of conditions. Change will be prioritised in five areas: health and care “rebalanced” towards proactive prevention that manages personalised risk factors; early diagnosis and treatment embedded in the community; managing multiple conditions with a mix of

generic and specialist professionals; integration of physical and mental health services; and giving people more choice and control over their care.

In a section of the report specifically on dementia, the government repeats its pledges to restore diagnosis rates to the pre-pandemic figure of 67% and to double dementia research funding to £160 million annually by 2024/25. “NHS [England] will continue mapping Alzheimer’s disease medicines and explore establishing a steering group to ensure the system is ready to deploy any new treatments,” the report adds.

www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2#annex-b-what-the-major-conditions-strategy-will-mean-for-each-condition

Lifetime achievement

Professor Tom Denning, former director of the Nottingham University Centre for Dementia, has won an award for lifetime achievement from the Royal College of Psychiatrists. Accepting the Lifetime Achievement Ward in Older People’s Mental Health.

Dr Shirley Evans

Dr Shirley Evans has been made director of the Association for Dementia Studies (ADS) at the University of Worcester following a spell as interim director. While at ADS Dr Evans has played a key part in driving forward the Meeting Centres programme in the UK, which has grown from 13 centres before the pandemic to around 60 now. She was promoted to the interim role after the retirement of Professor Dawn Brooker last year and now takes on the permanent role.

Donanemab benefits

New results from the final stage of extensive clinical trials for the anti-amyloid immunotherapy drug “donanemab” have confirmed significant benefits for people in the early stage of Alzheimer’s disease. The drug, which was shown to slow cognitive and functional decline by 22%, could receive regulatory approval for use in the USA by the end of the year. Applications by the manufacturer Eli Lilly to distribute donanemab in the UK and Europe are likely to follow. Donanemab was more effective during the earliest stages of symptomatic Alzheimer’s disease and also in people with mild cognitive impairment (MCI), slowing decline by 60% in these groups. There was an overall 40% slowing in decline of everyday activities such as driving, doing hobbies and managing finances. In a significant number, there was zero progression in disease symptoms over the 18 month trial. If US regulatory approval is forthcoming, donanemab will join two similar drugs licensed for distribution there, lecanemab and aducanumab. But aducanumab did not win approval from the UK regulatory agency and a decision on lecanemab is not expected here until next year.

Care worker vacancies fall

Figures from Skills for Care reveal that care worker vacancies have fallen from a historic high of 165,000 last year to just over 150,000. While the vacancy rate remains above pre-

Association for Dementia Studies

New resources for 2023:

- Dementia friendly environmental assessment tools App
- DemECH booklets
- Get Real with Meeting Centres booklets and videos

Study with us in 2024:

- Postgraduate Certificate in Person-Centred Dementia Studies
- Championing physical activity for people affected by dementia

PERSON-CENTRED DEMENTIA STUDIES LEADERSHIP
ADMIRAL NURSES
EXPERT PRACTICE
ADVANCED DEMENTIA
EMPOWERMENT
ENVIRONMENTS
FAMILY CONTEXT

Championing physical activity for people affected by dementia

Get in touch:
dementia@worc.ac.uk
www.worcester.ac.uk/dementia

University of Worcester
Association for Dementia Studies

Care UK is proud to sponsor this special issue on Equality, Diversity and Inclusion which is at the heart of the care and support delivered by Care UK.

At Care UK, we've spent over 40 years supporting individuals living with dementia and delivering care that enables residents to lead fulfilling lives. Our approach to care has been developed in consultation with residents, relatives, academics and sector experts, and is grounded in academic evidence provided as part of our long-term partnership with the Association for Dementia Studies (ADS) at the University of Worcester.

We are proud that almost 9,000 families trust us to deliver high quality services, from nursing care to residential, palliative and specialist dementia care.

Suzanne Mumford, Head of Nursing, Care & Dementia, Care UK

pandemic levels, it will provide some reassurance in a sector that has been struggling with skills shortages.

Responding to the report, Nuffield Trust deputy policy director Natasha Curry said the decision to add social care to the government's shortage occupation list and issue more visas to overseas workers appeared to be paying off.

"This has helped grow the care workforce by an estimated 70,000 workers, but questions remain about the sustainability of this approach for years to come, especially alongside the absence of a dedicated and comprehensive workforce plan for social care," she said.

National Care Forum CEO Vic Rayner said the welcome arrival of overseas workers masked a further shrinking in the domestic workforce. "Research from Age UK makes it abundantly clear that there are already hundreds of thousands of older people who are not able to access the care they need," she added.

Parkinson's dementia toolkit

Campaigning charity Parkinson's UK has called for better training for health professionals on Parkinson's related dementia and produced a new toolkit to help them. The toolkit gives an overview of Parkinson's dementia, including risk factors, symptoms and assessments, while also suggesting treatment strategies. It is aimed at health and care professionals who support people with Parkinson's.

"It was designed to help facilitate conversations about Parkinson's dementia in clinic because although dementia is common in Parkinson's, it is not always talked about enough and people with the condition can be fearful of and reluctant to discuss the topic," the charity said.

According to the charity, 3 in 10 people with Parkinson's have Parkinson's-related dementia and they are six times more likely to develop dementia than other people. It has urged people to sign a letter campaigning for better training after publishing findings in a new report – *Nobody really knows us* – which show that 48% of carers surveyed reported that hospital staff had insufficient knowledge of Parkinson's-related dementia, while 60% of health professionals said they needed more training.

Air pollution link

Air pollution is linked to higher use of mental health services by people with dementia, research published by *BMJ Mental Health* suggests. It says that cutting levels of nitrogen dioxide (NO₂) and particulate matter should be a priority in urban areas if demand on overstretched psychiatric services is to be reduced. Researchers looked back at community mental health service use by 5,024 older people with a dementia diagnosis in south London over a period of nine years. They found that people living in areas with the highest exposure to NO₂ were 27% more likely to use these services compared with those with the lowest exposure, while people exposed to the highest levels of small particulate matter were 33% more likely to use services.

They estimate that contacts with mental health services by older people with dementia could fall 13% for particulates and 38% for NO₂ if levels of these pollutants were brought within WHO-recommended limits. "Based on the evidence presented, we contend that air pollution could be considered an important population-level target to reduce mental health service use in people with dementia, particular for those with vascular dementia," the researchers claim. But Alzheimer's Research UK accused the government of "dragging their feet" on stricter air quality standards, saying that the current target date of 2040 was "a decade too late". Policy head Dr Susan Mitchell said: "Poor air quality is a significant public health issue, and this new research demonstrates its knock-on effect on already over-stretched health services and the lives of people living with dementia."

<https://mentalhealth.bmj.com/content/ebmental/26/1/e300762.full.pdf>



In 1971, Hilary vowed to stay with Pauline in sickness and in health.

In 2019, we vowed to do the same.

Since Pauline was diagnosed with Vascular Dementia, our Dementia Advisers have been providing her with regular guidance and support.

 **Alzheimer's Society**

Together we are help & hope for everyone living with dementia

Alzheimer's Society, Registered Charity, number 296645.

Campaign for justice

Describing itself as a “creative coalition for justice” the group Reimagining Dementia have launched a campaign called “Taking it to the streets”, calling on people to sign their petition and supporting those who want to host public-facing events or activities. intended “break the silence and shame” around dementia and to make change through “connection, creativity and activism”. Events planned included an exhibition of art work by people living with dementia with a drop-in print activity; a dementia friendly concert by professional musicians; and a memory café afternoon. More details at www.reimaginingdementia.com/takingstreets.

Sport United

Sport United Against Dementia is a new initiative from Alzheimer’s Society to ensure people with dementia can keep enjoying lives sport at venues across England. Among these venues is Wembley Stadium and in a blog on the Society’s website Tom Benoist talks about his role as a member of the supporter care team for the scheme as a former carer for his grandad, who he used to take to football matches. “Everything he loved about football was stripped away from him by dementia,” Tom says. “If the staff had understood, they could have completely transformed his experience.” www.alzheimers.org.uk/blog.

Open letter from carers

With more than 700,000 people caring for someone with dementia, an open letter from charity Dementia Carers Count (DCC) aims to put pressure on the government to act. Supporters of the charity have been invited to sign the open letter to care minister Helen Whately and make their voices heard. Saying that many carers feel “forgotten and alone,” the

letter calls for a long-term, fully funded carers’ strategy that prioritises wellbeing through better identification of those who take on caring responsibilities, recognition of their needs, rights awareness-raising, and access to personalised support and learning opportunities. DCC chief executive Frances Lawrence writes in the letter that carers should be supported to manage caring so as to remain independent, stay healthy and have time to themselves. <https://dementiacarers.org.uk>.

Software integrated

Care management software provider Nourish Care has extended its capability by integrating data with Whzan Digital Health, a health monitoring system. The initiative looks likely to bring adult social care and health care data together to help improve digital care planning. Nourish Care said the Whzan system was connected to the NHS and used in more than 3,000 care homes. “The collaboration between Nourish and Whzan means that vital observations will be available alongside daily care records giving care teams instant access to up-to-date clinical patient information,” Nourish Care said. <https://nourishcare.co.uk>

Adopt a Grandparent

Care England chief executive Professor Martin Green has been appointed as an ambassador for Adopt a Grandparent as part of its drive to raise £100,000 to help combat loneliness among older people in care. Adopt a Grandparent was founded during the Covid-19 pandemic to promote intergenerational relationships at a time when many older people were socially isolated. “Becoming an ambassador for Adopt a Grandparent is an opportunity to support the sector in a whole new way and tackle a major issue for those in care,” Professor Green said.

Join the **Young Dementia Network** to improve the lives of people with **young onset dementia** and their families



The **Young Dementia Network** is an online community of more than **5,000** people affected by young onset dementia, researchers, academics as well as professionals working in the field.

We believe everyone affected should be enabled to live life to the full.

We work to improve knowledge, understanding and awareness and campaign for changes to policy and practice nationally.

Working together we are determined to achieve this.

To find out more and become a member visit: youngdementianetwork.org



JDC Asks Challenge

Tell us what you are doing to make dementia care more inclusive

In this issue of the *Journal of Dementia Care*, there are many examples of excellent initiatives which are helping to make dementia services more inclusive. We know there are lots of other brilliant projects going on, and we would like to hear about them.

Are you, as a practitioner or researcher, or the organisation you work for, making an effort to reach out and co-create opportunities for effective support to individuals and communities who tend to be under-represented and under-served in dementia services?

You might have made quite a small change which has made a big difference, you might have undertaken a

stand-alone project, or you might have been involved in a major initiative to refocus your organisation's vision and mission. What challenges have you faced, and what have you achieved? Please write to tell us what you have been doing, by answering the following question in no more than 250 words

What have you or your organisation done to make your dementia practice or service inclusive and responsive to the needs of different communities?

Please also give your name and describe your role in one sentence. Send your replies to Sue Benson at sue@dementiapublishing.community by 7 December 2023.

The replies we receive will form the basis of our regular JDC Asks topical section in the January/February 2024 issue of the *Journal of Dementia Care*.

Dementia Diaries

We've a lot of work to do to make sure that Dementia Diarists are as diverse as the communities in which we live.

But we've benefited hugely from the words and advice of diarists over the years who bring our attention both to the diversity and difference of the dementia experience, and our need to do more to reflect it.

Here is a selection of diarists who have helped us along the way.

Dianne Campbell has been campaigning on behalf of both younger people with dementia, and those from the African-Caribbean Community for more than a decade. She is driven by a recognition of both the special needs of younger people, and the need for wider engagement with and within diverse communities. <https://dementiadiaries.org/entry/diarist/dianne-campbell/>



Dianne is a very active member of Dementia Voices Brent, an active part of the DEEP network – and you can learn more about their fantastic work, and hear more from Dianne here:

<https://www.youtube.com/watch?v=FeNaTIPcUzY>

"Women are disproportionately affected by dementia. But whereas the statistics relating to women and dementia...are clear, the voices of women affected with dementia...are missing" (*Dementia Through the Eyes of Women* – JRF 2015).

Nada Savitch and Emily Abbot authored this work for Joseph Rowntree Foundation. Nada is a founder member of Innovations in Dementia, and Emily is a long-term associate.

Dementia Diaries has always provided a platform for the voices of women with dementia, and offshoot groups like the ZOOMETTES provided a crucial support group for women with dementia to be together and inspire each other, not least during lockdown.

In this diary, Dory describes the impact of meeting other women with dementia has had upon her own journey:

<https://dementiadiaries.org/entry/13860/dory-is-feeling-strong-and-independent-on-international-womens-day/?highlight=women>



Women with dementia have inspired each other, and have also been a source of great inspiration for men too. Nigel Hullah pays tribute in this diary to the women who have inspired and supported him since his diagnosis:

<https://dementiadiaries.org/entry/10562/nigel-pays-tribute-to-the-women-he-has-worked-beside-since-his-diagnosis/?highlight=women>



Ronald Amanze's diaries are unusual in that they usually involve music, which elevates his already beautiful voice and phrasing to new levels. Ronald has had a life in music, and is very active in promoting the power of music to bring joy and expression to people with dementia. Here is the first diary he ever recorded, and it still packs a punch. Just wonderful.

<https://dementiadiaries.org/entry/10124/the-mountains-i-still-climb/>



Daithi Clayton has always challenged us to do better in the way in which we work with members of LGBTQ+ communities. Along the way, Daithi has made a series of brilliant diaries, including this one in which they celebrate finding the support they need to be as fabulous as they are...

<https://dementiadiaries.org/entry/20793/its-happening-for-me-what-a-joyous-and-affirmative-diary-from-daithi-so-glad-for-you-daithi/?highlight=daithi>



Steve Milton is a director of Innovations in Dementia.

Putting EDI into practice – key principles and guidelines

What do the terms equality, diversity and inclusion (EDI) mean in dementia care, what is their legal basis and how can they be effectively implemented?

Toby Williamson and colleagues explain the key terms and principles, and provide practice guidelines.

EDI stands for “Equality, Diversity and Inclusion” (some people prefer “Equity” to “Equality” – see below). EDI has become a key concept in public policy and practice, including health, social care and housing. EDI describes how services should be developed and delivered to take into account the different histories and needs of people from diverse communities (including experiences of discrimination, disadvantage and exclusion).



But what do the words that make up EDI mean? What is the relevance of EDI to dementia care and people affected by dementia? How do I put EDI into practice as a practitioner, or in an organisation involved with dementia? How does EDI link with person-centred care? This article tries to give some answers to these questions and provides some EDI principles and practical guidelines for individuals and organisations.

What is EDI?

“Equality” is about ensuring that everyone is treated fairly, taking into account the discrimination and disadvantage that some groups in the population experience. It is not about treating everybody the same, because people have different needs from each other. Some prefer the term “equity” because it recognises the need to provide additional or tailored support in response to the disadvantages that people from some groups are faced with. The reason that we prefer to stick with “equality” is that it makes a clear link with the Equality Act 2010.

The Equality Act identifies groups in the population who may experience discrimination and disadvantage, defined as groups with ‘protected characteristics’, such as race or ethnicity. The Act puts the onus on society at large, not members of those groups, to address inequalities by prohibiting discrimination based on a person’s protected characteristics. It requires organisations to make “reasonable adjustments” for its employees, customers and service users with protected characteristics so they are not

Toby Williamson is an independent consultant who does research and evaluation, workforce, service and policy development work, in adult and older people’s mental health, dementia, and mental capacity. He was supported by colleagues on the Dementia Community EDI Working Group: Karan Jutlla, Jude Sweeting, David Truswell and Lucy Whitman.

Summary

We explain what the terms equality, diversity and inclusion (EDI) mean in the context of service delivery, care and support for people affected by dementia, including family carers. Our aim is to show how equality legislation can help good EDI practice focus on different groups in the population who may experience disadvantage and discrimination, such as minority ethnic and LGBTQ+ communities.

We also emphasise that EDI is at the heart of all good person-centred care in dementia because dementia can be considered to be a disability and people affected by dementia have many identities including ethnicity, gender, sexual orientation and age; this is known as ‘intersectionality’. In conclusion, we outline key principles and practical guidelines for practitioners and organisations to put EDI into practice.

disadvantaged or excluded. Examples include “cultural competency” training for customer-facing staff about LGBTQ+ issues, or making shops and workplaces accessible for people with physical and sensory impairments. The Equality Act therefore aims to put equity into practice.

Cognitive impairments caused by dementia can constitute a disability which is a protected characteristic, so people with dementia are covered by the Act. In some ways “dementia friendly communities” reflect the spirit of the Act and a commitment to ensuring greater fairness for people affected by dementia, including raising awareness and challenging stigma through the Dementia Friends initiative, and the provision of dementia-inclusive design and signage in buildings.

Some factors that can lead to inequalities and disadvantage are referred to in the Act but are not defined as protected characteristics. These include caring responsibilities and socio-economic disadvantages, such as having a low income or living in a socially deprived area. (The latter can put people at greater risk of developing dementia compared to more affluent people (Voluntary Organisations Disability Group 2016)). Other groups not named in the Act, such as travellers, homeless and prison populations, and geographically isolated groups, may also experience discrimination and exclusion.

“Diversity” reflects society’s broad mix of people and communities. It relates in part to different population groups as defined by their protected characteristics but also refers to differences between individuals. Recognising and

“EDI doesn’t really apply to us.” Or does it? A case study

All the residents in a dementia specialist care home are of white British heritage which reflects the community where it is located, although the home has very few links with the community. Most of the residents are women. How might EDI apply? Just because the demographic characteristics of the residents appear quite similar, this doesn’t mean there isn’t diversity:

- White British people may have Irish, Jewish, or eastern European heritage for example and this may be reflected in their faith, family experiences and culture. Do staff have knowledge of this?
- Residents who identify as LGBTQ+ may be fearful of coming out in case they experience discrimination or abuse from other residents or staff. How can the home ensure that all residents feel safe to be themselves?
- Men experience a health inequality because they have shorter life expectancy than women. This means that activities for people with dementia are often female-focused which can exclude some men. Treating all residents equitably may require some separate activities for men. (The Men’s Sheds movement is a good example of this – see www.menssheds.org.uk).
- Inclusion doesn’t just mean involving residents in activities in the home. It also means that the home is part of the wider community and residents can continue to participate in community life as much as possible. Does the home support residents to go into the community, and invite the community into the home for events and projects?

responding appropriately to the diversity of individuals, and the population groups they are part of, is a key component of person-centred dementia care. As the saying goes, “When you’ve met one person with dementia, you’ve met one person with dementia.” But it’s vitally important also to understand the population group they are part of, such as their gender, their age, and whether they belong to a minority ethnic or LGBTQ+ community. In many cases, an individual belongs to more than one group which experiences discrimination and disadvantage, such as being black and gay; this is known as “intersectionality”.

“Inclusion” should also be a key component of person-centred care. Inclusion in dementia care means ensuring that no one affected by the condition is excluded from their communities or from services because of dementia-related stigma or discrimination of any kind. Generic services used by people with dementia, from GPs through to shops, public transport, or cultural and leisure organisations should ensure they are dementia-inclusive and accessible. Inclusion also means that services providing dementia care and support must ensure that they are not inadvertently excluding people with protected characteristics, especially those from minority communities. Dementia practitioners and services may need to be proactive in reaching out to specific communities.

The Equality Act prohibits discrimination based on age, and it is worth noting that for people with dementia, age discrimination may work in more than one way. Older people experience discrimination in society, and dementia is associated with old age, which may explain why dementia services and research are not as well-funded as other widespread conditions such as cancer. However, people who develop dementia at a young age are less likely to get a timely and accurate diagnosis than their older peers, and may find that the only support available is inappropriate for them, and experience additional discrimination and exclusion.

Awareness of human rights is another vital component of EDI. The UK has signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This aims to make human rights meaningful for people with disabilities, taking into account additional disadvantages they may face. Like the Equality Act, the UNCRPD includes people with cognitive impairments, and services for people with disabilities should be compliant with it. The UNCRPD protects individuals, but also places a responsibility on wider society to ensure that people with disabilities have the same access to services and can participate in their communities on an equal basis with people who don’t have disabilities. This is based on the ‘social model of disability’ (McGettrick & Williamson 2015).

Some people with dementia and family carers have been involved with working out how different aspects of EDI can be of help to them, including their rights under the Equality Act and the UNCRPD (DEEP & Innovations in Dementia 2016). But EDI applies to all people with dementia, whether or not they are aware of it, so the responsibility for putting it into practice lies with organisations and practitioners.

EDI principles

EDI may sound very challenging, but we have devised the following principles and guidelines to help organisations and professionals understand and implement EDI in the context of dementia.

- All communities are heterogeneous (diverse), not homogeneous (the same). Within wider society, differences in physical appearance may be more visible, while differences in sexuality or cultural heritage may be less visible. Some disabilities, including dementia, may be “hidden”. There are also many differences within communities – between people who share some characteristics but not others. It is also important not to make assumptions about anyone: having a Muslim name doesn’t necessarily mean that someone is a devout Muslim; the fact that someone has children doesn’t mean they can’t be gay or trans. Good person-centred care is about knowing the person.
- Dementia may not discriminate but it can exacerbate inequalities. Some groups who already experience health inequalities are more at risk of developing dementia (e.g. the very old, people of black Caribbean heritage, people with learning disabilities, people on low incomes).
- All organisations and services used by people with dementia need to be aware that the impairments caused by dementia can constitute a disability as defined by the

Equality Act. People with dementia are also protected under the UNCRPD. People with dementia may have additional disabilities as well.

- Intersectionality potentially applies to everyone affected by dementia because individuals may have several protected characteristics (disability, age, gender identity, etc) and may experience multiple discrimination and disadvantage (e.g. racism and homophobia).
- EDI is not an add-on to person-centred care but is a key component of it. Good person-centred care involves recognising diversity among people with dementia and their families, and responding to this in a positive, supportive and inclusive way.
- Language and terminology are important – criticisms about being “woke” or “politically correct” are unhelpful and disparaging, and undermine efforts to address inequalities that different groups experience. Proof of language being important and people’s willingness to change what they say is evident from the fact that words commonly used in pejorative ways 20 years ago are now considered to be deeply offensive.
- Some minority communities may require specific dementia support tailored to their needs.

EDI guidelines

We suggest the following guidelines for organisations to put EDI into practice:

- Every organisation should have an EDI policy and clear public EDI commitment. You may find it useful to refer to the National Institute for Health and Care Research (NIHR) Equality, Diversity and Inclusion Strategy 2022-2027, to help you identify the areas your policy should cover.
- Organisations should review their policies, procedures, quality assurance and public information about the organisation, to ensure it reflects current EDI good practice and is compliant with EDI legal frameworks and conventions (Equality Act, UNCRPD).
- Organisations that support people with dementia should carry out an audit to check whether people from all communities are accessing and benefiting from the service.
- Organisations should appoint someone senior as the EDI lead. They should be familiar with EDI legislation (Equality Act, UNCRPD) and good practice, and understand how it applies to the service they offer to people affected by dementia. They should provide or commission EDI training for all staff, be involved with the EDI reviews of policies, procedures, quality assurance and public information, and be able to advise staff on EDI issues.
- All staff and volunteers should be required to undertake EDI training relevant to dementia and it should be part of the induction process for new staff and volunteers.
- Training should make explicit that EDI is a key component of good person-centred care in dementia.
- Meaningful and properly supported involvement of people with lived experience of dementia is essential to

Key points

- EDI stands for equality, diversity and inclusion. “Equity” is sometimes used instead of “equality” but we prefer the latter because it makes a link with the Equality Act 2010.
- People affected by dementia may experience stigma, discrimination and disadvantage for a number of reasons, such as age, gender, ethnicity, sexual orientation, and disability (which includes dementia). The Equality Act calls these “protected characteristics”. The Act prohibits discrimination, and actively promotes inclusion through a requirement for “reasonable adjustments”.
- EDI emphasises the importance for practitioners and services to be aware and responsive to the different needs of particular groups affected by dementia, especially minority communities such as black, Asian and minority ethnic communities and LGBTQ+ communities.
- Someone’s identity is made up of many factors, not just one such as age, ethnicity or dementia. This combination of factors is known as “intersectionality”, so EDI applies to everyone affected by dementia, and all practitioners and services. EDI is an essential component of good person-centred dementia care.
- Dementia practitioners and organisations should consider how to apply the principles and guidelines described in this article in their everyday practice, policies and services provided to people affected by dementia.

EDI good practice through co-production, advisory groups etc. Involvement initiatives should reflect the diverse communities an organisation seeks to work with.

- Specialist dementia organisations should be able to demonstrate their commitment to EDI through policy, practice and public information which incorporates diversity and inclusion, eg, websites and leaflets should include images of people with young onset dementia, same sex couples, people from black, Asian and minority ethnic communities, etc; staff should have relevant expertise and be trained to develop constructive relationships with people from minority communities, etc.
- Generic health, social care, housing, and other public organisations that regularly support or come into contact with people with dementia should be able to demonstrate their commitment to EDI through policy, practice and public information which is inclusive of people with dementia, and reflects their diversity, eg, holding Dementia Friends awareness sessions and cultural competency training for staff and volunteers; dementia-inclusive audits of physical environments, information, services and staff practices, co-production, etc. ▷



- Specialist and non-specialist organisations supporting people with dementia should work in partnership with organisations representing or working with minority communities to better understand their histories, values, cultures and needs, to enable services for people affected by dementia to be as inclusive as possible. It is also important that those community organisations are dementia aware.
- Organisations need to have an explicit commitment to an open, learning culture about EDI. This includes not being afraid of “clumsy” conversations or making mistakes, and asking (and answering) questions, to better understand people from diverse communities affected by dementia and know what terminology is preferred.
- All organisations need to recognise that their employees and volunteers might have dementia or be caring for someone with dementia (including young onset dementia) and be aware of the types of reasonable adjustments they can make to comply with the Equality Act, eg, to enable employees affected by dementia to continue in work.

Conclusion

EDI in relation to dementia should not be seen as only relevant to certain services or in certain areas, or as too difficult or niche to implement. If you are providing good person-centred care, you will be responding to the diversity of experience and needs that people affected by dementia have, and doing this in a way that that does not exclude because of age, ethnicity, sexual orientation, low income or any other characteristic.

Addressing inequalities and inequities will therefore be a central part of what you do and EDI will be embedded in your work, and professional DNA.

We hope this article will help all practitioners and organisations to apply EDI in dementia care. EDI should be embraced – it’s what “good” looks like.

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Diversity and inequality in dementia care

There are notable inequalities both among people living with dementia and within the dementia care workforce. **Jill Manthorpe** explores the many social factors that can determine people’s experience of dementia and dementia services, and argues that reducing inequalities needs to be part of person-centred care and policy.

We are beginning to know far more about the links between public policies which have led to increased inequality in our society and the experiences of people affected by dementia who come from socially disadvantaged communities. The contents of this issue of the *Journal of Dementia Care* show the wide variations in personal experiences and suggest critical points to debate as we move towards the countdown to the next UK general election, scheduled to be held no later than 28 January 2025.



The greater diversity of people affected by dementia, as evident in visual presentations in policy, service and professional websites and documents, has been emerging over recent decades. But people affected by dementia have always been diverse, hidden in plain sight as residents of

Summary

This introductory paper considers the many facets of diversity affecting people living with dementia and carers. This is at a time when equality, diversity and inclusion are being promoted within services and research.

In the UK public policy has paid increasing attention to this subject with the advent of the Equality Act 2010 placing requirements on services to demonstrate they are fair and equitable. The financial position of people living with dementia and their carers may compound other disadvantages and this needs to be acknowledged by services and professionals.

Diversity in dementia also applies to the dementia care and support workforce. Reducing inequalities needs to be part of person-centred care and policy.

Jill Manthorpe is emerita professor of social work at King's College London.

long-stay hospitals and previously Poor Law hospitals and workhouses, or staying at home with family in conditions of care but also sometimes of neglect.

For the better off there were servants and companions to provide support, aided in families of all circumstances by single daughters or “needy” relatives, and sometimes at their mercy. For the poor there was the workhouse, the back wards of asylums and hospitals, or living on parish charity and their family or worse. The financial circumstances of people living with dementia have been treated as largely reflective of social conditions of the times. What then has changed?

Poverty is the price of disability

First, we have learned from disability activists and advocates that poverty is the price of disability for many people, as well as often the cause. The loss of potential to earn from employment for people who are less able to work when facing cognitive decline means for some people with dementia there is a rapid loss of income. Often more gradual is the impact of providing family care, since carer leave for people in the UK is very limited and family carers often give up paid work to support their relative.

Finnish researcher, Teppo Kröger (2023) argues that there are three different domains of care poverty among older people (personal care poverty, practical care poverty and socio-emotional care poverty). This can help us think about deprivation as wider than in simple monetary terms. Indeed, a term often used in the context of high owner occupation in England is that many older people are “capital rich and income poor” which applied to dementia has many implications, such as wanting to stay in one’s home and neighbourhood but feeling unable to take on the upheaval of repairs, renovations, and insulation or the runaway costs of a warm home.

As covered in *JDC* across the years, some very helpful initiatives can help here but they are not widespread and the resources may not be available to do the outreach work necessary to engage with families or individuals affected by dementia who might not trust the offers being made. Loss of trust has been the consequence among some groups of the pandemic experience, compounded for some by the Windrush scandal and continued compensation delays.

But, as other disability experts note, money does matter. There are increased costs and expenses of living with illness and long-term conditions. These arise from the need for extra heating, wear and tear on clothes and furnishings, special foods, equipment, travel costs and care costs. While some government help is available for such expenses, the under-claiming of benefits is substantial and often a complex process.

Surprisingly the implications of poverty, financial disadvantage and quantification of the costs of being affected by dementia are not commonly mentioned in dementia discussions, in contrast to the debates about housing inheritance. It is hard to think how anyone can “live well with dementia” when troubled by financial worries, and perhaps approaches such as “poverty proofing” services could be applied to dementia support (see Kersley 2023).

Current interest in the impact of the rising cost of living may be one way in which this subject is coming more into

Key points

- People living with dementia have always been diverse but this has not been acknowledged.
- Financial resources affect people’s experience of dementia and that of their carers.
- The dementia support workforce is diverse, and many experience financial insecurity.
- Such inequalities are increasingly well evidenced by research but research recommendations are not generally taken up.
- Intersectionality is of increasing importance to effective care and support for people affected by dementia.

the open, but wider than this is growing interest in the social determinants of health, through which poverty plays such a huge part in health and life inequalities. Perhaps one next step for dementia research and services will be to join up with groups worldwide and nationally seeking to promote greater health equity (<https://www.instituteofhealthequity.org/>)

Care equity matters too, for years of reductions in local government finance have meant many people living with dementia have been excluded from publicly funded social care or have had their care and support reduced. For those whose carers have had to give up employment or reduce their work commitments there will also be long-term disadvantages of reduced pensions in later life.

Cultural competence in dementia care

The second point is the growing appreciation that culture, ethnicity and migration combine together to form the person at the centre of ambitions for person-centred care. The new third edition of the edited textbook, *Ethnicity and the Dementias* (Yeo *et al* 2019), points to the need for dementia care to be culturally competent, with race and ethnicity understandings and knowledge needed in clinical care and health planning. This accumulation of evidence, mostly from the United States (US), covers both genetic and cultural factors, prevention and treatment, and enfolded family care within its separate coverage of 11 ethnic groups relevant to US dementia care.

Yeo *et al*’s revised text will perhaps be increasingly relevant to UK practice as new migrant groups are likely to seek dementia support, such as the small but growing Latino-American population. As with any other health and care provision, understanding local populations will be an essential part of dementia care practice and service planning. No longer will it be enough, if it ever was, simply to draw attention to growing numbers of older people, since their heterogeneity is remarkable.

Diversity among people affected by dementia applies too to the workforce, particularly in social care. Largely female and with people from minority ethnic groups over-represented in this workforce, it is also characterised by the problems of low pay and often insecure employment conditions. As Curry *et al* (2023) note, these problems were building up for several decades, only to be amplified by the stressors of the pandemic. Care for people affected by dementia has surely got to include care for people on

minimum wages, zero hours contracts and with poor terms and conditions of employment. Too often, little is said about how such conditions and associated worries and pressures must be affecting people receiving social care support.

Genuinely inclusive services

Dementia services that are genuinely inclusive are likely to be effectively responsive to the needs of all communities in our diverse society and this issue of *JDC* contains many examples of what people can do to make positive change. The Equality Act 2010 was a substantial move forward in many respects, not least enabling us to talk of “protected characteristics” in a meaningful way and to take small but important steps in collecting data and then thinking about what it meant.

Some time ago my colleague Jo Moriarty and I were asked to report the evidence on access to services by diverse older people and explored areas such as day centres, befriending schemes, falls services and handyperson services. We found that many did not collect data to show that they were offering services that reflected the communities they served (Moriarty & Manthorpe 2012).

However, the UK has far more data now, particularly from the NHS but also social security/taxation records and much increased analytical capacity. The interplays between race/ethnicity, sex, sexuality, gender identity, class/socio-economic status, lifelong/recent deprivation and dementia, and indeed of other protected characteristics (the terms used in the Equality Act 2010), could be more often analysed and then re-analysed. It may be that new studies are needed, but not before existing data have been used to their maximum realistic potential.

A recent example of making good use of data comes from Mukadam and colleagues (Mukadam *et al* 2022) who linked NHS primary care electronic health records, hospital episode statistics and mortality (death) data for people aged 65 years and over. They found dementia incidence was higher in black people than white, and that South Asian and black people living with dementia had a younger age of death than white participants. Implementing the recommendations of such studies, of which there are increasing numbers, should perhaps be a joint priority for the dementia community.

Sadly, researchers have not always been the shining light in providing evidence of diversity in their studies and reflecting on the subject, with notable exceptions in the UK, where this work has been covered since the early days of *JDC* and the UK Dementia Congress. Influential funders such as the National Institute for Health and Care Research (NIHR) are now far more insistent that research should be inclusive in its values, operations and excellence.

Unlike many others making commitments to this, NIHR has acknowledged the reasons why EDI (equality, diversity and inclusion) is so important to research: “Matters that have been highlighted nationally and globally include concerns around inequitable funding; under-representation in research participation; complex cultural issues of bullying, harassment and victimisation; and imbalances and

inequalities associated with sexual orientation, gender identity, socio-economic status, geographic location and ability to access health and social care.” This list applies equally of course to dementia research.

As the NIHR and others acknowledge, it can be useful to start change processes with thinking about the protected characteristics of the Equality Act 2010, say in relation to access and acceptability. However, any EDI strategy needs to extend to other factors which may also impact health and social care inequalities: “The concept of intersectionality – a framework that acknowledges that all people have unique experiences of discrimination and disadvantage exacerbated by the overlap of multiple social identities – is also fundamental to this strategy” (NIHR 2022).

Intersectionality is threaded through the contributions to this issue of *JDC*. Whether writing of personal or professional experiences or highlighting good practice, there is substantial evidence that good dementia care is built on the foundation stones of person-centredness, which has to include thinking about a person’s identity, relationships and their social context.

Combined with growing understanding of the social determinants of health and wellbeing, dementia care seems to be moving from understanding to thinking more about how to promote equity and social justice and what gets in the way of this. In this way, EDI developments may help other changes wanted by people affected with dementia to the benefit of all.

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The Centre for Applied Dementia Studies is one of the UK's leading centres for research into living with, and caring for, people with dementia and their families. We carry out high-quality pioneering research, deliver innovative education (MSc, PG Cert), training and consultancy alongside clinicians and professionals. Our activity is supported throughout by those living with dementia and carers (experts-by-experience).

Interested to chat?

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 <https://www.bradford.ac.uk/dementia/>

 @Dementia_UoB



The Blue Road to Recovery

Ronald Amanze (aka Ronald Ferguson) is writing a book about his life with dementia, with help from David Truswell. Here is an edited extract from Chapter 2: *The Blue Road to Recovery*.

I want to be honest about my experiences and what I feel. Especially as someone who feels that my heritage has brought me certain consequences which have really impacted on my health. My biggest motive for wanting to write a book is to share my experiences, in the hope it may lead to a training module for social workers and care services, as I invariably feel stigmatised and misunderstood due to outdated and inaccurate assumptions about dementia and my heritage. They so often seem to miss the main theme of what I'm actually trying to address, which is normally about me reaching out for some support and some help. I'm not one to ask for help unless I'm desperate.

I've realised that perhaps the book should start at the point where I had the stroke which changed my life. I woke up in Ward 17 of the local hospital, unable to walk, my vision all over the place, with an intense constant pain in my neck and respiratory difficulties. I was still alert and in tune with everything, but just unbelieving that I was still here and still alive. I literally thought I had died. Because when I got the first stroke, before the ambulance arrived to rescue me, I remember I thought I was going to die – only to wake up in the stroke unit alive and becoming a completely different person with new rules to my life. And not even realising that I had new rules to my life, because I was still arguing with the world. Or, should I say, the world was arguing with me.

I ended up falling out with all the doctors in the hospital. It escalated to the matron and the senior hospital personnel coming to meet me. It escalated to patient security being brought onto the ward. It escalated to me almost starting a campaign while in the stroke unit, just to get an MRI scan, and it ended up with my daughter and all the family asking, "Why is Ronald in here, when is he getting an MRI scan?"

I never received closure on that situation. I thought, "I'm in the stroke unit. I must've had a stroke because that's why they brought me here. But they haven't given me an MRI scan." And when they did give me a scan, suddenly it was as if all the alarm bells started ringing: "Ronald you've had a stroke! You've also got a blocked artery in your neck. And if we'd caught it earlier, we could have possibly unblocked it."

And I'm lying there thinking, "But I had a stroke in front of you in hospital and that was six days ago! Whereas if you had given me an MRI scan like everybody else gets, you would have found the blockage in my artery. Now I have to live with



this condition." And who knows, the reduction of oxygen to my brain might be responsible for the onset of dementia that I've got. It might be burning out my brain cells.

All the changes that have occurred in my life still traumatised me. They are things that I keep on referring back to, because I think people should learn that a lot of health issues that people have to live with are because the medical professionals don't pick up on them. Because mistakes do happen, and mistakes often happen in respect of people of my heritage because we are deemed to be frantic and

aggressive. Because I was too frantic, to the extent that they brought in security. Even in my medical report which I've got from the hospital.

When you look at my medical reports, one of the comments they made is, "All nurses are instructed to walk in twos when they attend Mr. Ferguson's bed." I said, "What!" It's in my medical report. It's remarkable. I'm in a stroke unit, I haven't had an MRI scan and my behaviour is frantic, and no one could work it out other than to say, "Oh no, you're being aggressive. We've got a little room downstairs for people like you." Then when I came out of hospital, I said let me get my medical report and all the MRI scans and when I read it, to my amazement it said all the staff were instructed, "When attending Mr. Ferguson, always walk in twos." Remarkable. That's because I was perceived as being a problem before I got the MRI scan, which they should have given me at the beginning.

After I'd had the MRI scan, the conversation became, "Mr. Ferguson you've had a very serious stroke, no wonder you're feeling those pains, no wonder you're anxious." Because now they could see what they had missed, and understand the reason for my behaviour. Because before, when I was in pain, crying out for assistance and no one would give it to me, I was seen as being aggressive. Nobody could understand my behaviour other than to say, "You're being aggressive and you're being a problem." Now on my medical report it said, "You have sustained a very large damage to your brain." Then I said, "Very large, not large?" They said, "No. Very large." They kept on looking at me. I think for the damage that was sustained to my brain they couldn't understand why I was so full of jubilation and enthusiasm. And they said because of the damage I shouldn't be able to walk straight upright, because theoretically someone who gets the damage like I'd got should be walking differently. And I was walking like that for a long time.

I'd be in my bed and the nurses would say, "Mr. Ferguson stay in your bed and don't get out," and as soon as they left the room I'd get up and try to walk. Also, for the first five

Ronald Amanze is passionate about the role of creativity in improving the quality of life for all living with dementia. A music producer by background, he has weekly "Talk Dementia" shows on Deepness Dementia Radio and Kbitplay.com, and is a Dementia Diarist with DEEP and a Trustee of Arts4Dementia.

days they used to bring in people to do the therapy to get people moving. But no one was attending to me. Nobody would come and say, "Let's get you moving. Mr. Ferguson. Let's get you out of bed." They ignored me because they were told, "Ignore Mr. Ferguson, he's a problem."

Then after I got an MRI scan, straightaway that afternoon they said, "Come on, we need to get you moving Mr. Ferguson, you've had a stroke." And then they said, "We need to get you on medication." Then the doctors came, and it was amazing. For a long period of time I thought, "I can't have had a stroke because I'm not being treated like a stroke patient." Because all the other people around me were being treated with a lot of attention and people coming and going and attending to them and I was just in my bed all the time. Fortunately, I had visitors. I had a lot of visitors. That all I got. I didn't get any medical attention.

But once they realised I had had a stroke, I got first class medical attention, more than anybody in the ward. It was crazy. It's like they discovered they had made a mistake and from then on, I got on with all the nurses; we got on amazingly, to this day. When I had a relapse and I went back into hospital, one of the nurses actually cried to see me again, and she said, "Oh, Mr. Ferguson we're so sorry to see you back here." All the nurses became my friends. Amazing, all the nurses who were fighting with me became

very sentimental towards me.

In addition to the hospital experience, there was the leaving the hospital experience and a period in which I was not leaving my house; I was not eating, I was not really washing properly. There was definitely no heating in my house. A lot of people tried to get me out of my house, rescue me and no one could do that, and then an amazing social worker came into my life, and she rescued me.

In her report, she says that when they came to see me, they were really worried. They didn't know what to do and did not know how to get me back on track again. I was missing all my appointments. I refused to go to PIP (Personal Independence Payment) appointments because I wanted to go back to work, and they were telling me I couldn't, because I had a brain injury. In fact for four years I needed to attend Headway (brain injury association <https://www.headway.org.uk>). It was at Headway I first noticed the difficulties which led to various x-rays and memory assessments and a dementia diagnosis.

The social worker's report shows the tremendous improvement that I've made because of this help. The social worker was a lady called Maria Pugh and she's one of the best people I have met in my life. This social worker saved my life.

Watch a film about Ronald: *Amanze – A Portrait of a Pirate* by Lucy Hawes

<https://www.youtube.com/watch?v=brGWHiEe-S0>

Portrait of a researcher

Teresa (Dory) Davies (below) was diagnosed with dementia 11 years ago and is a Dementia Pioneer, one of a group of people living with dementia leading the Dementia Enquirers programme. She told **Lucy Whitman** how dementia has 'given me wings!'

I was 59 when I got my diagnosis. But there was no support. They just suggest you go home and get your power of attorney sorted. They don't hand you any hope.

And I thought – I've overcome an abusive marriage – stayed positive through that; and then I'd had a car accident when I was 45, and they said I might never walk again. I was on the pavement, and a car hit me at 80 miles an hour. I broke my neck in four places and my leg was smashed. I had a head injury, and they say that's probably what brought on my dementia. It took me three years to get out of neck braces. But I stayed positive.

But when I got the diagnosis of dementia I thought – I can't fight this one. They gave me no hope, and said I had



five to eight years life expectancy.

It wasn't until I got introduced to the DEEP network that I started meeting people in the same boat as me, and they helped give me confidence. I started public speaking then, because I realised it's not the end, when you get a diagnosis. You can still have a life.

I did a talk somewhere, and a few months later I got a letter, that said, 'Dear Teresa, I heard your talk. I was living with my mother who had dementia, and we were always arguing, but after listening to your talk, I went home and interacted with my mother and went along with her reality. Thank you, because you gave me my mother back. In the last six months of her life she was happy, and relaxed.' And do you know, I thought, 'If I can help one person...' That's why we do it. All of us who go out there and challenge things.

When I was invited to join the Dementia Pioneers. I must admit, the first meeting that I went to, I thought, 'I don't think this is for me.' Because it seemed very academic, and I didn't think I was up for it. I left school at fifteen with no qualifications. I wasn't even put in for any exams, because

Dementia Pioneers

The Dementia Pioneers are a group of people living with dementia who were invited by Innovations in Dementia to lead their Dementia Enquirers programme. The Dementia Pioneers worked together, with support from experienced academic researchers, to develop a new research methodology which puts people with dementia "in the driving seat" of dementia research: choosing the topic, the research question and the methods.

Lucy Whitman is a writer and editor. Lucy's anthology of personal accounts by people living with dementia, People with dementia speak out, is published by Jessica Kingsley Publishers.

you had to be in the top set to sit any GCSEs.

But I thought, “See how it goes.” I went to other meetings, and I found it *could* be for me. They gave me the support, and everything was explained. And once I understood what was expected, I found that I could understand what was being asked, and had the confidence to give my point of view. Because I never had that. Because of my abusive marriage, I was made to feel stupid and of no consequence.

Innovations in Dementia and the DEEP network have really made me feel valued. Plus the other Pioneers as well, people living with dementia. The group were very supportive and we would talk each project through, and work it all out between us.

I do talks at Bangor University for the second and third year and the Masters student nurses and doctors. And the researchers at Bangor, they ask me to help a lot with things they do. I took some of the Dementia Enquirers packs for them and they were very impressed.

When we won the Dementia Heroes award for our pack,

and for the work we’ve done, I just felt so proud. Proud of everyone that had been involved, because we **will** change things.

On the pack, it says “Teresa Davies, Researcher”.

I was asked once, what was my happiest decade, and I said, “My sixties.” And they said, “But that’s when you got your diagnosis of dementia!” I says, “Yeah, and I’m happier now than I’ve ever been. It has changed my life for the better.” Before I had dementia, I’d never travelled anywhere. I’ve met all these wonderful people from all walks of life. I’d never have met them otherwise. It’s given me wings!

Meet the Dementia Pioneers:

https://www.youtube.com/watch?v=b0YOgiGZjZw&list=PLYEHjkaV2Fx0_V-ty6T43Gxh3EuxG8RTC

Find out more about Dementia Enquirers:

<https://dementiaenquirers.org.uk>
<https://www.alzheimers.org.uk/dementia-professionals/conferences-and-events/dementia-hero-awards>

Caring without culturally appropriate support

Jagdish Brar-Orgill describes caring for her mother with dementia at a distance without culturally appropriate support, and shares the pain of her mother’s last days in a hospital ward without compassionate end of life care

A year after my husband and I adopted our longed-for, amazing daughter, who has a rare condition, I gave up my career to become Mum’s carer. Following her diagnosis of dementia in 2017 (and in hindsight, Mum had been displaying symptoms since 2012), I was advocating for Mum on all fronts, being pushed from pillar to post by service after service.

Being a long-distance carer, I fell in between the cracks. I wasn’t eligible for official support, nor could I be assigned an Admiral Nurse. There was no dementia pathway in Mum’s borough, so I was the coordinator for all the fragmented services. It became my full-time job.

It was imperative to keep Mum in her home but there was no culturally appropriate support available. I was constantly having to explain why Mum had reverted to her native tongue, having spoken good English. I was faced with mixed messages, with the GP telling me there was no care in the community, and being told otherwise by other professionals.

My pain, desperation and gut-wrenching crying was off the scale. Stress and grief were my everyday norm, which took a toll on my mental and physical health, not to mention on my marriage. I firmly believe that the lived

experience of carers like me should be an integral part of research, and should influence policy makers.

I recall being told by a senior official, when they discharged Mum from the mental health team, that it wasn’t worth raising my concerns with the clinical commissioning group, as it was then called, as to why there were no resources serving the South Asian community, as it comprised “white middle class people” who wouldn’t listen to my issues. I never got the time to follow this up, as I was constantly firefighting.

I endured conscious and unconscious bias. I was my Mum’s voice, and yet, if I questioned anything, as a woman of colour, asking health professionals questions while overseeing Mum’s care 24/7, I was deemed “aggressive”. My experience was that dementia services are Caucasian-centric. But dementia doesn’t discriminate.

I know many carers before me from marginalised communities have voiced similar concerns over the years and yet nothing has changed. We are still an afterthought, a tick box exercise for services and organisations.

I left no stone unturned to source culturally appropriate carers – even approaching Indian women in supermarkets, I was that desperate. I reached out to my community, Gurdwaras and even Sikh public figures – all to no avail. I trained, managed and guided 30 Punjabi Sikh carers, who knew nothing about dementia. Only three were compassionate and trustworthy. Mum was abandoned by absolutely everyone, except my sister and me.

I learnt about dementia the hard way and knew

Jagdish Brar-Orgill is a tenacious activist who gave up her career to care for her Mum, and hopes to use her lived experience to raise awareness, influence decision makers and improve services for marginalised communities.

everything about my Mum's health. I had to navigate my way around the care system to fight for all services, the speech and language therapy team, community matrons, district nurses and so on. In 2019, I asked for a multi-disciplinary team meeting and a care plan, which amounted to nothing. Carers like me aren't listened to or heard, despite managing every detail of our loved one's care.

I had care professionals advising me to put Mum into a care home. My response was always that it would fast track Mum to the inevitable, as her home of over forty years was her haven and held so many memories for her. Culturally appropriate care was essential in terms of language, music and food which she wouldn't necessarily get in a care home.

Latterly, I was diagnosing Mum and knew when Mum had an aspirating attack, sepsis, oral thrush which was overlooked by professionals, and yet I still wasn't listened to. I monitored everything in Mum's house and knew Mum's food and fluid in-take, or if she had engaged in activities. The lymphoedema I flagged up with palliative care was never addressed. I couldn't even cuddle Mum in the last week of her life in hospital, as her limbs were so swollen.

Community matrons stopped making home visits six months before Mum passed away, and over the same period, I was told on two occasions by a clinician from palliative care that Mum "didn't warrant a visit" from them. These words still haunt me. Mum was displaying psychotic episodes in January 2022, and unbeknown to me, they were the beginning of the end.

My beautiful Mum passed away in May 2022. She had been denied end of life care. It was painful for Mum and traumatic for me and my sister. I'm still trying to manage the trauma of the failings I witnessed.

I had called Mum's GP in April and explained that she had been coughing for months, and we knew what that could lead to. The GP gave me the same speech as he had in 2021, saying that he'd never come across a patient who had been afforded so many services and so much time. In 2021 I told him that I had had to fight for all the services she had received, and pointed out that in the time it took me to call for an appointment to discuss my concerns, it would have been easier for him to drive five minutes down the road to visit Mum personally.

He reacted by suggesting I seek another GP Practice. However, when he repeated this same speech to me in April 2022, I remained silent. I told my sister I never wanted to deal with him again. When the GP visited Mum the following week when my sister was looking after her, he said he was far more concerned about my mental health than about my Mum. Yet at that point, she already had the infection that would prove fatal.

Three weeks later, Mum stopped eating. The kind carer couldn't wake her up, and her oxygen levels had dropped dangerously low, so I dialled 999. The carer accompanied Mum in the ambulance. I texted her all the relevant information about Mum's current health and drugs to show the consultant within A&E. I also spoke to him, and Mum



Jagdish (right) with her mother Gurdev Kaur Brar and her sister, Cooky

was admitted. But if the palliative care team or GP had intervened at home, I wouldn't have had Mum hospitalised as she had wanted to pass away in her own home. I remember vividly, Mum was dazed and distraught, with tears appearing from the corners of her eyes. She hadn't spoken for days. I massaged her head gently whilst she was sat upright, and kept on kissing her head and comforting her while crying. I was with Mum all week and was asking the right questions as I always did, but it was as if I was paralysed in pursuing the

answers this time. Mum was admitted on a Sunday, but I wasn't able to speak to the consultant on the ward until after the bank holiday, and he was just so dismissive. My sister and I kept chasing the hospital palliative care team, but no one visited Mum for five days.

When someone finally showed up, she said she had skimmed Mum's notes and in her opinion, Mum had six to twelve months to live. My response to her was, "Mum has barely got six days, let alone six weeks!" Yet my words weren't even registering with *me*! I was on autopilot, as I always was, so I lost sight of what was unfolding right in front of me.

I don't recall watching my Mum drift off on the Thursday night. It was only when I woke up at 4.30am on the Friday and alerted the overnight nurse, they realised Mum's cannula had become detached. Shortly after, two separate consultants tried to cannulate Mum. They couldn't, as Mum's arms and legs were swollen, so they couldn't find a vein.

At this point, I was still liaising with the secretary from the palliative care team at the hospice. I asked for the vascular assessor to insert a picc line (which delivers medication close to the heart) and had to wait until he started his shift at 8.30am. When this failed, and they tried the other shoulder, Mum's blood pressure dropped dramatically. That's when my sister and I were told Mum only had a few hours to live.

I had to plead with the nurses to move Mum into a side room. They couldn't as the ward was busy. I was distraught. The ward sister showed compassion, and emptied a side room. (Why hadn't I approached her with my concerns before, as I had always done during previous numerous admissions?) An hour later Mum drew her last breath.

No one told me that Mum had reached the end of life, and so my sister and I were denied quality time with her at the end, as we were still chasing medical professionals. The hospital ward just wasn't equipped for end of life patients.

I'm crippled with layers of grief, having looked after Mum and micro-managed all her care for over six years, while watching her deteriorate from this cruel condition. The trauma I witnessed, especially during her last days in hospital, layered with grieving the loss of my beautiful Mum – the injustice of it all! I still feel I let her down. The images in hospital haunt me every single day. My beautiful Mum deserved better.

Once I had a secret love

Pauline and Hilary Nowell talk to Lucy Whitman about the value of “rainbow” support groups for LGBTQ+ people affected by dementia

Since Pauline’s diagnosis with vascular dementia in 2019, she and her wife Hilary have received excellent personalised support from their local Alzheimer’s Society branch, and enjoy going together to Singing for the Brain, where they have always felt welcome.

Nevertheless, Hilary says it was “life-changing” when they started attending the LGBTQ+ dementia support groups at Opening Doors London: the *Speak Out with Dementia* peer support group for Pauline, the *Rainbow Carers Group* for Hilary, and the *Rainbow Memory Café* which they attend together. Hilary says “the three different groups have all been vital to our own individual journey and acceptance. If we hadn’t had them it would have been like losing a limb.”

Hilary insists “it’s hugely important for Pauline and me to be able to attend the Rainbow Memory Café as a couple. We feel comfortable amongst like-minded, helpful people, who have come together with mutual respect. In a gay group one feels safe and free to be able to discuss very personal subjects that others in the group know about and have experienced.”

Pauline and Hilary have recently starred in an Alzheimer’s Society film about their enduring love, and their determination to support each other through the challenge of dementia. But for most of their life together they were not able to be open about their relationship.

Now in their eighties, the couple met and fell in love as teenagers, in 1955, but parental pressure forced them apart, and Hilary got married and had two children. The marriage didn’t last, and Pauline moved in with Hilary and the children in 1971. This was a time when lesbians were not regarded as “fit” to be mothers, and many lesbians lost custody of their children. Pauline, who would eventually become a Director of Social Services, was the breadwinner, and would certainly have lost her job if her relationship with Hilary had become known.

Pauline has enjoyed going to the Speak Out with Dementia group where she can socialise with other LGBTQ+ people who have a diagnosis of dementia. “And for me,” says Hilary, “attending the Rainbow Carers group is tremendously important: to be able to ask questions and learn from others who are on this same journey; to be able to open up about our fears and our feelings, and share each other’s ups and downs, not feeling we are alone on this journey. Our regular online meetings have created a unique bond between us.”

Hilary found a “mainstream” carers group just didn’t hit the spot. “Having already had the experience of the



Hilary (left) and Pauline in 1955, and on their wedding day in 2017



Rainbow Carers group, where everyone is gay, I felt so awkward when I attended an online group where everyone else was heterosexual. I was immediately aware I was not able to be myself. It wasn’t for me, and I quit after one session.”

After a lifetime navigating other people’s prejudices, and trying to keep yourself and your family safe

from harm, it is not easy to drop your guard. To get the benefit of a dementia support group, you need to be able to talk openly about your life and about intimate matters. When you are feeling vulnerable, the last thing you want is to have to justify your identity and relationships, on top of having to deal with the challenges of dementia.

After Pauline retired, and same sex marriage was finally legalised, Hilary and Pauline married in 2017. “We didn’t want a civil partnership, we wanted to be wife and wife,” says Pauline.

Pauline and Hilary are convinced that being legally married makes a difference to how they are treated by health and care professionals. Gay couples often complain that their relationships are not regarded as equal to heterosexual unions: they may be perceived as “friends” or “sisters”, instead of partners in a permanent, loving relationship. “We immediately state our relationship to medical professionals, from the first introduction,” says Hilary. “It is so important to feel we can be open and accepted. It takes away that first barrier, to show that we are there for each other, whatever we are dealing with, and it makes it possible to concentrate on the matter in hand.”

“Once I had a secret love” has always been a favourite song, which Pauline still loves to sing. On their wedding day, the words finally came true: ‘But my secret love’s no secret any more.’

Watch the Alzheimer’s Society video about Pauline and Hilary:

<https://www.youtube.com/watch?v=O0ORwQxQYMY>

Dementia support for people who identify as LGBTQ+ is available from:

Opening Doors (formerly Opening Doors London):
<https://www.openingdoors.lgbt>

Brighton and Hove LGBT Switchboard: <https://www.switchboard.org.uk>

Greater Manchester Age UK Bury: <https://www.ageuk.org.uk/bury/our-services/gm-lgbtq-online-dementia-support-group/>

Lucy Whitman was dementia engagement officer at Opening Doors from 2019-2022.

Using co-production to create culturally inclusive dementia resources

Family carers are often poorly supported by care services, especially in minority ethnic communities. **Karan Jutlla** celebrates a successful community initiative in Wolverhampton to co-design the resources carers need

Family carers are the largest resource for dementia care in the UK. The significant challenges on family members and informal carers presented by a person living with dementia are well reported, and yet support for these carers is inadequate.



Challenges for informal carers are universal, but it is important to note that there are additional challenges for those from ethnic minority communities. The lack of linguistically and culturally appropriate dementia support available in the UK has left many family carers without formal support from services. Research with South Asian carers has also highlighted experiences of discrimination in services, leading to mistrust (Jutlla & Kaur 2019).

Furthermore, the frequent lack of understanding about dementia in minority communities means that many carers have little informal support, exacerbating feelings of isolation and loneliness (Jutlla & Arblaster 2023). I have been researching the challenges of dementia care in minority ethnic communities for some seventeen years, and it is heartbreaking to witness how little has changed.

There is an urgent need for services to be designed so they support families affected by dementia to live well with the condition. It is important that carers are able to influence services in the way that they are designed, commissioned and delivered, moving towards a more equal and meaningful role for carers in the services they receive. The most effective way to do this is through co-production (SCIE 2022).

True co-production happens when the very people who are in need of a service or intervention tell you exactly what that intervention should be and then work with you to develop it. In the last two years I have had the privilege of doing this with members of the Punjabi-speaking community in England who are caring for family members with dementia. Not only is Punjabi the third most spoken language in England, but it is also my second language as a British born Sikh.

Initially I carried out research, commissioned by Alzheimer's Society, on the post-diagnostic dementia support experiences of the South Asian community in England, which highlighted the need for resources about dementia in South Asian languages (Jutlla 2021).

I found that not only were South Asian carers living with

Summary

Family carers are the largest resource for dementia care in the UK, and yet support for carers remains inadequate. Those from ethnic minority backgrounds experience additional challenges, including not always being able to communicate in their parents' mother tongue or explain dementia to older family members. The lack of culturally appropriate resources in a range of community languages exacerbates feelings of isolation and loneliness for South Asian carers. This article highlights the benefits of co-production, working with carers to design the resources they need, and shares an example of a successful community project in Wolverhampton.

the anxiety of potentially giving up careers they had spent their entire lives working towards but, without appropriate resources, they were also struggling to communicate with family members about dementia. Many carers told me that their loved one with dementia had reverted to their mother tongue and to a place that younger family members were unfamiliar with.

Understanding life history is pertinent to supporting a person to live well with their dementia as it helps us to understand the perceived realities they may be living in. British-born carers said they struggled to understand the life history of a parent born and raised in a different country, and described the difficulties of being expected to "break bad news" and educate their family members about dementia, without being fluent in their parents' mother tongue. Being unable to explain dementia meant that older family members remained unhelpful as they mis-conceptualised dementia as a mental health problem that could be treated.

Building on these findings, Alzheimer's Society further commissioned me to carry out a pilot project to co-produce resources to support South Asian families affected by dementia. We only had three months to complete the project in time for Dementia Action Week 2022, so decided to co-produce resources in Punjabi only.

Step 1 was complete, as participants from the 2021 report had already stated what they need. Step 2 was to bring together a group of people to co-produce the resources. I'm from Wolverhampton, which has the second largest Punjabi community in the UK, so I quickly drew upon my networks to bring together Punjabi-speaking members of the community and third sector organisations working directly with the Punjabi community in Wolverhampton. Our group included two Punjabi-speaking people living with

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Speakers at a dementia event in Wolverhampton. Left to right: Anuja Jalota, Lee Allen, Alzheimer's Society, with Harjinder Kaur, retired community psychiatric nurse; Kuldip Chana, BME United, with Harjinder Kaur

Key points

- Carers of people with dementia often do not receive adequate support, and those from minority ethnic communities face additional challenges
- There is a lack of culturally appropriate resources about dementia to meet the needs of South Asian communities in the UK, and younger carers are often unable to explain a dementia diagnosis to their parents and extended family members due to language barriers.
- This project worked with carers, people living with dementia and clinicians to co-produce resources about dementia in Punjabi – the third most spoken language in England.
- To provide better support for family members and carers from communities which are traditionally under-served, we must develop services and interventions *with* them and not *for* them.

dementia, four Punjabi-speaking carers from the 2021 report, and two clinicians.

We met online to clarify what was required: written materials and two videos – an informational video about dementia and a video to help change perceptions of dementia in the Punjabi community. The group discussed what the content of the videos should be, and the scripts for both videos were developed and reviewed by the group. Furthermore, members of the group participated in the videos: the informational video was delivered by a retired Punjabi-speaking community psychiatric nurse, and a case-study video “Changing perceptions of dementia in the Punjabi community” was created, featuring a lady from Wolverhampton called Bhagwant, who is living with dementia, talking about her experiences.

Once the videos were produced, they were firstly shared with the group and sent directly to participants in the previous project. They were then shared more widely as part of a campaign for Dementia Action Week.

Since their development, the resources have proved successful in raising awareness of dementia, supporting families to live better with the condition and building relationships and trust with community members. Participants from the initial research project used the videos to raise awareness about dementia in their families.

For example, one carer stated, *“I played this video to my dad last week and finally, it felt like the penny had dropped. He now knows what dementia is because it’s been explained to him in a language that he understands.*

He hasn’t accused mum of doing things on purpose this week and seems a lot calmer about things.”

Other carers reported that the resources have alleviated the pressures on them to explain the diagnosis. Furthermore, the group said that they felt ‘listened to’ and were really pleased to see that their viewpoints were taken on board.

Consequently, not only have they offered their support for future projects but, the group themselves have been organising a series of dementia awareness events for the Punjabi community in Wolverhampton, utilising these resources. Funded by local temples, these events have reached 326 members of the Punjabi community to date and are a useful resource for healthcare professionals wanting to help families understand the condition. I have since been contacted by temples in Birmingham and London to hold similar events.

We are a far cry from culturally inclusive services in dementia care, which arises, in part, from the lack of co-productive methods to develop them. Although the project was not difficult, it is important that there is expert input from individuals and organisations that are knowledgeable about both dementia and the particular community that is the focus of the project.

I believe that this pilot project was effective because the idea, development and delivery came from the very people who need it. To provide better support for family members and carers who are traditionally under-served, we must develop services and interventions *with* them and not *for* them. It is through such methods that meaningful relationships are developed, and we can achieve true impact.

To access resources about dementia in Punjabi, and other South Asian languages visit: www.drjutlla.com/resources.

For more on the Dementia Action Week campaign, go to <https://www.alzheimers.org.uk/blog/changing-perceptions-dementia-punjabi-community>.

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Nubian Life – delivering culturally appropriate day care

Nubian Life's intercultural approach depends on principles of cultural competence, person-centred care and co-production. **Jazz Browne** describes the vital work of this thriving community hub in west London

Nubian Life is an established specialist provider of culturally specific activity-based care, with over 25 years of experience in the adult social care sector. Our service extends to clients with complex needs such as dementia, long-term health conditions, physical disabilities, sensory impairments and mental health issues.



We have been at the forefront of developments in the adult social care and community sectors, collaborating with a range of organisations to deliver innovative projects that have improved service provision and shaped guidelines for best practice. Our efforts give voice to the specific needs of Black and Asian older people accessing statutory and community services. We pride ourselves on our unique approach to person-centred care, drawing on cultural traditions and individual needs.

Our intercultural approach to care at Nubian Life is based on three core principles: cultural competence, person-centred care, and co-production. We are acutely aware of the unequal and disproportionate health and social care outcomes for our demographic and therefore develop activities and partnerships at local and wider strategic levels to achieve better health and wellbeing outcomes.

The aim of our service has always been to create a home-from-home experience within the day care setting. The familiarity of dialect, the sound of music as you enter the building each day, meals at lunchtime reflecting traditional tastes, the security of being around people who understand you and your cultural needs, all support a sense of safety that should be included in the design, delivery, and most importantly, the commissioning of services.

Members of Nubian Life taking part in Side-by-side cycling, computer classes and Hammersmith and Fulham Windrush Celebration.



Key points

- There are three core principles: cultural competence, person-centred care and co-production
- Person-centred care draws on cultural traditions and individual needs
- "The Club" reinforces the home from home experience – a place where people feel secure, happy, and engaged
- Clients can continue to attend even after moving into residential care
- Developing circles of support strengthens our care offer

Our activities are co-designed with clients, focusing on keeping them socially active and connected to the wider community. The day care service has been fondly renamed "The Club" by clients, and for us, that means that the day centre is a place where they feel secure, happy, and engaged.

We deliver a range of activities that reflect the interests of our clients. For example, last summer, we spent the day horse racing at Newmarket, clients tried side-by-side cycling, and one client now uses the side-by-side taxi service to attend local appointments. This summer, clients have requested trips to the theatre, horseracing and the Oval cricket ground, and one client wants to learn to swim. It is essential that older people have something to look forward to each day, that they are supported to maintain skills and interests, and, if they want, to develop new interests.

While Nubian Life is not a dementia service, 65% of our clients are living with dementia at various stages. Using a person-centred



approach enables us to get to know our clients as individuals. Staff across the team, from transport to day care to catering, develop a working knowledge of each client, so the approach is consistently personalised. It is therefore a natural process to care for the individual, not just their condition.

We believe it is essential to have supportive relationships with carers, other family members, and referring agencies. Developing circles of support strengthens our care offer and provides support to carers (in some cases 24-hour advocacy) when the caring role becomes challenging or when they find it difficult to navigate services.

A unique element of person-centred care is that your service grows, moves, and changes with the client group. Presently, our client age range is 67-99. A client will age with the service and often spend five or more years in our care. This means that our clients rarely leave the service unless they become chronically ill or pass away.

Years ago, we advocated for clients placed in residential care to still be able to attend the day centre. Social services deemed the care homes “able to meet all their needs”, but

we argued that it is harmful and unacceptable to cut an older person off from their friends/peer group (particularly if they are living with dementia). Nubian Life knows from experience that older people from Black and Asian backgrounds are less likely to have their cultural needs met within care homes and are more likely to experience isolation and loneliness.

Delivering a person-centred care model is undoubtedly resource-intensive (staffing, transport, equipment, training, etc.). However, the benefits of keeping older people healthy, engaged, and within the community are achievable and can be cost-effective. But this requires statutory, health, and third-sector organisations to work together as a holistic model, not in silos that create unnecessary competition and unconsciously allow gaps to occur, so as to provide fully inclusive provision.

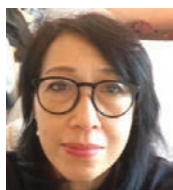
Read more about Nubian Life here: <https://www.nubianlife.org.uk>

Jazz Browne is chief executive of the Nubian Life Resource Centre

Engaging with UK Chinese communities about dementia

Talking about “brain health” rather than “cognitive deterioration” may be a better way to initiate conversations about dementia in communities where the terms used to describe dementia are highly stigmatising. **Jennifer Lim** describes how she implemented the Chinese Think Brain Health Project to increase understanding of dementia and brain health among Chinese communities in the UK

The Chinese population in the UK has reached over 600,000 (UK Government 2023a, 2023b). The Hong Kong Chinese have been the largest group in this population ever since the 1950s, and now include recent migrants. Other Chinese migrated from Malaysia, Singapore, and Vietnam in the 1970s; and China in the 2000s (Wikipedia 2023).



There is great diversity among us, in our historical, political, and educational background; spoken and written languages; cultural practices; food; and previous experience of health and social care. A significant difference is our languages, particularly between the Hong Kong and China Chinese, where communication requires interpretation/translation.

Hong Kong Chinese speak Cantonese while China Chinese speak Mandarin; the former write in Traditional Chinese language while the latter use Simplified Chinese language. The

medical term for dementia is pronounced as *chi ngoi zing* in Cantonese and *chi dai zheng* in Mandarin. There are yet more language differences between Chinese people from Malaysia, Singapore and Vietnam. The differences between us, based on our country of origin, affect the way we socialise and relate to other Chinese groups.

Our communities have experienced discrimination and racial harassment. Being brought up to follow Confucius’ teaching, our attitude is to “keep your head down and work hard”. As ‘foreigners’, we tend to be self-reliant and keep to ourselves, hence we are perceived as a ‘silent’ community. We are scattered in small numbers across the country, and as a minority group, we are often neglected by funders and invisible to service providers.

Chinese people and dementia

There are 2,720 Chinese people over 65 years living with dementia in the UK, and this number is expected to rise to over 4,000 people by 2025 (UK Government 2023a).

However, there are no official data about the number who have a diagnosis and/or have accessed dementia services. There is also little research in this population. I have found only one small study, involving nine Chinese carers (Baghirathan S *et al* 2000), compared with more than thirty

Dr Jennifer NW Lim is senior lecturer in public health, researching on health inequalities in accessing care and services for people from culturally diverse backgrounds, at the University of Wolverhampton

Key points

- Apply a positive thought-flipping technique in communicating messages, to break down negative thinking.
- If possible, use researchers and experts with the same culture who speak the same language and use familiar imagery to implement interventions in the community.
- Collaborate with community organisations to access their members, and provide training to sustain awareness activities.
- Don't stop at raising awareness: extend to reinforcing knowledge through co-creation of tangible products or materials for local dissemination, leading to empowerment.
- Make full use of the opportunity to promote and motivate ongoing research participation from the community.

studies on the South Asian and Black communities, reporting on diagnosis, prevalence, knowledge, experience, and interventions (Lim, in press).

Think Brain Health campaign

In January 2021, Alzheimer's Research UK (ARUK) launched their first public health campaign, Think Brain Health. This digital campaign has three elements: a quiz to raise appreciation of brain health; three simple rules to keep a healthy brain ("Love your heart, stay sharp, keep connected"), and, finally, "four things you need to know about dementia".

This campaign is relevant to minority ethnic communities because, by focusing on brain health rather than on a condition that causes the brain to deteriorate, it addresses the social stigma which may prevent people from seeking help.

For Chinese people, the positive "thought-flipping" term "brain health" can break negative thinking about dementia, shifting attention away from the derogatory and stigmatising Chinese medical term (*Chi ngoi zing*) to achieve the goal of improving access to health services.

However, to be useful to us, the original brain health campaign needed adaptation to make it culturally appropriate, and had to be implemented largely in person, to overcome digital exclusion.

Chinese Think Brain Health project

To bridge the above gaps, I organised a network to bring the Chinese communities across the country together and successfully created a coalition with Chinese community organisations in five cities with the highest Chinese populations (London, Manchester, Birmingham, Liverpool and Bristol). To create a credible dementia research team, Professor Richard Cheston and Mei Champ from the University of the West of England joined the coalition. Together, we secured the ARUK Inspire Gold Award for one year to conduct the first nationwide dementia and brain health project focused on Chinese people.

Our project aimed to increase knowledge of dementia and good brain health amongst the UK Chinese population



The Manchester workshop in action

and build capacity in local communities. We collaborated with community partners to deliver fifteen workshops in the five cities, in which participants learned about brain health and dementia and were then asked to co-design culturally appropriate information posters and leaflets. We distributed 30 posters and 900 leaflets that were produced in these workshops. Additionally, 105 Chinese people across the country completed our online national survey; and two experts presented in Chinese languages at a national capacity-building webinar. We also formed a Chinese network for future work.

Cultural tailoring and community collaboration

I tailored the project with the aim of improving help-seeking, by including information about normal ageing; Chinese terms for dementia and definitions of dementia; four common types of dementia; symptoms; and causes.

In our presentations, we explained the importance of our public health goal. We worked closely with our community partners to plan the delivery of each workshop, including agreeing which language and which term for dementia should be used. We used Chinese images and examples, and took account of cultural, social, historical, environmental, and psychological factors that influence health behaviour, because addressing these factors can lead to attitudinal and behavioural change.

We spoke in Cantonese or Mandarin to suit our participants in the workshops, and produced four different versions of our information materials to meet language needs and our partners' preferences on which dementia term to use.

We scheduled activities (hours, location) to suit members of the local community, and we provided incentives such as a participation fee and/or lunch and refreshments, to ensure retention throughout the three workshops.

Participants in the workshops said:

Using my spoken language in delivering the messages really has transformed this health promotion event.

Having someone from Chinese culture develop and lead the sessions made discussions more engaging and we feel free to express our views.

Additionally, Mei Champ tailored and translated the ARUK Think Brain Health quiz and online Dementia Attitudes Monitor questionnaire into both Simplified and Traditional Chinese.

We found there was no one term for dementia that

everyone agreed on. Many in the workshops preferred *Nou teoi faa zing*; some liked the medical term *Chi ngoi zing*. We found similar results in our national survey: a third (37.1%) preferred *Chi ngoi zing*, 16.1% *Sat zi zing*, 49.5% *Nou teoi faa zing*, and 24.8% *Teoi zi zing*, while 31.4% accepted all the terms, and 10.4% wanted other terms.

However, we did create attitudinal change in the workshops about the Cantonese medical term for dementia, *Chi ngoi zing*. These participants said:

If other terms are used instead of Chi ngoi zing, many people have no idea what it is ...

Although it does not sound good, we can attract people's attention ... that this is a real disease, it can be prevented

If we always say that the word is not nice, we are avoiding the problem.

Co-designing materials

In each city, we implemented three workshops to co-design information materials, using the “What? So what? And now what?” structure. In the first workshop we presented information about the Chinese Think Brain Health campaign and why it is important; in the second workshop participants co-designed posters and leaflets to raise awareness about dementia and brain health; and in the third, we evaluated participants’ experience. We also provided information on the importance of research participation, and facts on dementia research in this population and other minority ethnic communities.

For the co-design session, we repeated the key information from workshop 1, directed participants to our public health goal, and provided guidance to produce the poster and leaflet. Participants discussed the messages and dementia term(s) to use, and brainstormed about the images, colour and design. Community partners and researchers facilitated the discussions when needed. We sought community designers and created six posters and six leaflets. A total of 30 posters and 900 leaflets were printed and delivered to the partners and participants for distribution.

Participants enjoyed the co-design session and said:

The design of poster and leaflet is brain stimulation for everyone, like brain health.

I have enjoyed taking part in this event. During the whole process, I learnt a lot, participated in discussion and brainstorming, shared our opinions, reinforced our learning with the poster and leaflet design.

Achievements and challenges

We successfully completed our ambitious project and presented our findings and experience in a national dissemination webinar.

We faced some challenges to implement our project. In two cities where virtual workshops were preferred, community partners had to invest additional resources to collect informed consent, interpret Mandarin to Cantonese, and address the issue of digital access. We did not budget for professional design support, but our community partners sought local design expertise from their participants and members to produce the leaflets and posters successfully.

We created a trusting and fun environment for

participation and engagement in the workshops. The participants said they “*felt a sense of pride in the co-design session, producing posters and leaflets to share with family and friends, and increase knowledge and understanding in the community.*”

Chinese communities in the UK were invigorated by the Chinese Think Brain Health campaign. We garnered interest in the topics of dementia and brain health: 76% of the 54 workshop participants said that they want to know more about dementia and brain health. Here are some of their comments:

I am thankful to Dr Lim for delivering and motivating our engagement in this workshop. I have benefited a lot from it.

After the first workshop about dementia and brain health, I spent two hours on the Internet looking for more information about dementia.

Our Chinese people are conservative and seldom take initiative and feel shy to express ourselves. But this warm environment created by the organiser and presenter has encouraged us to speak freely and share our opinions.

There is still much work to be done in the Chinese population given its diverse characteristics. Our workshops reached mostly Chinese people originating from Hong Kong, and a few from Malaysia, Singapore and China. Our national survey was completed by 60% Chinese from China, 22% from Hong Kong and 8% from Malaysia. We need to reach out to other Chinese groups who do not access community organisations, and to the new Hong Kong settlers, who consider themselves as a separate Chinese group.

Acknowledgements

The project was led by the author with collaboration from Mei Champ and Richard Cheston (University of West England), Rosa Hui *MBE DL* (Chinese Community Wellbeing Society, Bristol), Eddie Chan and Lisa Yeung-Donaldson (Chinese Welfare Trust, London), Shirley He (Manchester Chinese Health Information Centre), Di Burbidge (Chinese Wellbeing, Liverpool), and Kate Gordon (Birmingham Chinese Community Centre). Qianting Liao, a Public Health student provided some translated work. This project received the Inspire Gold Award, Alzheimer’s Research UK (ARUK-IF2021-003).

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Eddie Chan: Dedicated Chinese community leader

Eddie Chan (pictured below) is a community activist dedicated to improving the lives and wellbeing of Chinese people in the UK. **Jennifer Lim** spoke to him about the dementia projects he has set up, including the Chinese Admiral Nurse in London Project

Q: Tell us about your career and how you became involved with the Chinese community in London

I was a civil engineer. I managed construction projects in the UK and around the world which required a lot of travelling. I often had to spend months away from home. Then one of my sons fell ill, and to care for him, I reduced my travelling and subsequently resigned from my job in 1999.

In 2000, I became director of the Chinese National Healthy Living Centre, a small London-based charity founded in 1987 to promote healthy living and reduce health inequalities for the Chinese population in the UK. I worked there for 19 years until my retirement in 2019. During this period, I expanded the charity's operations from London to Birmingham, Manchester, Newcastle, Swansea, Glasgow, as well as Northern Ireland.

Q: Tell us about the projects you implemented at The Chinese National Healthy Living Centre

The London Chinese Community Network was the first project I set up, with the Chinese in Britain Forum, with funding from the Home Office. The Network promoted the interests of Chinese voluntary and community organisations in London. This covered research, publishing, brokering partnerships, organisational capacity-building, consultation conferences and community activities.

The second project was the first British Chinese All Party Parliamentary Group in 2003. I convened the group for seven years. Chinese people work hard, prefer to keep a low profile and not complain. Their political involvement was low, and to improve this, we started conducting political awareness raising events with the Chinese people in London, Birmingham, and Manchester, to encourage open discussions about political issues and voting rights.

We initiated the first dementia support services in London with three-year funding from the City Bridge Trust in 2013, which was extended to 2018. It started with people asking for help and information about dementia. The funding enabled us to employ two half-time staff to set up the service.

We conducted awareness raising workshops about dementia, improved knowledge through Chinese TV and



radio stations, provided support and space for respite, created Chinese Dementia Friends, carer support groups and a support helpline. We also provided services to help people understand Lasting Power of Attorney, and assistance to complete the form. We developed a booklet about dementia in Traditional Chinese language, and organised a hybrid national conference. This was how my involvement in dementia started.

Q: You have recently set up the Chinese Admiral Nurse in London project. What is it?

I started developing this idea with Dementia UK at the end of 2018 and invited the Chinese Welfare Trust to collaborate. This is an organisation aiming to improve the wellbeing of older Chinese people in London who are marginalised and isolated due to language barriers. There are more than 300 Admiral Nurses in the UK, but none could communicate in Chinese (Cantonese or Mandarin). Our people need dementia support from someone who can speak their language.

After the Covid 19 pandemic we finally secured funding to deliver a 2-year pilot Chinese Admiral Nurse in London project and launched the initiative in 2022. We have now supported 51 families and delivered 11 dementia awareness talks across 5 boroughs and 3 carers support sessions, all in either Cantonese or Mandarin.

People who have used the service have said:

"I could understand and express more accurately in my own language... I've felt easier and more comfortable with the Chinese Admiral Nurse."

"The Chinese Admiral Nurse is very kind, friendly, helpful and patient. She's followed up closely on my problems and proactively found solutions for me." ▷

Key points

- Elderly Chinese people in the UK need dementia support from someone who can speak their language
- It is vital to build relationships between dementia organisations/ services and local community groups
- The Chinese Admiral Nurse in London Project came into being after years of community engagement, including a dedicated local dementia awareness and support project
- You need to understand the local demographics if you want to make the case for local change
- Always start fundraising as soon as possible

Dr Jennifer NW Lim is senior lecturer in public health, researching on health inequalities in accessing care and services for people from culturally diverse backgrounds, at the University of Wolverhampton

▷ **Q:** *The Chinese Admiral Nurse in London project is a pilot study for 2 years. How are you ensuring its sustainability?*

The pilot project is part-funded by Dementia UK (with support from one of their corporate partners, Invesco), and we matched the rest with funds raised by the Chinese Welfare Trust. We are relentlessly raising money to extend the project beyond its current term, and are also collecting data to support future funding applications.

Q: *What advice would you give to other Chinese community organisations if they want to set up an Admiral Nurse service in their city?*

This service is beneficial if the community in the area has large numbers of elderly Chinese people. Check the data before considering this approach. Secondly, start fundraising as soon as possible, because Dementia UK provides only a part of the total cost.

Read an interview with **Emily Ka-Hei-Lui, Chinese Admiral Nurse** (pictured above):

<https://www.dementiauk.org/getting-to-know-you-emily-ka-hei-lui/>



Peace of Mind

Cheryl Jackson (pictured below) runs Peace of Mind Home Care Solutions. She tells **David Truswell** how her agency provides culturally competent domiciliary care to the African-Caribbean Community

Peace of Mind Homecare Solutions is a small domiciliary care agency based in north west London, supporting people in the community. The service rehabilitates people back into the community after a stay in hospital. Approximately one third of the people supported at any given time are from an African-Caribbean background which on average includes six or seven service users living with dementia.



Many African-Caribbean people do not access dementia services for various reasons. Dementia is still considered a taboo subject, with many families hiding the illness and not seeking support from local services. Many African-Caribbean people who do not have children to support them tend to get lost outside the system. Once people have been given the diagnosis they are often left to cope alone, until an incident occurs or they are in crisis, which usually results in an admission to hospital via Accident and Emergency.

A lot of the people we now see developing dementia are from the Windrush generation. One of the things Peace of Mind has found is that the same values and core strengths that got people through moving to the UK and helped them to survive once they were here, are hindering them now, such as wanting to be independent and self-reliant, telling themselves, "I can do this on my own." People from the Caribbean are very proud and will say, "We are OK. We don't need help." But in all the cases we see it's clear they do need support and they are struggling, but find it really difficult to ask for help.

One of the ways we make a difference is by recognising the importance of culture. When we go to see a family, 70% of the issues that would normally arise disappear because we are coming from the same cultural perspective. For example, the majority of the households we visit with older Caribbean people will expect the workers to wear

shoe covers in the house. They expect it to be automatically understood that there is one cloth for cleaning the upper body and a separate cloth for personal hygiene for the lower body. They expect the worker to know about creaming the skin. Each family will have its own idiosyncrasies in what they consider to be appropriate behaviour.

An important part of our staff training is on-site, in people's homes. When we employ a non-Caribbean member of staff they are accompanied by a Caribbean staff member as part of their induction to show them how to behave and what they are expected to do when they enter a Caribbean home. Hands-on coaching and shadowing with experienced Caribbean staff from the start has proven invaluable to make our service successful for Caribbean families. All new staff have online training as well, to provide extra support in understanding people's idiosyncrasies, but much of this cannot be taught online. People learn better when they encounter real people.

Providing a domiciliary service involves catering for each community, all of which will have their own ways of doing things. Having staff from the same cultural background not only helps deliver culturally inclusive care but, through feedback and onsite coaching, also supports the rest of the organisation to understand what is important to people.

More information on Peace of Mind Homecare Solutions can be found at <https://www.peaceofmindhcs.co.uk>

Key points

- Every family will have its own idiosyncrasies
- Understanding the culture removes 70% of potential problems
- New care staff need to be fully prepared for their first visit
- Online training in cultural awareness must be supplemented with on-the-job coaching.

David Truswell is a writer and researcher on the impact of dementia on Black, Asian and minority ethnic communities

Engaging with the South Asian community about memory loss

Clinician and researcher **Naaheed Mukadam** shares her experience of using music and dance to explore memory and identity with South Asian people with dementia and their families

As a researcher, I have always been interested in ethnic inequalities in dementia. My clinical experience in a memory clinic suggested that people from minority ethnic groups presented at a later stage of dementia, and many times in a crisis, which led to distress for the person with dementia and their family. Since that initial observation, I have conducted systematic reviews (Mukadam *et al* 2011b), qualitative (Mukadam *et al* 2011a) and quantitative work (Mukadam *et al* 2019) exploring pathways to diagnosis in dementia.



I have designed and tested an intervention to encourage earlier help-seeking for dementia in the South Asian (Mukadam *et al* 2018) and black population (Roche *et al* 2018). I realised while working on other epidemiological work (Livingston *et al* 2017) that relatively little research had examined differences in risk factors and prevalence of dementia in minority ethnic groups.

I therefore set about investigating this, using a variety of data sources, and found that dementia risk factors were more common in people from minority ethnic groups (Mukadam *et al* 2022b), that dementia onset was earlier in these groups and that dementia incidence and prevalence were higher in the black population.

Furthermore, survival after dementia diagnosis was shorter in people from minority ethnic groups (Mukadam 2023). I also found that certain genetic risk factors may be more common in minority ethnic groups (Mukadam *et al* 2022a) which could explain higher dementia rates.

Much of my work has received media coverage, including national newspaper articles and appearances on national television, giving me hope that information about dementia in minority ethnic groups was being disseminated. However, I felt that the personal stories of people with dementia and their families were lost in the statistics, and I wasn't sure how represented people from minority communities felt when they saw articles or television programmes about research.

I started thinking about how best to show personal stories and experiences outside of a purely research space, especially given the growing recognition of the importance of public engagement within research (Wellcome Trust 2011, Wellcome Trust 2016). At this time I also became aware of research showing the benefit of music for the brain (UK Music/Music for Dementia 2022), and

Key points

- There has been much research about how dementia epidemiology and pathways to diagnosis and post-diagnostic support for people from diverse ethnic groups vary, and how the care pathways should be optimised
- However, there is relatively little work on public engagement using the creative arts in people with experience of dementia in minority ethnic groups
- Working in a creative way without a research question has allowed me to connect with people in a different way
- Using music and movement to express complex experiences, we have created work that will hopefully speak to a wider range of people and open up conversations around memory loss in the South Asian community.

organisations engaging the public about dementia using creative arts. Some examples were the Alzheimer's Society "Singing for the Brain" initiative, Music for Dementia and Arts 4 Dementia.

However, when I looked into these, I found that they almost exclusively benefited people from the UK majority population. The only example I could find that was for minority ethnic groups is the Hamaari Yaadain programme which is a singing programme run in a virtual café for older South Asians by the charity Touchstone.*

I wanted to bring the public together to examine the experience of people with dementia and what it means to them and their families. Being from a South Asian background, it made sense to start with the South Asian community.

I spoke to Dr Shibley Rahman (honorary research associate at UCL and carer for his mother who had dementia) about how he had used music to connect with his mother and bring her joy. I also reflected on my own clinical experience of listening to family carers.

With Soumik Datta, an award-winning musician and his company Soumik Datta Arts, and a talented dance artist called Jesal Patel, affiliated with dance group Akademi, we ran workshops in a care home and a day centre, playing a variety of music including South Asian classical and contemporary, as well as some popular English songs by artists familiar to the participants.

Some workshops included guided movement from a seated position (as many participants had mobility

Dr Naaheed Mukadam is an old age psychiatrist working in the UCLH Mental Health Liaison Team, and an Alzheimer's Society senior research fellow at UCL



problems). In all workshops we held informal conversations about peoples' lives, important memories and what pieces of music held particular meaning for them.

The process was very unusual for me as a researcher. I have been so used to posing specific questions and focused on finding specific answers that initially it felt formless and disorientating. But I felt a sense of freedom and inspiration listening to and connecting with people in the different settings and just giving them space to talk, or even just observing their expressions, body language and interactions with each other. In one session I noted that participants were very engaged in the music and even acted out certain sequences.

Being present and connecting with people's personal stories inspired me to compose some songs, based on the comments people had made, which I sing in Hindi and Bengali. Through these songs I am trying to bring to life their experiences, particularly the feeling of slowly losing the person you love, but also getting glimpses of their true self and connecting through shared activities.

Soumik used his experiences at the workshop to compose original music, playing with echoes and transitioning from one raga to another to demonstrate the effect of slowly losing memory. In his words, "the musical equivalent of a memory is an echo, a partial fragment of the original". Jesal has composed an original dance piece with a partner to reflect the stories of people we met. We all took part in a public performance at the Bloomsbury Theatre in London in June (*Music, meaning and memory – an evening of South Asian dance and music*) with proceeds donated to the Alzheimer's Society.

As Soumik put it:

"Spending time with elderly people living with dementia made me realise how precious our memories are. We are shaped by what we remember which gives us our very identities. So to start losing them is to lose our selves. This inspired me to compose music where beats fade and notes gradually diminish, as a way to start a conversation about our shared, collective histories."

And Jesal said:

"Both settings that we visited had a very different dynamic. We gained info in different ways, one group being very vocal and the other with more non-verbal actions... which gave us a range of mediums to work with. A sense of community really promoted confidence and conversations/communication."

My experience has taught me that the connection from learning and reflecting people's stories is highly valuable, and one that is undervalued in mainstream research. People have told me about the uncertainties and variations in having memory problems or caring for someone with dementia, but among the struggles have been stories of connection, and music and other non-verbal forms of communication have been key to that.

Participants in our workshops seemed to really enjoy their time with us and asked when we would be going again. Overall, I have learned a lot as a researcher and hope to continue to use this form of engagement going forward.

*For more information on Hamari Yaadain, go to https://arts4dementia.org.uk/?post_type=event&p=10573.

Read a report on Naaheed Mukadam's work in the Guardian:

<https://www.theguardian.com/society/2022/sep/18/britons-of-black-and-south-asian-origin-with-dementia-die-younger-study-finds>

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Queering up dementia care: the next steps

LGBTQ+ people affected by dementia have experienced a lifetime of discrimination and their needs often go unmet. **Mike Parish, John Angel Bond** and colleagues describe the process of transforming a small group of passionate volunteers into a community interest company committed to changing things for the better.

There is an increasing body of research and personal testimony demonstrating that LGBTQ+ people affected by dementia do not receive an acceptable level of care (Harper 2019, Hafford-Letchfield 2022). It is a community that has long experienced discrimination in statutory, private and third sector care support.

Navigating support that doesn't feel tuned to your needs or identity or long held fears of being able to express yourself openly without encountering prejudice or humiliation creates huge barriers to those trying to access dementia care, especially when you factor in cognitive decline (Clayton 2023, Ettenes 2023). Despite legislation and the positive efforts of some organisations to deliver safe and appropriate care, services are still extraordinarily patchy, unreliable, and not fit for the twenty-first century.

Without clear pathways to safe and relevant support there is a danger that those needing help will experience an extremely negative journey that will lead to isolation, a lack of timely interventions and a rapid decline in well-being, hastening cognitive decline – in other words, the absence of the very minimum healthcare we should expect from providers.

In the dementia world, LGBTQ+ voices are currently few and far between which is the result of a lack of attention to this minority over many decades. Those who do come forward to seek change and improvements in dementia services can feel lonely and isolated. One person cannot change the vast statutory and formal and informal dementia infrastructure alone.

Forming the Advisory Group

Once motivated by personal circumstances, it's almost impossible not to want to help others through the confusing tangle of the dementia pathway and, most importantly, to challenge the lack of equality and diversity in dementia services and stop the cycle of struggling for safe spaces, respect and understanding.

In the absence of national policies to change this, it has been left to individuals and small third sector organisations to collaborate to provide peer support, information, and

Mike Parish cared for his husband Tom Hughes for eight years and is a long-standing advocate for the rights of LGBTQ+ people with dementia and carers. John Angel Bond is a former social care worker, now researching the experiences of LGBTQ+ people affected by dementia as a PhD student at the University of Stirling, alongside being an unpaid carer for his mother.

Key points

- On our journey to become a CIC – a community interest company - we have learnt that:
- Involving people living with dementia is essential in efforts to influence policy and service delivery.
- The participation of people living with dementia to shape our group has been a vital ingredient in our success.
- Individuals with a shared interest are willing to give up their time to drive change.
- At any time, someone's capacity or understanding may change, so it is essential to have the right support networks in place.

reassurance, as well as to highlight these unfair experiences and influence change wherever possible.

Following the pioneering efforts of Sally Knocker, who established the first Rainbow Memory Café for LGBTQ+ people with dementia and carers at Opening Doors London in 2017, and partly in response to the additional isolation we all experienced during the pandemic, several peer support groups for LGBTQ+ people affected by dementia, both online and in-person, have been created in different parts of the UK over the past few years.

People involved in these groups soon recognised that we had crucial knowledge and experience to share, and as a result, a group of volunteers created the LGBTQ+ Dementia Advisory Group in 2021. The Advisory Group is led by people who identify as LGBTQ+ and are either living with dementia, caring for someone with dementia or working in the dementia field as practitioners or researchers, with staunch support from allies in the voluntary and statutory sectors.

The need for an advisory group like this has been amply demonstrated since we came into being. We have been contacted more than fifty times with requests for help and information, and invitations to take part in projects including:

- invitations to speak at specialised conferences and events.
- involvement in research projects concerning the experiences of sexual/gender minorities within the realm of dementia.
- advice on the production of LGBTQ+ films and television series, both in the UK and Europe. ▷



Above L to R, some members of the LGBTQ+ dementia advisory group: Mike Parish, John Angel Bond, Christine Maddocks, Claude Chidiac, Julie McCaughey, John Hammond. Right: Chris Kelly, Thomas Williams leading a workshop at UK Dementia Congress

- advising several dementia service providers on how to make their services more inclusive.
- influencing policy and procedures both on a local, national, and international level.

There are enormous demands on our time, but our passion to be involved gives us energy and drives the group speedily forwards.

We conducted a very well-received two-part online webinar with more than 300 online attendees during Dementia Action Week 2022 (LGBTQ+ Dementia Advisory Group 2022). We also designed a poster and delivered an awareness workshop (which quickly became over-subscribed) at the 2022 UK Dementia Congress.

We recently received a referral enquiry from Stonewall. This is an incredibly important step for our organisation: to be recognised by other leading LGBTQ+ based charities for the work we are doing, and to be seen as the “go to” organisation for information relating to dementia – because members of this community who need to find out more about dementia are likely to seek reliable LGBTQ+ friendly sources.

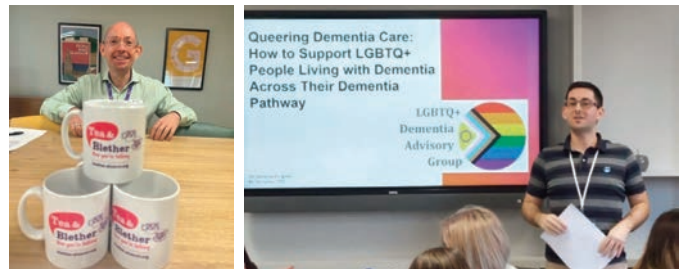
Why become a CIC?

It quickly became clear that this group of like-minded individuals, experiencing or working in dementia services, could raise awareness and influence dementia service provision through our activities. But a band of volunteers, however competent and knowledgeable, in a group without a formal structure, can only influence wider policies so far. We found that we would not be eligible to apply for grants to support projects we have the expertise to deliver without setting ourselves up as a social enterprise or charity, with legal mechanisms for accountability. So as a group, we explored the options available to become a recognised, authoritative organisation.

In May 2023, the LGBTQ+ Dementia Advisory Group became a community interest company (CIC). This is a special type of limited company which exists to benefit the community rather than shareholders. A CIC is an excellent solution to enable the group to move forward and expand its activities to match our mission statement.

Using co-production

In transforming the LGBTQ+ Dementia Advisory Group into a CIC, we are committed to the principles and practice of co-production. Co-production is a way of working where service users and providers collaborate to reach a



shared outcome. The co-production route is values-driven and is based on the principle that those affected by a service are beneficially placed to help design it (Realpe & Wallace 2010, SCIE 2022).

Many dementia organisations and services are still run by professionals who decide what is best on behalf of people who are living with dementia (Baldwin 2008). But co-production stemming from solidarity and collaboration between people with shared experience and knowledge is one of the most effective ways to bring about change. In our case, it means that people living with dementia who identify as members of the LGBTQ+ community are fully involved in all the decisions and activities of our organisation. This is incredibly empowering for all participants and provides a strong sense of purpose and well-being.

People with dementia and carers have always been at the heart of all the activities of the LGBTQ+ Dementia Advisory Group, and co-production is our default method of operation. Thus, we practised co-production in the very process of setting ourselves up as a CIC, with the members of the group who are living with dementia fully involved at every stage. We are currently finalising our strategy that outlines our mission, values, and objectives for the next three years.

The lived experience of people affected by dementia who identify as LGBTQ+, with personal knowledge of the LGBTQ+ community and its history, are essential ingredients in creating an organisation which truly meets the needs of its members and beneficiaries. Our messages are heartfelt and authentic, coming from people with shared experiences working together, and this gives our organisation gravity and authority. To get in touch with us, please email info@lgbtqdementia.org

Postscript

After we had written this article, we came across this recent account of serious homophobic abuse in a London care home: <https://www.theguardian.com/society/2023/jun/01/noel-glynn-ted-brown-homophobic-abuse-care-home-croydon-london>

This case is shocking not just because of the criminal abuse which took place, but because of the discriminatory culture within both the care home and the enforcement authorities, which meant that timely, proportionate action

was not taken when the abuse was reported. Although this is of course an extreme example, it does illustrate why LGBTQ+ people affected by dementia do not always trust care providers to respect their human rights, and why we need a strong voice advocating on our behalf.

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Bristol Dementia Wellbeing Service – an integrated dementia pathway

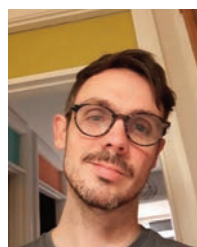
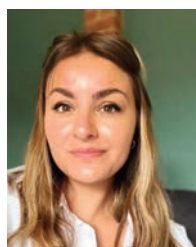
Inspired commissioning, a highly integrated approach and close relationships with diverse communities are key components of the Bristol Dementia Wellbeing Service. **Carrie Holmes** (left below) and **Stephen Collings** describe how it works

Bristol Dementia Wellbeing Service (BDWS) is a unique service delivered in partnership between Alzheimer's Society and Devon Partnership NHS Trust. Operating since 1 April 2015, the service is commissioned by Bristol, North Somerset and South Gloucestershire Integrated Care Board and works alongside GPs across Bristol to support people living with dementia from diagnosis to end of life.

The service was commissioned after feedback from people living with dementia, their carers and families and other stakeholders, that dementia should be treated as a separate pathway, with support provided throughout people's journey with dementia – to live as well as possible, for as long as possible.

It is fully funded by the local integrated care board as dementia support is one of the four pillars of its Ageing Well Strategy, underpinned by the commissioning ethos to promote people's quality of life as they get older, including supporting people to stay healthy at home. Bristol has a population of approximately 700,000 with 61,000 over 65. Expected dementia prevalence is estimated at 4,340 (March 2023). Working with Bristol's GPs, the service helped to improve the city's diagnosis rate from 50% in 2015 to 76% in early 2020. After dipping during Covid, currently Bristol's diagnosis rate (71%+ July 2023) remains higher than the national rate of 63% and the national target of 66.7%.

Carrie Holmes has worked for Alzheimer's Society since 2015, and was a local services manager leading on community development with the Bristol Dementia Wellbeing Service from 2020 to 2022. Stephen Collings is the contract business manager for Bristol Dementia Wellbeing Service



One of the unique features of the service is that it does not discharge, and is currently actively supporting over 3,300 people living with dementia and their families at all stages through to end of life. Often this means they have the same assigned member of staff as their point of contact throughout their journey, providing the continuity of care that people affected by dementia asked for. ▷

Summary

Bristol Dementia Wellbeing Service is a unique partnership between Alzheimer's Society and Devon Partnership NHS Trust, fully funded by the local integrated care board, and serving a very diverse population. It was set up after extensive consultation with local people who asked for a dedicated dementia pathway providing continuity of care from diagnosis through to end of life.

No one is discharged from the service. People with dementia are assigned a named dementia navigator who maintains regular contact, and are supported by dementia practitioners according to need. The service recognises longstanding social and health inequalities and employs community development coordinators to build and maintain relationships with different local communities.

Interpretation and translation are provided where required, and information about dementia is available in seven languages including BSL on the service's website. The local dementia diagnosis rate exceeds national targets and friends and family survey responses indicate a high level of satisfaction with the service.

Key points

- Bristol Dementia Wellbeing Service, a partnership between Alzheimer's Society and Devon Partnership NHS Trust, is a fully integrated service
- The service was commissioned after feedback from local people who asked for a separate dementia pathway providing support from diagnosis to end of life
- The service does not discharge
- Community development coordinators build and maintain relationships with local minority communities
- Information and support are available in different languages including BSL
- Local diagnosis rates are higher than average, and local people express satisfaction with the service

▷ The service has just over 100 staff across a variety of roles. The majority are either dementia navigators (employed by Alzheimer's Society) or NHS-employed dementia practitioners (social workers, nurses, occupational therapists and physios). There is a care home liaison team who are linked with every care and nursing home in Bristol. The service also includes a psychology and medical team, administration support, and community development team.

Bristol is a diverse city, with large populations of Polish, Chinese, South Asian, Black Caribbean, Black African and Arab communities. The Bristol Dementia Wellbeing Service (BDWS) took part as a partner organisation in the research project "The Dementia Experiences of people from Caribbean, Chinese and South Asian communities in Bristol" overseen by the University of West of England (Bristol BME People Dementia Research Group 2017).

In recognition of the diverse communities served by BDWS, the role of community development coordinators was introduced, to ensure the service is able to meet the needs of all people diagnosed with dementia in Bristol.

Service overview

Here is how BDWS works:

- Access to early diagnosis. While GPs continue to diagnose more straightforward cases, where the presentation is more complex, they refer to BDWS for assessment and diagnosis.
- The service has never operated a waiting list – people's first appointments with us are booked within 10 days following acceptance of the referral from the GP.
- Every GP practice in Bristol has a named dementia navigator and a dementia practitioner. Navigators support the person with dementia alongside their family and carers, working to maintain independence and promote quality of life. Alongside diagnostics, practitioners provide specialist input where there is greater complexity, or at times of significant change.
- The GP remains the care coordinator when someone may have dementia and for post-diagnosis support, but

can access advice and education through the service, whether this is in relation to diagnosing dementia, managing risk or prescribing.

- Following diagnosis, everyone receives a personalised wellbeing plan, developed by the dementia practitioner or navigator alongside the individual, their carers and family. This includes health and functional skills as well as a broader assessment of the psychosocial context.
- The service has a dedicated website* and a phone-based access point open to all, whether carers are calling concerned about changes for a loved one, or professionals seeking advice. This line is open Monday to Friday, 8am to 6pm.
- BDWS's care home liaison team supports a whole-home approach to nursing and residential care.
- Specialised young onset support.
- Support for people to engage with research opportunities.

The wellbeing plan drawn up for each individual is person-centred, and responsive to what the dementia navigator or practitioner observes or is told by the person with dementia and their family regarding what is important to them, both now and into the future, including advance care planning. It is not a checklist. Its focus is on maintaining independence, through psychoeducation, to enhance people's ability to manage their own condition, alongside signposting to peer support groups or interventions that improve or maintain social connectivity.

The majority of people living with dementia in the community are supported by dementia navigators who will contact them at least once every six months to explore how their circumstances may be changing. They provide practical guidance and emotional support, tailoring information and signposting to people with dementia and their care network. They help carers access a carer's assessment.

Navigators can also signpost to other local Alzheimer's Society groups, such as dementia support cafés, Singing for the Brain or carers' groups. The service also includes the local Alzheimer's Society 'Side by Side' offer, whereby service users are paired with volunteers based on a shared interest.

At times of significant change, the assigned dementia practitioner can also provide additional support and offer timely interventions. If someone ultimately needs to move into a care home, there is an internal handover between the navigator and a practitioner working in the care home liaison team, who will then pick up this support.

The care home liaison team maintain this person-centred delivery with a whole-home approach, engaging with staff at all levels, with a focus on prevention, and reviewing and reducing the use of antipsychotic and other psychotropic medications. The work of this team has helped avoid admissions to hospital and assisted with discharges back to care homes.

In addition, during the pandemic, the care home liaison team provided extra support to care homes, including offering support for the emotional wellbeing of care home staff and jointly producing a resource pack to help them relate to their clients. ▷

▷ Adult social care is not a formal partner of the service, but the service works closely with its partners in social services. A number of practitioners come from social work professions, so there is a good understanding of the social care needs of people affected by dementia.

The service has a psychology-led additional therapies team which can deliver targeted interventions such as cognitive stimulation therapy, living well with dementia education, psychoeducation and one to one therapy.

Benefits for minority communities

BDWS recognises the impact of health inequalities. The community development team is wrapped around the core provision of the service, acting as a resource to the clinical teams. Community development coordinators are dedicated to building relationships with seldom heard-from groups and communities, identifying and highlighting barriers that people are experienced in accessing the service. They work together with leadership and the clinical teams to develop solutions and bring about organisational change, enabling better access to the service.

Once a relationship has been established with a community group, a consultation is offered to hear what communities and their members find prohibits them from accessing health care services: for example, poor lived experiences of health services, cultural beliefs around dementia, language barriers, etc.

The outcomes of the consultation are shared internally with the whole service leadership team, and recommendations are made to adapt the service to meet the needs and wishes of the community or group who have been consulted. This keeps equality, diversity and inclusion at the heart of service decision-making and allows for a whole-service view and approach to adaptations. The true impact of community development within an integrated service can be seen in the fact that the influence extends across the entire dementia pathway.

For example, it was identified that standard cognitive assessment tools such as the Addenbrookes test (ACE III) were not always appropriate for assessing a person who is not culturally British, due to the euro-centricity of language and formatting. Following engagement of leadership, including the service's clinical psychologist, the RUDAS (Rowland Universal Dementia Assessment Scale) was added to the suite of assessment tools used by the service, and full training was provided to practitioners on its application and use.

Other outcomes from this approach include:

- The production of six short films in local languages about dementia, viewed over 20,000 times and available on the service's website
- Investment in translation and interpretation options, including telephone interpretation
- Establishing a Deaf BSL pathway, including diagnostics undertaken alongside the local specialised deaf service, a self-referral route for Deaf BSL users, and service information provided in BSL videos.

The community development coordinator team also provides dementia education and awareness across communities where dementia may not be well understood, and supports other local groups or services to become

more dementia-friendly through education and advice.

Staff seeking further cultural understanding to support them in their roles can access fact sheets on cultural, spiritual and communication needs for different heritages that have been produced by the community development team to ensure inclusion in the widest sense.

Additionally, one of the community development coordinators provides education to children and young people in primary and secondary schools across Bristol, building learning through the key stages, including age-appropriate assemblies, Dementia Friends sessions, parents' evenings and also a project to deliver sessions alongside people affected by dementia to raise awareness and reduce stigma. The team can also work directly with navigators or practitioners when a child is struggling with the diagnosis of a parent or grandparent.

Service impact

Since BDWS went live it has resulted in some marked improvements and achievements, as these figures indicate:

- Local diagnosis rates have increased from 50% to 69%-plus.
- Number of admissions from the BDWS to mental health inpatient beds has significantly reduced. This means that people are being supported to remain well for longer in their own homes, including those in care homes.
- The service takes a proactive approach to staying in touch. Of the 3,300-plus people who receive the service, whether in the community or care homes, over 97% have received a clinical contact in the previous six months.
- BDWS receives regular feedback through a friends and family survey. Over 98% of returns indicate people are either likely or extremely likely to recommend the service.

You can read about the BDWS's pioneering model of access for the Deaf BSL community in "EDI: Actions not words – a recipe for change to address health inequalities" in this year's March/April issue of JDC (Caverly & Holton 2023). *For the BDWS website, go to www.bristoldementiawellbeing.org.

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The 17th UK Dementia Congress
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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

LGBT Caregivers

This review concluded that there is limited cultural competency in services, and a subsequent reluctance by caregivers to seek help impacts on the use of support services among LGBT caregivers. Implications for practice include the development of cost-effective, feasible, and acceptable inclusiveness training. Implications for policy include implementation in organisations of top-down agendas supporting staff to understand sexuality and non-heteronormative relationships in older age.

Di Lorito C, Bosco A, Peel E *et al* (2022) Are dementia services and support organisations meeting the needs of Lesbian, Gay, Bisexual and Transgender (LGBT) caregivers of LGBT people living with dementia? A scoping review of the literature. *Aging & Mental Health*. Published May 30 2022. <https://doi.org/10.1080/13607863.2021.2008870> Open access.

Data, ethnicity and dementia

Using linked data, this UK study found that Black and South Asian people are diagnosed with dementia at a younger age and die at a younger age with dementia than White people.

This identifies a priority for reduction of inequities, and for targeted prevention and care strategies to facilitate take-up.

Mukadam M, Marston L, Lewis G *et al*. Incidence, age at diagnosis and survival with dementia across ethnic groups in England: A longitudinal study using electronic health records. *Alzheimer's and Dementia*. Publ. September 1 2022. <https://doi.org/10.1002/alz.12774> (Open access)

Deaf people with dementia in care homes

This research project aimed to find out how to improve care for Deaf residents with dementia in care homes, from the point of view of Deaf people and that of care home providers.

All data were collected by Deaf researchers in BSL through interviews and focus groups. It was found that perspectives of Deaf people and care home perspectives are quite different, although identifying some of the same challenges and opportunities to learn from each other. The report includes recommendations for improving care practice.

British Deaf Association, Life Changes Trust, SORD (Social Research with Deaf People) and University of Manchester. Deaf People with Dementia and Care Homes in Scotland. Published March 2022. <https://bda.org.uk/dementiaresearch/> Open access

Young Dementia

A collection of research focusing on the most prominent subjects relating to young onset dementia, gathered by members of the Young Dementia Network steering group and other experienced researchers is at:

<https://www.youngdementianetwork.org/research-evidence/>

Person-centred practice support tool

Using surveys and focus groups in UK, Norway and Spain, this evaluation indicated that the Person-Centred Observation and Reflection Tool (PORT) is accessible, easy and acceptable for use in health and social care settings to support older people with dementia.

Surr C, Rokstad AMM, Miravent JV *et al*. Development and acceptability of the person-centred observation and reflection tool for supporting staff and practice development in dementia care services. *International Journal of Older People Nursing*. Published June 18 2023. <https://doi.org/10.1111/opn.12555>. Open access

Radiographer perceptions of person-centred care

This qualitative study concluded that many radiography practitioners feel unprepared when caring for people living with dementia despite the clinical practice guidelines. The findings suggest a need for profession specific education for radiography practitioners and for dementia friendly environmental design in diagnostic imaging and radiotherapy departments.

Higgins R, Spacey A, Innes A. Delivering person-centred dementia care: Perceptions of radiography practitioners within diagnostic imaging and radiotherapy departments. *Dementia*. Published July 14 2023. <https://doi.org/10.1177/14713012231189061>. Open access.

Physical restrictions in care plan meetings

This study used conversational analysis to examine 15 care plan meetings in long-term dementia care settings to identify the professional practices of discussing the physical restrictions posed to residents with severe dementia. It recommends involving family members in decision-making about restraining at an earlier stage, adjusting the protocol in care plan meetings, and engaging the family in minimizing and preventing restraints. In general, staff members should

pay more attention to the residents' experiences and the family members' lifeworld knowledge of the residents. Paananen J, Lindholm C. Discussing physical restrictions in care plan meetings between family members of residents with dementia and nursing home staff. *Dementia*. Published June 30 2023. <https://doi.org/10.1177/14713012231186346> Open access..

Caregiver intervention to improve pain assessment

Family caregivers of persons with comorbid pain and moderate-to-advanced dementia were randomly assigned to the Pain Identification and Communication Toolkit (PICT) or a control group. PICT caregivers reported that the intervention helped them to feel more confident in their ability to recognize and communicate about pain symptoms. At 12-weeks, caregivers in the PICT group showed a statistically significant improvement in self-efficacy in pain-related communication. In qualitative interviews, caregivers emphasized the utility of PICT's components, including pain assessment tools, and offered considerations for future enhancements, such as technology-based adaptations and integration within care delivery systems. Overall, the trial demonstrates that PICT is feasible to implement, acceptable to caregivers, and has the potential to improve confidence in recognizing and communicating about pain.

Riffin C, Brody L, Mukhi P et al. Establishing the feasibility and acceptability of a caregiver targeted intervention to improve pain assessment among persons with dementia. *Innovation in Aging*. Igad074. Published July 2023. <https://doi.org/10.1093/geroni/igad074>. Open access but available only as a pdf.

Self-guided interventions in carers

This systematic literature review examined the effects of self-guided interventions on stress, burden, and mental health of unpaid caregivers of people living with dementia. Stress was generally reduced after the interventions. However, the results of burden and mental health from each intervention were mixed and inconsistent. Interestingly, interventions that lasted less than three months were more likely to have better efficacy. Although the results of self-guided interventions are mixed, this is a potentially useful tool in improving emotional well-being for unpaid caregivers of people living with dementia due to low time burden, ease-to-access, and affordability. Future direction in intervention development should include identifying the optimal length and components of self-guided interventions and collaboration with clinicians for wider distribution to unpaid caregivers of people living with dementia.

Ko E, Wongvibul T, Rose KM, Jun J. The effects of self-guided interventions on stress, burden and mental health in caregivers of people living with dementia: A systematic review. *International Journal of Nursing Studies Advances*. Published July 13 2023. <https://doi.org/10.1016/j.ijnsa.2023.100141>. Open access.

Exercise

This randomised controlled pilot study examined the feasibility of delivering a Seniors Exercise Park Programme to people living with dementia in residential aged care in Australia. It also evaluated the programme's structure, safety, and supervision needs along with the physical, social, health and cognitive benefits of participation. The programme was found to be safe and feasible for people living with dementia in residential care, with high levels of enjoyment, positive attitude, and engagement reported in the intervention group. Individualised communication during program delivery was

needed to facilitate motivation and participation.

Levinger P, Goh AMY, Dunn J et al. Exercise intervention outdoor project in the cOMmunity – results from the ENJOY program for independence in dementia: a feasibility pilot randomised controlled trial. *BMC Geriatrics*, 23, 426. Published July 12 2023. <https://doi.org/10.1186/s12877-023-04132-5>. Open access.

The adoption of apps

This study explores the barriers and facilitators to app acceptance and adoption, including the importance of “feel good moments” and positive experiences, challenges associated with living with dementia, the importance of ongoing support, and security of the user's information. It captures the views and experiences of people living with dementia in relation to the factors influencing the adoption of apps.

Conway A, Ryan A, Harkin D, McCauley CM. “It's another feather in my hat” – Exploring factors influencing the adoption of Apps with people living with dementia. *Dementia*. Published June 26 2023. <https://doi.org/10.1177/147130122311852833>. Open access.

Young-onset dementia and euthanasia

This Belgian study aimed to explore the considerations that people with young-onset dementia and their family caregivers expressed on euthanasia. The topic arose at ‘key’ moments, mostly with family caregivers, and was motivated by patients considering the impact of disease progression for themselves and their loved-ones. Caregivers shared opinions on the euthanasia law and discussed the emotional impact of discussing euthanasia. Considerations of people with young-onset dementia towards euthanasia appear rooted in personal, as well as in anticipated interpersonal and societal suffering. The negative image associated with dementia and dementia care seemed to influence people's expectations for and thoughts on the future. The authors recommend that patient-physician communication should include detangling motives for euthanasia requests, openly discussing fears and reflecting on prognosis.

Rickstal RV, De Vieminck A, Chambaere K, Van den Block L. People with young-onset dementia and their family caregivers discussing euthanasia: a qualitative analysis of their considerations. *Patient Education and Counseling*. Published July 12 2023. <https://doi.org/10.1016/j.pec.2023.107882>

Support priorities of older carers

Through nominal group technique focus groups, this study sought to understand the support priorities of older (65+ years old) carers of people living with dementia. Overarching themes consisted of prioritising the carers' holistic needs; having a sense of belonging; support needs to be accessible and timely; support to meet the wellbeing and personhood of the person living with dementia; and understanding and training for the wider community. The identified priorities can be used by services and organisations to enhance the support and services that older carers receive.

Herron D, Runacres J. The support priorities of older carers of people living with dementia: A nominal group technique study. *Healthcare*. 11 (14) 1998. Published July 11 2023. <https://doi.org/10.3390/healthcare11141998>. Open access.

Spousal grief in cognitive decline

Pre-death grief in the context of dementia caregiving is a significant risk factor for depression, burden, anxiety, and adjustment difficulties. The Two-Track Model of Dementia Grief (TTM-DG) provides a bifocal perspective addressing

the nature of the emotional attachment to a loved one living with cognitive impairment, along with a medico-psychiatric perspective associated with stress, trauma, and change in life. Evaluating the model, this study provides empirical support for the utility of the TTM-DG in the identification of risk factors associated with maladaptive responses and pre-death grief following a spousal cognitive decline. It concludes that the TTM-DG can assist in the formulation of evidence-based evaluations and interventions to assist spouses caring for their loved ones living with dementia.

Manevich A, Rubin SS, Katz M *et al.* Risk, Resilience, and the Two-Track Model of Dementia Grief Among Spouses of People Living With Cognitive Decline. *Gerontology and Geriatric Medicine*. 2023;9. Published June 17 2023. doi:[10.1177/23337214231171264](https://doi.org/10.1177/23337214231171264). Open access.

Palliative care support

Evidence from clinical trials supports the ability of palliative care to improve patient and caregiver outcomes by the use of outpatient or home-based palliative care interventions for people with motor neuron disease, multiple sclerosis, or Parkinson's disease; inpatient palliative care consultations for people with advanced dementia; telephone-based case management for people with dementia in the community; and nurse-led discussions with decision aids for people with advanced dementia in long-term care. This paper highlights that, unfortunately, most people with neurological diseases do not get the support that they need for their palliative care under current standards of healthcare. Improving this situation requires the deployment of routine screening to identify individual palliative care needs, the integration of palliative care approaches into routine neurological care, and collaboration between neurologists and palliative care specialists. Research, education, and advocacy are also needed to raise standards of care.

Kluger BM, Hudson P, Hanson L *et al.* Palliative care to support the needs of adults with neurological disease. *The Lancet Neurology*. 22(7) 619-631. Published July 2023. [https://doi.org/10.1016/S1474-4422\(23\)00129-1](https://doi.org/10.1016/S1474-4422(23)00129-1). Restricted access.

Blogs I'm watching

By Mark Ivory

Is it time to reinvigorate old networks, asks the Institute of Mental Health (IMH) blog, which expresses scepticism about the resolve of UK governments (with the honourable exception of Scotland) to maintain the momentum of dementia policy. The writer would like to see a revival of the "North Sea Dementia Group," which brought together university-based dementia services development centres.

<https://institutemh.org.uk/news>

As the row continued about the extension of London's ULEZ (ultra-low emissions zone) across the capital, a well timed Alzheimer's Research UK (ARUK) blogpost insisted that it was "time to clear the air on pollution and dementia."

"There's growing body of evidence that suggests air pollution could be putting us at a greater risk of developing dementia, but we don't know how this happens," Dr Jake Brooks told the blog, "My research aims to show how tiny metal-containing pollution particles may accumulate and distribute in the brain, and how they associate with Alzheimer's disease proteins like tau and amyloid."

www.alzheimersresearchuk.org/blog

Resources with an EDI focus to support people affected by dementia

This is a small selection of the resources which are available to support person-centred care for people with dementia and carers from diverse backgrounds.

Please send JDC more examples of resources you have created or found useful - email sue@dementiapublishing.community

Minority ethnic communities

ADAPT Toolkit: The toolkit includes films, animations, assessment tools & more – all culturally and linguistically adapted for South Asian communities. The toolkit is a co-production between academic researchers, carers, people living with dementia and filmmakers, providing a rich and comprehensive resource

<https://raceequalityfoundation.org.uk/adapt/>

Dr Karan Jutla provides links on her website to many useful resources for supporting people from South Asian communities

<https://drjutla.com/resources/>

Cuimhne Campaign – Irish in Britain:

The Cuimhne (Irish word for memory) Campaign has been running since 2012 and has raised awareness of dementia and supported the development of culturally sensitive community services for Irish people affected by dementia in the UK.

<https://www.irishinbritain.org/what-we-do/our-campaigns/cuimhne-irish-memory-loss-alliance/cuimhne-carers-project>

Dementia Alliance for Culture and Ethnicity:

An eclectic collection of resources for UK migrant communities, encompassing awareness-raising videos in English and a variety of community languages, links to other resources and research, and practical tools for supporting people affected by dementia in minority ethnic communities.

www.demace.com

Alzheimer's Society dementia information in different languages:

<https://www.alzheimers.org.uk/get-support/publications-factsheets/accessible-resources/information-in-your-language>

LGBTQ+ communities

Alzheimer's Society LGBTQ+ resources:

Information for LGBTQ+ people who are living with dementia and advice on how to access appropriate support

<https://www.alzheimers.org.uk/get-support/daily-living/lgbtq-living-with-dementia>

Information and advice for those who are supporting an LGBTQ+ person who is living with dementia.

<https://www.alzheimers.org.uk/get-support/help-dementia-care/supporting-lgbtq-dementia>

Skills for care LGBTQ+ Learning Framework:

A learning framework for the social care workforce to help staff develop the insights, knowledge and skills to enable them to work effectively with LGBTQ+ people in later life. <https://www.skillsforcare.org.uk/Support-for-leaders-and-managers/Supporting-a-diverse-workforce/LGBTQ-learning-framework.aspx>

Deaf BSL community

British Deaf Association Scotland Dementia Toolkit:

Invaluable information for Deaf people living with dementia and their families and for professionals supporting them. Includes a series of videos in BSL, and a comprehensive booklet in English setting out good practice. <https://bda.org.uk/dementiatoolkit/>

Alzheimer's Society resources for the Deaf BSL community:

A series of videos in British Sign Language on different types of dementia and related topics. <https://www.alzheimers.org.uk/get-support/publications-factsheets/accessible-resources/information-in-your-language/dementia-information-bsl>

Co-production

Co-production – what it is and how to do it:

Explains the principles and practice of co-production, and its benefits for people who require care and support <https://www.scie.org.uk/co-production/what-how>

Inclusive research

Dementia Enquirers:

A wealth of resources demonstrating the benefits of including people with dementia as research partners, and providing guidance to people with dementia and professional researchers about how to co-produce research. <https://dementiaenquirers.org.uk/publications/>

Human Rights

World Health Organization briefing on “[Ensuring a human rights based approach for people living with dementia](https://www.ohchr.org/sites/default/files/Documents/Issues/OlderPersons/Dementia/ThematicBrief.pdf)”. <https://www.ohchr.org/sites/default/files/Documents/Issues/OlderPersons/Dementia/ThematicBrief.pdf>

Our dementia our rights:

Accessible booklet explaining the principles and practice of a human rights based approach for people living with dementia and their families. <https://www.dementiavoices.org.uk/wp-content/uploads/2016/11/Our-dementia-Our-rights-booklet.pdf>

Books

Theory and practice

The Practical Handbook of Living with Dementia eds. Isla Parker, Richard Coaten and Mark Hopfenbeck, PCCS Books 2022

A wide-ranging handbook for practitioners exploring many aspects of dementia care. Includes chapters on the experience of people living with dementia from diverse communities and practical guidance for providing support and inclusion.

The Dementia Manifesto: Putting Values-Based Practice to Work. Julian C Hughes, Toby Williamson. Cambridge University Press 2019

Explores how a values-based, person-centred and rights-based approach can be applied to every aspect of the experience of dementia, including diagnosis, treatment, care, social attitudes, research, public policy and funding.

Supporting People Living with Dementia in Black, Asian and Minority Ethnic Communities: Key Issues and Strategies for Change. Ed. David Truswell. Jessica Kingsley Publishers 2020

Explores the experience of dementia in various minority ethnic communities in the UK, highlighting the additional barriers faced by members of these communities, and sharing examples of successful initiatives to overcome these challenges.

LGBTQ+ People and Dementia: A Good Practice Guide Sue Westwood and Elizabeth Price. Jessica Kingsley Publishers 2023

Brings together research, policy and the voices of LGBTQ+ people with dementia, highlighting the importance of a person-centred approach – moving away from the idea of equality as treating everyone the same, towards treating everyone as individuals.

Lived experience

People with dementia speak out

Ed. Lucy Whitman. Jessica Kingsley Publishers 2016
Personal accounts by people living with dementia. “It brings alive the experience of living with dementia through the stories of people from all walks of life in the UK, and eloquently illustrates ... that *dementia does not discriminate*.”

Telling tales about dementia: the experience of caring

Ed. Lucy Whitman. Jessica Kingsley Publishers 2010
Personal accounts by family carers from diverse backgrounds. “Vivid personalities shine through, reminding us that every person with dementia, every carer and every caring relationship is different and individual, therefore services need to be sensitive, personal and flexible.”

Resources update

A fully online **postgraduate certificate** in person-centred dementia studies is open for applications at the University of Worcester. The certificate, which reflects the requirements of the Dementia Training Standards Framework, focuses on leadership and how to make a difference in settings where students have influence. There are modules on person-centred leadership, supporting people with advanced dementia, engagement and empowerment, person-centred care, enabling environments and dementia in the family context. www.worcester.ac.uk/dementia (email dementia@worc.ac.uk).

Guidance for care homes on nutrition and hydration has been produced by apetito. The company says that its new free ***Guide to Catering for Specialist Diets in Your Care Home*** contains lots of useful information and guidance ▷

▷ on best practice in catering for residents with dysphagia, dementia and allergies while also maintaining the quality and appeal of meals.
<https://apetito.link/specialist-diets-guide>.

Alzheimer's disease research on new treatments is too focused on amyloid build-up in the brain and doesn't pay adequate attention to other promising research paths, according to a **new book**. *Alzheimer's Disease Research: What has guided research so far and why it is high time for a paradigm shift*, by Professor Christian Behl, was published by Springer Nature in August. In the book Professor Behl argues that it is time to re-evaluate the amyloid cascade hypothesis and raises questions about research strategies, the funding landscape and what he regards as a too narrow focus on one dominating hypothesis.
<https://link.springer.com>

Would you like to learn how to deliver **cognitive stimulation therapy** (CST) as a group treatment for people living with mild to moderate dementia? This course teaches attendees to apply the key principles and is suitable for health care professionals including psychologists, occupational therapists and nurses as well as community-based organisations running meeting centres and day opportunities, health care assistants and managers within health and social care. Taught by Dr Helen Donovan, it is an online course via Zoom.
<https://www.dementiathfinders.org/training-workshops>

Dementia Summit is a new conference from the King's Fund think tank around the theme "It's Time to Talk about Dementia". Taking place at King's Fund HQ in London on 31 October, the one day conference will include a "thought provoking programme" on education, research and care in dementia. It will take place in the context of the government's proposed 10 year plan for dementia and a planned £375 million investment in neurodegenerative disease research. <https://dementiasummit.co.uk>.

The government-based Office for Health Improvement and Disparities has produced a **palliative and end of life care factsheet** covering dementia as well as other conditions. The factsheet describes patterns of care near the end of life for four of the six conditions that will be included in the government's forthcoming Major Conditions Strategy – dementia, cancer, cardiovascular disease and respiratory disease. Statistics are provided in the document such as number of deaths, number of hospital admissions in the months before death, and place of death. https://fingertips.phe.org.uk/documents/peolc_patterns_of_care_factsheet_2021.html

Environmental Assessment Tools App available
An App version of the popular suite of environmental assessment tools originally developed by The King's Fund and recently refreshed by the Association for Dementia Studies (ADS) is now available. Thanks to funding and support from Betsi Cadwaladr University Health Board in Wales, the tools covering care homes, gardens, health

Journal of Dementia Care Webinars

For up-to-date information and to book, go to www.journalofdementiacare.co.uk—Events—Webinars

Tues 31 October 2023, 2-3pm

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

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

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

centres, hospitals, housing and wards are available in an App which can be downloaded for free from the ADS website <http://www.worcester.ac.uk/discover/kings-fund-environmental-assessment-tools.html>

The App is available in both Welsh and English and is aimed at helping health and care staff, together with people living with dementia and their carers, to assess and improve care environments. The original paper versions of the tools are still available and remain free to download from the ADS website

Royal Star & Garter, which runs dementia specialist care homes, has produced **top tips** for organising safe trips out. The tips, which can be downloaded, are aimed at anyone supporting someone living with a disability or dementia. "We know that organising fun but safe trips out can be difficult so our team have put together some top tips for planning the perfect day for you and your loved ones," says Royal Star & Garter.

www.facebook.com/100064489432215/posts/pfbid0JxCUUQF5cmh2bUPUTMEeqn1o2Fyp8UCTsmQ5DK9LAKx4pgwiLKUWaHUi2UetEjJ4l/

Information on common side effects of dementia drugs and how they may affect the heart has been published on the Alzheimer's Society website. It says that drugs like cholinesterase inhibitors can result in side effects like a slow heartbeat, describing briefly the latest research and indicating how to deal with the side effects.

www.alzheimers.org.uk/blog

A free resource titled **Be inspired – The role of music in dementia care** has been produced by the charity Music as Therapy International. It is designed to explore the role music can play in care and includes ideas, questions and inspiration for choosing the right music. The resource is part of a new online training course, Music Helps, which the charity aims to launch later this year.

www.musicastherapy.org

Supporting a better life for people living with dementia



Through our dementia strategy, HC-One is seeking to lead the way in the delivery of innovation and excellence in the standard of enhanced dementia care services we offer, and in doing so, become a sector leader and provider of choice for those living with dementia.

As the UK's largest provider of dementia care to the public sector, HC-One is responding to the increasing complexity of dementia by developing our new Specialist Dementia Care Community (SDCC) proposition as a service that sits above the traditional categories of care.

For more information about the specialist care we provide in your community, including immediate placements and spot purchases, please contact one of our professional Careline advisors.

T: 0333 999 8699 | **E:** [hc-one.co.uk](https://www.hc-one.co.uk)





Dementia advice from experts

One step at a time

A video guide to navigating dementia

Our new online guide offers expert advice to help you navigate dementia, from initial diagnosis, to living well with the condition and self-care tips for carers.

Download the guide at
careuk.com/one-step-at-a-time
or scan the QR code.



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