

The Journal of DementiaCare



For all who work with people with dementia

Vol 32 No 5 September/October 2024

Physical comfort and freedom from pain

Esteem

Control over environment and possessions

Occupation and exploration

Fun

Positive touch

Perception of safety

Love and belonging

Non-pharmacological prescribing: meeting fundamental needs

**Also inside
this issue:**

- Reducing psychoactive medication use: Find the 'why'
- Reading Well for dementia
- Living with Dementia Toolkit



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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The Journal of DementiaCare



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

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

Monday 23 September 2024

Unleash the power of personally meaningful music with Playlist for Life

Presenter: Rebecca Kennedy, Head of Communities, Playlist for Life

Description: Personalised music can reduce anxiety, distress and the need for medication by up to 80%, improving quality of life for people with dementia. In celebration of National Playlist Day (20 September), this webinar will share how personally meaningful music can help people to live well with dementia, covering:

- Why music is special
- How playlists support wellbeing
- How to get started on a Playlist for yourself or someone you support.

Monday 7 October 2024

Brain Health Clinics

Presenter: Vanessa Raymont, Associate Professor and Honorary Consultant Psychiatrist, Department of Psychiatry, University of Oxford and R&D Director, Oxford Health NHS Foundation Trust

Tuesday 22 October 2024
2.00pm-3.00pm

Dementia Community Space

Your Open Forum Webinar

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

Tuesday 5 November 2024

A Good Life with Dementia

Presenters: Kate Gridley, University of York and Irene Donaldson, Expert by experience/Good Life peer-tutor

Description: The Good Life with Dementia course is an innovative co-produced course led by and for people with dementia, with professional facilitation. An evaluation aimed to better understand how courses like this could help people to live as well as possible with dementia. People affected by dementia in different communities were consulted about how peer-support could help them, and whether the Good Life model would need to be adapted to be transferable to different contexts (especially South Asian communities).

Monday 18 November 2024

Driving safely with dementia and other transport issues

Presenters: Nigel Hullah, Amy Kordiak and colleagues from the 3 National Dementia Working Group, with the Regional Driving Assessment centre (RDAC)

Monday 2 December 2024


Validation: the gift of connection and communication


Presenter: Vicki De Klerk, Validation Master Teacher and Executive Director of the Validation Training Institute.



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

Details at: <https://journalofdementiacare.co.uk/events/national-dementia-care-awards>

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www.facebook.com/
JournalOfDementiaCare

Editor **Sue Benson**

sue@dementiapublishing.community

News Editor **Beth Britton**

bethb@dementiapublishing.community

Designer **Rob Wheele**

Editor-in-chief **Dr Richard Hawkins**

Website editor/social media **Beth Lang**

beth@dementiapublishing.community

General Manager **Melanie Blake**

melanie@dementiapublishing.community

Sales and Marketing Executive **Isabella Barclay**

isabella@dementiapublishing.community

Tel: 0300 030 1028 (10am-1pm Mon-Fri)

Subscriptions

subs@dementiapublishing.community

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Dementia Community Advisory Group

Caroline Baker, Belong

Paola Barbarino, Alzheimer's Disease International

Kate Lee, Alzheimer's Society

Professor Dawn Brooker, University of Worcester

Theresa Ellmers, University of Southampton

Ruth Eley, Together in Dementia Everyday (tide)

Dr Nori Graham, Alzheimer's Society

and Alzheimer's Disease International

Reinhard Guss, Oxleas NHS Foundation Trust

Karen Harrison-Dening, Dementia UK

Hazel Heath, independent nurse consultant: older people

Jo James, Imperial College Healthcare NHS Trust

Karan Jutla – University of Wolverhampton

Kellyn Lee, University of Southampton

Professor Jill Manthorpe, Professor of Social Work,

King's College London

Jan Oyebo, Young Dementia Network

Maria Pasiecznik Parsons, Creative Dementia Arts Network

Lynne Phair, independent consultant nurse & expert witness

Kritika Samsi, Kings College London

Professor Graham Stokes, HC-One

Professor Claire Surr, Leeds Beckett University

Jude Sweeting, Dementia Pathfinders

Dr Amanda Thompsell, National Specialty Advisor:

OPMH at NHS E&I

Toby Williamson, independent consultant

Lucy Whitman, former carer, writer, editor and trainer

Hilary Woodhead, NAPA

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

The 3 Nations Dementia Working Group –

Alzheimer's Society (with Nathan Bolton)

David Truswell – Dementia Alliance for Culture and Ethnicity

Jane Ward – Dementia Friendly Hampshire

Dr Nadia Wahid – Dementia Primary Care Clinical Lead,
Birmingham

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

The challenge to connect



David Truswell, member of the Equality, Diversity and Inclusion

Group of Dementia Community and an independent writer on the impact of dementia on migrant and minority ethnic communities, and Sue Benson, Editor, JDC.

The *Journal of Dementia Care* has always focused on sharing good practice, illustrating solutions as well as identifying problems, and ensuring contributors communicate in an engaging and person-oriented way. There have been changes, and some progress, over the years across many areas of dementia care and support, as the wide spread of topics covered in this issue demonstrates.

We have to acknowledge that we are always on a developmental journey in our work, and to this end we have recently been working to strengthen our own understanding and response to Equality, Diversity and Inclusion (EDI) issues in the dementia field. We have done this by forming an internal EDI group as part of the executive advisory structure of Dementia Community. This group includes people who have made important contributions to taking action on EDI issues in the dementia field over the years. The special issue the group produced last year* was a powerful example of this work, and the group will continue to support us in adding greater understanding of EDI issues as a central plank of our commitment to improving the quality of dementia care and support for everyone. We are resolved that the use of terms such as 'hard to reach' communities can have no place in contemporary person-centred dementia care. The challenge for modern dementia services is always for them to reach the person, whoever they may be, not just be for some folks some of the time.

Highlights of progress in inclusive dementia care in this issue include the Silver Pride event described by Arlene Bunton (p10) - a fantastic example of community celebration of diversity and improving the appreciation of the experience of people in the LGBT+ community living with dementia, that reaches into the local community including - importantly - care homes. Then Versha Sood and Gabriel Mandal (p22) report on partnership work to co- design and deliver tailored engagements to connect with citizens from ignored and marginalised communities that are often mislabelled 'hard to reach'. Also Suman Kurana and colleagues (p26) describe an important online initiative supporting South Asian caregivers that also involves highlighting solutions to assumed barriers to access to digital support for minority communities.

Over the last two years our UK Dementia Congress has had a strong focus on Equality, Diversity and Inclusion, and this year's event will continue that focus, threaded through the whole event and all sessions. To that end we are working with all presenters, requiring them to give us more information about how they or their services have addressed the challenges for underserved populations, and what concrete steps they have taken to engage with individuals and communities. In some cases this may involve an admission that past practice was inadequate, and determination to improve in future. We are all on a developmental journey.

The articles highlighted above do point to some progress in the right direction. I hope you find them, and the whole of this issue, thought-provoking, educational, inspiring and a damn good read. ■

**Journal of Dementia Care* September/October 2023: Equality, Diversity and Inclusion – A special issue. This publication is still available free to download on the home page of our website: www.journalofdementiacare.co.uk

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

Writing for JDC:

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

Contact the editor, Sue Benson: sue@dementiapublishing.community

News round-up

This is a brief round-up of the news and resources regularly posted and updated on our website. See more at: www.journalofdementiacare.co.uk

EDI workshops on dementia and neurodegeneration

The NIHR Policy Research Unit Dementia and Neurodegeneration of the University of Exeter (DeNPRU Exeter) is running two workshops with an EDI focus.

On 15 October, those working with minority ethnic communities affected by neurodegenerative conditions are invited to take part in this workshop:

<https://www.eventbrite.co.uk/e/raising-awareness-of-neurodegenerative-conditions-tickets-946418943537?aff=oddtcreator>.

On 16 October, for those with strategic responsibilities for EDI: <https://www.eventbrite.co.uk/e/raising-awareness-of-neurodegenerative-conditions-tickets-946423477097?aff=oddtcreator>

DeNPRU Exeter conducts policy research relating to all forms of dementia, Parkinson's Disease, Motor Neurone Disease, Huntington's Disease and rarer neurodegenerative conditions. Find out more about DeNPRU Exeter and its projects here: www.denpruexeter.nihr.ac.uk.

New LGBTQ+ resources from SCIE

The Social Care Institute for Excellence (SCIE) has published new resources linked to the LGBTQ+ Older Adult Social Care Assessment (LOASCA) project, led by the University of Birmingham. The resources include:

- A new animated video depicting a range of social care assessment responses to 'Fran' an older LGBTQ+ adult: <https://youtu.be/t8T8HxaPTS4?si=o0kWZRvP3-gQYolg>
- A graphic novel presenting some of the stories told by older LGBTQ+ people in the LOASCA study: https://www.scie.org.uk/app/uploads/2024/08/LOASCA-Graphic-Novel_Final-version.pdf
- A three-part podcast on collaborative social work research with older people: <https://soundcloud.com/paul-b-willis-academic-social-care-researcher/sets/collaborative-social-care-research-with-older-people-a-series>
- Slides from the Older LGBTQ+ People and Social Care 2024 conference: <https://www.scie.org.uk/app/uploads/2024/08/LOASCA.pdf>

Think Local Act Personal (TLAP) has published a report entitled: **'Values and the workforce: the expectations of people with lived experience'**. The report is the culmination of work undertaken by TLAP, at the request of the Department of Health and Social Care (DHSC), to support the development of the Care Workforce Pathway. TLAP talked to people who draw on care and support to find out what values they think the workforce should have to enable good person-centred care. <https://www.thinklocalactpersonal.org.uk/assets/Values-and-the-workforce-TLAP-report.pdf>

Dementia Summit conference

You can't be person-centred without being culturally inclusive, and you can't be culturally inclusive without being person-centred. The two go hand in hand.

Dr Karan Jutla, Head of the Centre for Applied and Inclusive Health Research and Dementia Lead, University of Wolverhampton, opened her address with this statement, and went on to give telling examples showing that a compassionate, person-led approach will always be more important than, for example, matching the cultures of care worker and client. Being from the same cultural background is no guarantee of sympathy and understanding—the support worker may be judgemental of the family member's care, or of the person with dementia (for drinking alcohol, for example).

Cultural competence is the key, she said: "It involves more than having an awareness of cultural norms and defeating language barriers... It requires 'cultural humility' [that] reflects on cultural biases and stereotypes through appropriate training and education."

Dr Jutla was speaking at the Dementia Summit conference 'It's time to talk about dementia' held in London in September 2024.

In an afternoon session on young onset dementia, Philip Angrave, a retired nurse lecturer with lived experience of dementia, told a moving personal story of his developing condition and diagnosis. Dr Janet Carter, Consultant Old Age Psychiatrist, North East London NHS Trust then spoke on 'Improving awareness, practice and support for people with young onset dementia'. She emphasised the vital importance of access to specialist investigations at an early stage, and the need for ongoing tailored and age-appropriate support services for people and their families. The Young Dementia Network's national ambition includes calls for progress in these areas, plus the need to raise public awareness to foster a more supportive environment. A lack of reliable data and targets made it hard to even define the challenge and argue for services, she said, concluding with an urgent call to NHS England to improve these.

New animation: awareness of young onset dementia

Dementia UK has shared a new animation to increase awareness of young onset dementia.

The animation includes information about symptoms that can be experienced by younger people, what those symptoms can be mistaken for, and the different challenges younger people face when living with dementia. View the animation here:

<https://vimeo.com/993493332/20524d71e1>

The Young Dementia Network has launched a refreshed website, with new features to make it more accessible. The website includes information about the network and young onset dementia, research opportunities and numerous resources, newsletters and webinars. <https://youngdementianetwork.org>



NAPA Arts in Care Homes 24 September 2024

Arts in Care Homes is a programme run by the National Activity Providers Association (NAPA) that underscores the well-being benefits of arts, creativity, and cultural engagement in care settings. Celebrated on 24th September each year, this initiative promotes positive outcomes for individuals in care, staff teams, and relatives, while also championing good practice across the sector.

NAPA encourages care settings to embrace creativity by organising an arts activity, whether big or small, involving any art form. More information at <https://napa-activities.co.uk/arts-in-care-homes/art-in-care-homes> or contact aich@napa-activities.co.uk

A two-day training in reminiscence arts in dementia care is to be held at the University of Greenwich on 9 and 10 October 2024. The experiential course, led by skilled practitioners and trainers with input from volunteers and former carers, will be certificated by the European Reminiscence Network. A four-month apprenticeship scheme in reminiscence arts in dementia care is also available with up to 10 places for trainees to become accredited facilitators.

Information and details on how to apply at: pamschweitzer.com/training-october-2024.pdf

Memory Services Spotlight Audit 2023-24

The Royal College of Psychiatrists, as part of the National Audit of Dementia, has published its Memory Services Spotlight Audit 2023-24. Statistics from the audit include:

- A large increase in the average waiting time from referral to diagnosis, up to 151 days.
- A wide variation between services with the lowest average 44 days and the highest 347.
- Time for assessment to diagnosis is significantly higher for patients from the most deprived areas.
- A wide variation in results from each service on each item measured. This includes physical health checks, specific diagnoses, and post diagnostic support such as Cognitive Stimulation Therapy.

Standards for this audit were drawn from the Dementia Care Pathway Full Implementation Guidance by the National Collaborating Centre for Mental Health and Memory Services National Accreditation Programme (MSNAP) standards 8th edition. [https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-\(2023-2024\)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf](https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/nad-round-6-(2023-2024)/mas-r6/nad-mas-2023-national-report-05082024-final.pdf)

In-depth analysis from ARUK here: <https://www.alzheimersresearchuk.org/news/five-things-weve-learned-from-the-2024-memory-assessment-services-audit/>

New CST vlog goes live

Simon's Dementia Cognitive Stimulation Therapy (CST) Activities Blog is a free, accessible library of over 250 themed activity pages designed to support ongoing (or maintenance) CST for people with mild to moderate dementia. The new YouTube vlog, featuring Simon O'Donovan MBE, a retired dementia nurse specialist, is aimed at people living with dementia at home who don't have access to a local CST group or don't want to join a group. Simon is aiming to translate all his current blog-based activity pages (that can be found here: <http://www.simondementia.co.uk>) into videos in the coming months. You can view the first vlog, CST Intro & Game Changers Taster here: <https://youtu.be/n0ImuUsIUtg?si=i7UEeg6-2FEnfKz-> Simon's CST Activities YouTube Channel is here: <https://www.youtube.com/@simondementia>

Alzheimer's Society is investing £9million into funding three new **Doctoral Training Centres**. The centres will support nearly 90 students over five years to enter dementia research and will be led by Professor Stuart Allan at Manchester University, Professor John-Paul Taylor at Newcastle University, and Professor Nathan Davies and Professor Claudia Cooper at Queen Mary University of London. The centres focus on "building knowledge and understanding in areas that have been particularly underfunded". These are: Vascular and Immune Contributors to Dementia; Lewy Body Dementia; Integrated Care. More information at: <https://www.alzheimers.org.uk/news/2024-08-28/9m-investment-championing-next-generation-dementia-researchers>

Joseph Rowntree Foundation (JRF) has published a new briefing entitled **The future of care needs: a whole systems approach**. The briefing predicts the changing care landscape across the next decade, suggesting that an extra 400,000 people in the UK could be providing care for more than 10 hours a week by 2035. JRF also makes recommendations, including for the creation of a Future Care Needs Taskforce. More information at: <https://www.jrf.org.uk/care/the-future-of-care-needs-a-whole-systems-approach>

NHS England has published a refreshed Dementia Scenario highlighting key elements of optimal care across the dementia pathway. It puts a fictional person at the centre of the story to show the difference between a suboptimal – but realistic – pathway of care, compared to an optimal one.

The scenario is available on the NHS England website here: <https://gettingitrightfirsttime.co.uk/academy-resources/population-health/>

Supporting summaries of the scenario and summary dementia data packs can be found on the FutureNHS website (login required): <https://future.nhs.uk/system/login?nextURL=%2Fconnect%2Eti%2FNationalRightCare%2Fview%3FobjectId%3D48796112>

JDC asks:

What do you hope and expect from the new UK government that will have an impact on dementia care?

Ruth Eley is founding director and chair of trustees of Together in Dementia Everyday (tide)

My hope is that the role of unpaid carers is recognised and valued – not just in warm words, but in real action that will make a difference. Health and social care are devolved to the four nations, but the UK government can do a lot to address some of the critical issues that face unpaid carers – the largest dementia care workforce who contribute over £14b a year to the economy.



The Carers Allowance would be a good place to start. The previous government refused to tackle the long-running scandal over prosecutions of unpaid carers who unwittingly earned more than they were entitled to, thus jeopardising the whole of their Carers' Allowance for that payment period, and were accused of fraud. This government could ask for the charges to be dropped, unless there is clear and irrefutable evidence of fraud, and thus remove the anxiety and financial stresses caused by the criminal prosecutions; the exoneration of postmasters and mistresses is a reasonable comparator. The Allowance itself works out at something like £2.30 an hour if you provide 35 hours of care and should be raised to the level of the Living Wage – currently £11.44 per hour. The DWP could put Carers' Allowance on the same basis as Universal Credit; if you earn more than the threshold, your allowance is deducted by that amount rather than having to lose the whole lot.

What do I expect? Certainly more than the last government that let dementia slip right down the agenda and did not even take their 'oven-ready' solution for social care out of the fridge. They have left a financial and policy mess for the new government to sort out; it will take some time.

David Truswell, member of the Equality, Diversity and Inclusion Group of Dementia Community and an independent writer on the impact of dementia on migrant and minority ethnic communities:

Quality of life for people living with dementia and their carers needs to come back into the focus in policy and spending. Most people living with dementia are living in community settings and supported by family, informal carers or paid carers. The quality of everyday life for those living with dementia and their carers matters as it is the core of their psychological sense of well-being. Pharmacological solutions to dementia are in practice some way off, yet the social and psychological challenges of living with dementia and promoting the dignity and human rights of people living

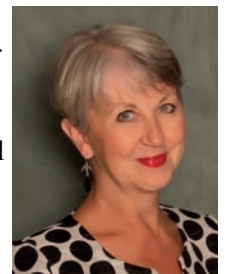


with dementia are issues faced every day. The government must look beyond a narrow focus on a medicalised approach to support and care for people living with dementia to address the social and psychological challenges. What is needed is a mature review to address the social care of people living with dementia and better support carers (whether family carers or paid carers) with their carer role. The government does not appear to appreciate the urgency of this. It could have a rapid impact on dementia care by having more generous and flexible benefits provision for unpaid carers and improved pay and conditions for paid care workers. This should be supported by access to a national skills programme for both paid and unpaid carers. We also cannot look at quality of life in all its individual richness without looking at how we can best support those who are from underserved populations, such as those from marginalised ethnic and faith communities, from the LGBT+ communities or living with lifelong health or ability challenges. Quality of life isn't just about symptom reduction but also about feeling valued and able to participate and must go beyond needs assessment into creativity, inclusion and enjoyment of life despite living with dementia.

▷

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

In health care the term parity of esteem has been used to mean assigning equal value to mental health care as to physical health care. It is proposed that having parity with physical health care would ensure equal access to the most effective and safest care and treatment, high quality of care, time, effort and resources on a basis commensurate with need, to name a few.



Dementia is no longer considered a mental illness but still faces a lack parity of esteem with physical health care. There are several expectations I would have of the new government but my first would be parity of esteem for people with dementia in having equal access to NHS continuing healthcare funding (CHC).

CHC is for adults with long term, complex and unpredictable health needs which are over and beyond what can be met by social care, but all too often, families affected by dementia are missing out on this crucial funding because of a flawed assessment process. Families affected by dementia are finding themselves denied access to such funding or waiting years for it to be granted, sometimes needing to be fast tracked at the very end of life.

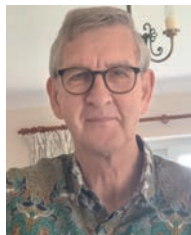
Many families affected by dementia lack awareness of CHC or how it applies to them; similarly some health and social care professionals applying CHC do not have a clear understanding of dementia and its effects. Applying the

CHC process to dementia requires expert input and support, but despite current guidance, assessments often take place without the involvement of a dementia specialist and their essential knowledge and expertise. Assessors often rely on a Decision Support Tool which fails to consistently recognise the impact of the behavioural and cognitive needs of people living with dementia, and how they can fluctuate in intensity and complexity. This means people with dementia who should be eligible often end up missing out. The current government must urgently review the CHC processes to recognise the complex health needs of people with dementia, embracing a specific focus on how cognitive and behavioural needs are assessed, and ensuring dementia specialists are involved in the assessment process. Dementia UK manifesto:

dementia-uk-manifesto-summary-put-dementia-on-the-agenda.pdf (dementiauk.org)

Keith Oliver, living with dementia

Windows of opportunity, as the phrase suggests, are short-lived and need grasping if one is to benefit; a new government is a case in point. While empty promises have abounded since David Cameron left office as PM, Labour have been cautious in making statements about dementia or social care generally. They know the size of the problem, they know the cost of doing nothing and need to grasp the nettle and sit down with a range of stakeholders including representatives of family carers and those diagnosed, and devise a fully costed, deliverable five-year plan for their term in office, with aspirations for the following five years. They need to continue to build additional research funding into **both** cure and care, and establish career pathways in social care with parity to the NHS. Strong central leadership, resulting in realistic, achievable goals will build hope for now and the future.



Graham Stokes, Director of Dementia and Specialist Service Innovation, HC-One

We hope the government will recognise that a crisis in social care is a crisis for people with dementia, and work with the sector to overcome this. Over a third of those living with dementia reside in care homes, and three quarters of care home residents have dementia or severe memory loss. As the number of people living with dementia dramatically increases over the coming decades, care needs will increase in scale and complexity. We have to change how we think about and deliver social care.



HC-One is Britain's largest provider of commissioned dementia care, and we've found that existing commissioning categories are limited catch-alls for a myriad of differing needs, resulting in people with dementia being inappropriately placed, requiring one-to-one support or prescribed anti-psychotic medications. In response, we've developed our Specialist Dementia Care Communities (SDCCs) to sit outside traditional care categories, providing person-centred therapeutic support for those who are distressed.

While innovation improves outcomes, local authorities are often not adequately resourced to adapt. Budgets are tight, but the government has previously committed to funding councils over longer periods. We hope this stability is passed on through longer-term commissioning.

Stability for care providers could transform dementia care. We could depend upon income and invest at scale in new services to find what works and why; in our workforce to upskill colleagues and introduce new roles as HC-One is doing in its SDCCs; because too many care settings are not fit for purpose. We also hope that this stability is backed up by a UK government-endorsed dementia strategy that allows commissioners to think beyond limited categories, beyond the disease, and to the person living with dementia and the outcomes we want for them.



Learning - Sharing - Inspiring: Building a Dementia Community

The 18th UK Dementia Congress will be held at
Coventry Building Society Arena, Coventry CV6 6GE on 26-27 November 2024

Academic Partner: University of Worcester

Congress Partner: Alzheimer's Society

Gold Sponsor: Care UK

Silver Sponsor: Hamberley Care Homes

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Sponsorship and exhibition stands are available - contact Isabella Barclay:
isabella@dementiapublishing.community

All details at: <https://journalofdementiacare.co.uk/events/uk-dementia-congress>

Silver Pride: a celebration and challenge

Arlene Bunton reports on the success of an older adult specific LGBTQ event in East Ayrshire, celebrating diversity and promoting inclusivity; it will be followed by a free training package for social care providers

The inspiration for hosting Silver Pride – Scotland’s first Older Adult specific LGBTQ Event on 27 June 2024 in East Ayrshire – came from multiple sources. Visiting a nursing care home in East Ayrshire in April 2024 as part of my role with Scottish Care, I spoke with a support worker who asked for advice on supporting a gay resident who chose to express his feminine side through clothing choice. This was not an issue for the care home staff themselves, they respected his choice to express himself freely, but the issue she needed support with was the other residents’ reaction to this gentleman. He was being ostracised, spoken about and excluded. The staff are well experienced in managing the difficult relationships that can occur within group living but this was different – there was a culture of non-acceptance growing and we needed to halt this in its tracks. I supported her, offering some advice and committed to seeking out training for all staff members on LGBT and dementia.

This led to me finding Mike Parish, an LGBT activist who supported his husband who was living with dementia within a nursing home environment for over 10 years. Mike agreed to share his experience on a Teams call with 18 older adult care home managers from across East Ayrshire, and you could have heard a pin drop throughout. Mike’s depiction of his experience coming out as a gay man; living through periods of his life where being gay was illegal; where he would have lost his job as a firefighter; and on to finding and marrying the love of his life; having to surrender his care to that of a nursing home whilst fighting by his side - was both a beautiful and painful story to hear.

It made me think of the earlier discussion with the support worker and how we can improve upon the experience of those identifying as LGBT within social care. We need to support the staff and offer reassurance that we are ready to support this culture, this community, for who they are.

One of the first barriers we faced when approaching this topic was the questions of ‘Are we there yet with older adults in care homes identifying as LGBT?’ and ‘Is this all about sex?’ It is these things, but it is also so much more. Cultural stereotypes tend to link LGBT people with excessively sexualised behaviours, but behind this, pushing this aside, we have a community who have lived lives, who have stories, experiences and lifestyles which make them who they are – just they do with heterosexual persons. In one report by Age UK (2015) this was summed

Arlene Bunton is Independent Sector Lead, Scottish Care

Summary

Scottish Care and East Ayrshire Health and Social Care Partnership combined forces to host Scotland’s first ever older adult Pride Event in response to sector need which demonstrated we need to spread awareness of our older adults’ sexual identities and differing needs. Funding was sought from the National Lottery Community Fund which has funded a celebratory event with guest speakers and entertainment, to be followed by delivery of a training package to social care providers – freely available online and hard copies across East Ayrshire. We are strong advocates of being your authentic self within Scottish Care and East Ayrshire and for all those who receive social care to know that ‘You are Safe with Us’.

up by a female participant who said, “Even if I never have sex with a woman in my whole life, I am still a lesbian. It’s as integral to my identity as the job I hold, being a mother, or my beliefs. It’s not all of me but it is a part of me.” Human rights are inclusive of sexual rights, and the freedom to express your sexuality is key within all lives, not just those who identify as LGBT.

Creating a working group to bring Silver Pride to reality was an easy task: everyone wanted to be included. We soon realised that the fantastic buy-in for this catalyst event and subsequent training we could provide could really support the social care sector in a meaningful way: firstly to celebrate the wonderful diversity we have across social care in East Ayrshire, but also to educate the workforce and begin our work to flip the narrative and change the culture for those with LGBT identities in older age.

A very short history of LGBT

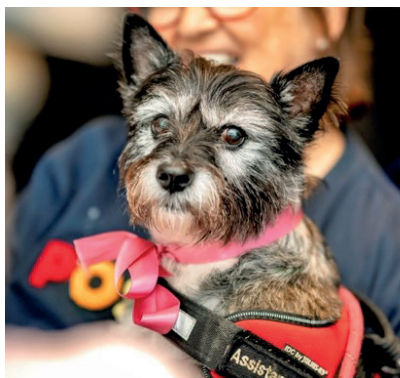
We don’t need to go back far to reach a point in Scotland’s history when it was illegal to identify as gay. In 1980 (only 44 years ago) Scotland decriminalised being gay, but only for those over the age of 21 at a time when the legal age of sexual consent was 16, as it is today. This means that anyone who was born in 1965 or before has lived at a time where they reached puberty and sexual maturation when it was illegal to engage in sexual activity with a same-sex partner. It also means that those who did identify as gay in this time had to be born before 1959 to legally have a sexual relationship with their partner.

In 1994 the age of consent for LGBT sexual activity was lowered to 18, which was still not equal with the population of heterosexual individuals. Only in 2000, at

Twenty-seven local organisations were invited to celebrate diversity at “an amazing event” ... “thought-provoking and incredibly inspiring at the same time.”



the turn of the millennium 24 years ago, could persons identifying as gay have the legal protection of their heterosexual counterparts and engage in sexual activity at 16. And at the same time, identifying as gay was no longer a barrier to serving your country in the armed forces.



Only in 2007 was discrimination banned on grounds of sexual orientation, later joining the Equality Act 2010 as a protected characteristic on the same grounds of age, sex, disability etc. And only as late as 2014 did it become legal to marry your partner of the same sex, not a civil partnership (which was 2004), but marry, as equals with heterosexuals.

Sexual expression and the interaction with dementia

Within aged care in Scotland the prevalence of dementia, particularly as this journey advances, can be a predictor to requiring social care supports. Dementia is a global health priority and poses a disproportionately high risk to those identifying as LGBT (Smith *et al* 2024). Despite this, research often is lacking in identifying what living with a dementia and identifying as LGBT is like. Having dementia does not remove your need or right to sexual expression but it may change the way in which you seek love and affection and how this is reciprocated (Eshmaewy 2022). Having a dementia can affect how the brain works, and this can impact on how a person will behave, potentially in a way that's out of character or socially inappropriate. Dementia can affect a person's ability to inhibit their thoughts and behaviour.

This can lead to a range of behaviours which loosely align with diagnosis. In Alzheimer's disease, over 50% of men may experience erectile dysfunction (Eshmaewy 2022). This is higher than age-matched data with no dementia present, which suggests that this is caused by the disease itself more than any other factor (D'Cruz *et al* 2020) and with women this is likely to present as decreased sexual desire (although no independent studies have looked at this). Up to 25% of those living with Alzheimer's disease may have inappropriate sexual behaviours (Black *et al* 2005) which may present as changes to sexual drive, sexual aggression, lack of impulse control or complete withdrawal (Tabak *et al* 2006). In non-Alzheimer's disease dementias, you might see an increased prevalence of



inappropriate sexual behaviour which can often be associated with frontal temporal dementias (Dementia UK 2024). In vascular dementia 58% of those diagnosed may experience an increase in inappropriate behaviour and with Lewy body disease, these behaviours can fluctuate across the course. Disinhibition, misunderstanding the intent of others towards you and the need for closeness with others may all lead to judgements, prejudice and misunderstandings (Dementia UK 2024).

Funding and delivering Silver Pride

With so much interest in not only the event but the learning opportunities which were to come of this, we applied to the National Lottery Community Fund – proposing we deliver this event for 100 older adults and hold three locality training events. In a wonderfully easy application, I was able to express why this event was needed and we were fortunate to be awarded the requested amount. The working group was able to start planning. The original 100 older adults quickly grew to 130, 150, and then at 180 we had to close the booking facility for spaces. We also had 25 community partners, SL33, East Ayrshire Carers Centres, East Ayrshire Advocacy, Scottish Fire Brigade, to name a few, keen to come along and host stalls on the work they do with LGBTQ persons and locally.

The media were soon informed of our plans and again the phenomenal interest demonstrated the desire to celebrate diversity and learn more about LGBTQ older adults. STV, That's TV and West FM attended on the day to film and record us – making the STV News at 6pm and 10pm and wide coverage across social media from other media interests. Relatives and family members were approaching me and telling me how proud they were of their relative attending, that they brought back learning from the event and were holding debates about transpeople. It was incredibly inspiring and heart-warming to hear.

A true community event

Guest speakers who attended and presented at the event were Patrick Ettennes – Bringing Out Dementia; Philli Mi Up – Drag Artist and Performer; Jacqueline Wilde – Trans Pride Scotland; Colm McBriarty – About Dementia; and David Wilson Wynne – Stirling University. Our presentations covered lived experience of having HIV-related dementia, dementia friendly communities, HIV prejudice, the experience of transpersons within our

communities and this unique perspective, as well as a strong presentation on the phenomenal activity of Stirling University's Dementia Services Development Centre.

We enlisted the support of a team of talented young persons at SL33, led by the wonderful Margorie Harvie – who work to gain skills, employment and opportunities for young adults within East Ayrshire. They displayed exceptional skill in their creation of our décor and balloons, media and communications, DJ and lighting on the day. Supported by Equalities Team from East Ayrshire Council, we were able to invite 27 local organisations to come along and celebrate diversity with us – these groups each had a stall and were handing out information and chatting with the guests, before joining us for the guest speakers and lunch. A local enterprise created our pin badges for the day to proudly show others that 'You are Safe with Us' and take our wave of change back to their own homes and workforces.

What next...

The wonderful group of speakers who attended on the day have since agreed we will come together and create a training pack and materials to be widely dispersed across Scotland to reach as many practitioners in social care as possible and spread the wave of positivity which was born of the passion for inclusivity in East Ayrshire across Scotland.

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Silver Pride was an amazing event. It was about everyone coming together to celebrate diversity, making a statement about living lives to the full. It shone a light on human identity, what's important to people in being themselves and overcoming stereotyping in older age. I felt privileged to be part of this joyful and moving day. Silver Pride generated such a 'buzz' at the event itself and across Scotland. Silver Pride is more than the event as it has the support of a whole range of agencies and marks a commitment to continuing awareness, learning and inclusion.

Erik Sutherland: Head of Locality Health and Social Care, East Ayrshire HSCP

How incredible the event was: thought provoking and incredibly inspiring at the same time. We had many tears at our table during one of the talks. I am excited to see what's to come next and you have put a fire under me for what we as an organisation can be doing.

William McGregor, Regional Manager, Sanctuary Care

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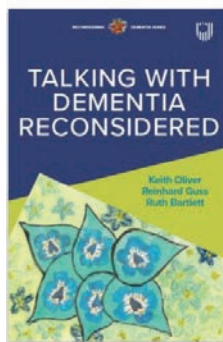
Book review

Talking with Dementia Reconsidered McGraw Hill 0335251285 · 9780335251285 by Keith Oliver, Reinhard Guss, Ruth Bartlett

Already knowing Keith Oliver through my work at University of Bradford's Centre for Applied Dementia Studies and DEEP (Dementia Engagement and Empowerment Project), I approached this book with eager anticipation. I was not disappointed: the book offered new perspectives that reinforced my understanding. It begins with introductions by the authors and students who supported them, followed by biographies of fifteen individuals. I know some of 'the fifteen', but I still learned a great deal. These biographies deepened my appreciation for each person's experiences. The personal stories provide a powerful context for the discussions, grounding theoretical concepts in real-world experiences.

The book is based on Tom Kitwood's 'flower', a model of psychological needs used as a basis for semi-structured interviews with 'the fifteen'. A highlight is Reinhard's exploration of Kitwood's flower along with the Enriched Model of dementia. I use both models in my teaching and was interested to learn of his views and application, particularly in assessment and diagnosis. The book examines 'the fifteen's' experiences of dementia through this lens.

Another useful aspect is the often-overlooked role of religious faith in relation to identity. Keith Day discusses



how faith can profoundly shape one's sense of self, even amid the challenges of dementia.

Researched during the covid pandemic, the book touches on the challenges people faced before, during and after it, with the added difficulties presented by dementia. Julie Hayden discusses how the psychological need for comfort was met by her being in her own home during the pandemic. This highlights the resilience and adaptability of people with dementia, and their need for familiar surroundings.

Ruth's contributions complement those of Keith and Reinhard, adding breadth to the discussion. She reflects on how dementia has been reported on over the last 30 years, emphasising how people with dementia were previously excluded from many reports and labelled in unhelpful ways. Her insights underpin the importance of the interviews and reflections of Keith and Reinhard, bringing a critical historical perspective enriching the overall narrative. The book also features beautiful poetry, a treat for the reader that adds a personal and artistic touch to the comprehensive collaboration of dementia.

Talking with Dementia Reconsidered is an insightful exploration of dementia, and testament to the power of collaborative storytelling and shared knowledge. It stands as a significant contribution to dementia studies and a book committed to understanding those living with dementia.

Clare Mason, University of Bradford

Reading Well for dementia: the power of co-production

Amy Niven, Rachael Litherland and colleagues describe the process of co-production, including people living with dementia and family carers alongside other experts, that led to the latest Reading Well for dementia list

Increased understanding and knowledge of dementia via high-quality book-based information and advice can play an important role in supporting people affected by dementia. Reading Well for dementia provides an up-to-date resource that reflects national clinical guidelines, best practice, advice and support.

Evidence shows that Reading Well empowers individuals to better understand and manage their health and wellbeing. Since 2013, over 3.8 million Reading Well books have been borrowed from public libraries with 92% of people saying they found their book helpful. 90% of health professionals have also said that the books helped to provide valuable support for their patients and carers outside of consultation time (The Reading Agency 2022).

Selection through co-production

Reading Well books are chosen through a rigorous selection process that includes policy and evidence mapping, needs analysis, consultation, and co-production with people with lived experience.

Co-production has been embedded in the Reading Well development process since it launched in 2013. People with lived experience inform all aspects of the development, design and content of Reading Well schemes. The learning from each co-production process has resulted in a robust co-production framework, and feedback from the groups influences the ongoing development of the programme.

The Reading Agency worked with Innovations in Dementia and involved 38 people with dementia and carers from across England and Wales, including a panel of 10 people, over a 6-month period. Involvement included four workshops with the panel and online questionnaires for the wider group. This ensured people living with dementia and carers were represented throughout the development process informing all aspects from design to book selection.

Members from the co-production group joined the book selection panel alongside health professionals and librarians to share their feedback, including their preferences for the type of books and resources they wanted included.

Co-production group members described their experiences of being involved: ▷

*Amy Niven, Hannah Pimble and Gemma Jolly,
The Reading Agency.
Rachael Litherland, Innovations in Dementia*

Reading Well

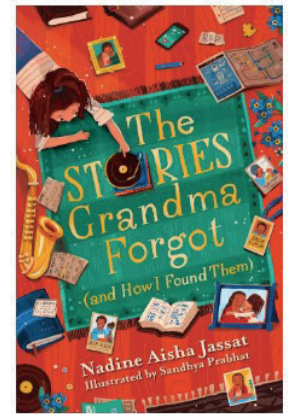
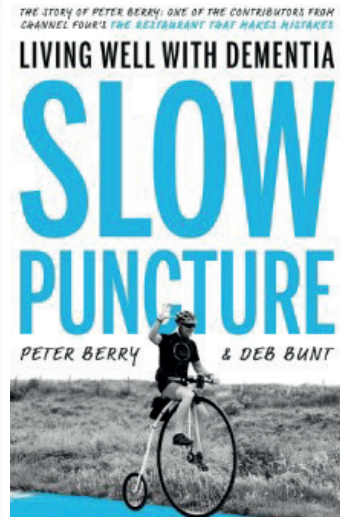
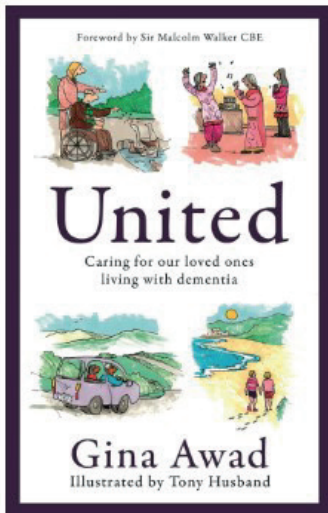
Reading Well is part of The Reading Agency's mission to use the proven power of reading to boost wellbeing and improve people's health across the UK. It is an evidence-based, quality-assured programme that provides helpful reading to support people to understand and manage their health and wellbeing. Reading Well books are all recommended by health experts, as well as people with lived experience. Reading Well titles are available for anyone to borrow free from public libraries across England and Wales. Professionals can recommend titles from the list to support individuals and families, or people can visit their local library and choose a book to borrow.

Reading Well for dementia is a free-to-access, expertly curated booklist, with accompanying digital resources, that supports those living with dementia as well as their family and carers. It is a refresh of the successful 2015 Reading Well for dementia – books on prescription scheme.

The scheme features 20 titles in England and 21 in Wales (including an original Welsh language title) chosen by dementia professionals and those living with dementia and carers. The aim is to provide information and support to boost understanding and awareness of dementia. It features personal accounts and practical advice for people living with dementia as well as family and carers. It also includes age-appropriate, engaging books for younger children with a family member who has dementia. Many titles are available in eBook and audio formats. In Wales, The Reading Agency works with the Books Council of Wales to translate books into Welsh and the programme is supported by bilingual user leaflets and Welsh specific signposting.

Reading Well for dementia is supported by Age UK, Alzheimer's Society, Bangor University, British Psychological Society, Cardiff and Vale University Health Board, Carers UK, Dementia UK, Improvement Cymru, Innovations in Dementia, National Academy for Social Prescribing, National Association of Primary Care, Royal College of General Practitioners, Royal College of Nursing and the Royal College of Psychiatrists.

It was funded by Arts Council England and Welsh Government and developed with Libraries Connected and Society of Chief Librarians (SCL) Cymru. Reading Well for dementia is one of four Reading Well schemes, alongside Reading Well for mental health, Reading Well for teens and Reading Well for children.



Illustrations show nine of the twenty books selected (full list at www.readingagency.org.uk/reading-well)

▷ *My role was to read the books, to score the books ... to give some sense of authenticity to the views of people, in some really quite complex discussions ... with people who were involved in the selection panel.* Keith.

It's been a partnership of equals. In no way have I ever felt like my opinion, because I have dementia, has been diluted in any way. My opinions have counted equally with everyone else's, which I call real co-production. Andy.

What we learned through the co-production process

People want access to **high quality** and accurate information about dementia, including resources that use respectful words about dementia experiences. Resources should be about a whole range of experiences, recognising that different people need different resources at different times.

Accessibility was another key consideration raised by the process, and many of the books selected for the list are available in a range of formats including audiobooks and e-books. Most of the titles from the list are also being translated into Welsh language.

Co-production group members highlighted the importance of including personal stories:

Reading other people's lived experience, both as a family carer and as a person with dementia, does help you to know that you're not alone... If it's a book written by someone with dementia, then I have that sense of connection to it and I can recognise similarities in their stories, but also differences as well. Keith

Dementia is very isolating... Reading personal stories that are on this list help you realise that you're not alone, that self-help is great. Andy.

The co-production group's recommendations informed the design of accompanying publicity materials for Reading Well for dementia, including colour choice, contrast, font size and the use of pictures:

It's important to get the message across briefly so when it catches your eye you will understand immediately. We want something that is nice and colourful. It's got to be eye catching. Andy.

Another key consideration was the inclusion of **age-appropriate and engaging books for younger children**. The Reading Well list features four books to support younger children with a family member who has dementia.

I'm really pleased that these books include children's books because that's the most difficult... How do you explain to a child that grandad or grandma doesn't recognise me anymore? These books address that. Andy

Finally, people identified a need for books that convey that people can **live with dementia** and still do things. This includes practical techniques that can improve people's quality of life.

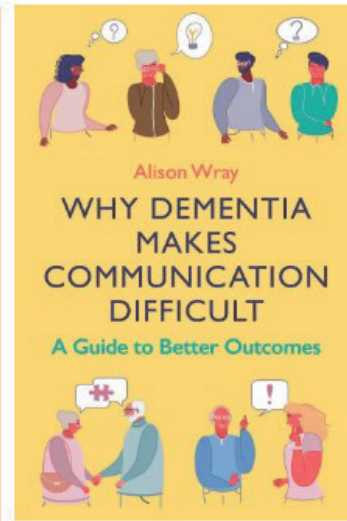
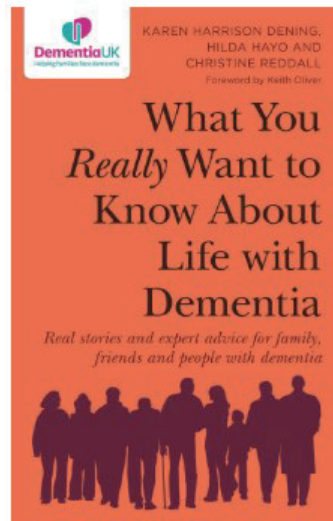
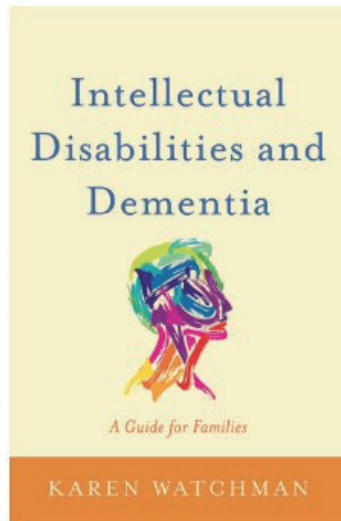
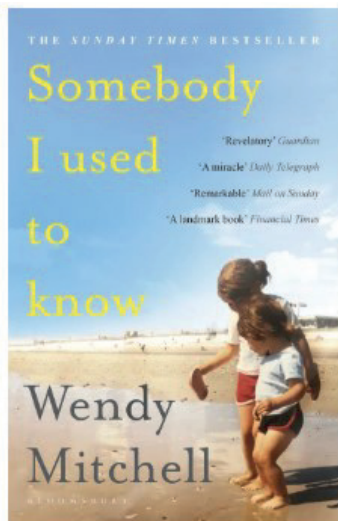
I'm passionate about having your own life and not the life that others would want you to have. We can be the individuals that we are, even though we do have dementia. Jacqui

Challenges

The Reading Well development process did identify challenges, including balancing the needs and feedback of different people. For example, different members of the co-production panel had different views on personal stories and certain topic areas. ▷

Key points

- The Reading Agency's Reading Well for dementia scheme is an evidence-based curated collection of books and resources to support the health and wellbeing of people living with dementia, their carers and family members, including younger children.
- Reading Well for dementia books are available for anyone to borrow for free from public libraries across England and Wales. People can be recommended a title by a professional or they can visit their local library to browse and choose a book to borrow.
- The booklist was co-produced with people affected by dementia and co-production was embedded throughout the development process from approach, design and book selection to launch and communications.
- Innovations in Dementia facilitated four workshops and online questionnaires over a 6-month period and involved 38 people with dementia and their carers.
- Co-production learnings from the project have been shared with UK-based publishers through a series of online events to inspire user-led commissioning within the sector.



▷ *I enjoyed being on the co-production group – [but] sometimes found it limiting as there were differing approaches. We each need different ways of picking up what we need to know. There's the science, the how-to, the research – and there's the personal, the stories, the books which are aware of dementia issues, and pay attention.* Maxine

The use of an evidence-based book selection framework and having clear aims and objectives, in relation to the scheme, helped The Reading Agency balance the needs of different stakeholders. This process resulted Reading Well for dementia being reflective of the needs of the audience.

The co-production group's satisfaction with the final booklist is testament to this success:

I think the final book list is excellent. I'm happy and proud to stand by it. Keith

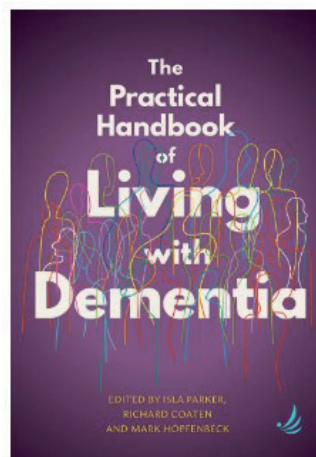
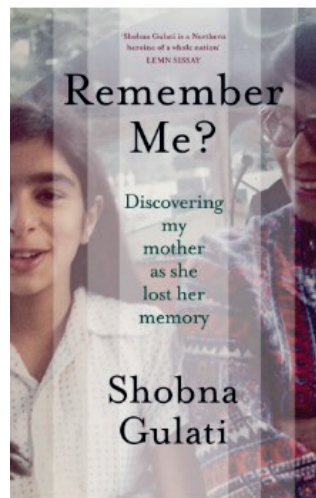
As someone living with dementia, I can say that the journey we're on has its ups and downs, and these books help explain for those living with dementia and their families. I can recommend this list because I believe it is really important. Andy

Looking ahead

The Reading Well for dementia co-production and book selection processes identified gaps in relation to certain topic areas. For example, the co-production group expressed interest in books with a main focus on end of life care and planning ahead, but there was a gap in terms of available books in this area.

As part of a wider Arts Council England funded project, The Reading Agency is sharing insights from the development of Reading Well (including Reading Well for dementia) with UK-publishers. This evidence is being used to inform publishing outputs and build awareness of areas where there is a need for more information.

Publishers have learned as much from me as I have from them. I would suggest that they will learn from this project



as well. Keith, who presented insights to publishers.

The Reading Agency continues to promote the proven power of reading as an effective and cost-effective health and wellbeing intervention and works to embed Reading Well to support the people who need it most. The real success of Reading Well is that it is a co-produced scheme trusted by health professionals and people with lived experience alike.

People with dementia will pick up these books and realise by reading them they are not alone. There are things in those books that can certainly help them. In a direct way, books on the list are those which people living with dementia can be signposted to and encouraged to read. It will improve their knowledge... and give them hope and strategies to live as well as possible and to know that people care. Keith

Following the launch of Reading Well for dementia, members of the co-production group have said:

It's great that this new list exists now, and I hope it gives us all opportunities to explore and develop... Because we will all come into contact with dementia at some time in our lives. Maxine.

This great selection of books has been extremely helpful. When I was diagnosed with dementia, there was no support post diagnosis... with the right support and the right information, we can live well with dementia, or live better with dementia. Andy.

The full Reading Well for dementia list is available now at libraries across England and Wales. For more information, visit:

www.readingagency.org.uk/reading-well.

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Dementia the Montessori Way

Advancing practice and embedding culture with Dementia Care Coaches

This is the third of three articles on the Montessori approach and how it can enable person-centred care to be integrated across a whole organisation. Here **Lynne Phair** and colleagues describe how Milford Care has adopted and implemented Dementia Care Coach (DCC) training, how this is embraced across the company and how it is reinforcing the culture change and improved practice

The continued difficulties of improving the culture of practice, the quality of dementia care training, and the link to the excessive use of antipsychotics and responsive behaviour (traditionally called behavioural or psychological symptoms) has been understood for many years. (Fossey & James 2008)

Training in dementia care is a requirement for all those who care and support people living with the condition. Despite a plethora of dementia care training, the content and quality of dementia training is variable and low levels of knowledge continue (Surr *et al* 2017).

Professor Bob Woods reflected on how research conducted in 2000 demonstrated that staff training alone does not change the culture of care. It is vital to consider not only the content of the training, but the culture of the organisation, opportunities for staff and the style and knowledge of the trainer (Woods 2019; Surr *et al* 2017).

The Association for Dementia Studies at the University of Worcester was aware of the issues and reviewed the work of Fossey (Fossey *et al* 2006) This research initiated Focussed Intervention Training and Support (FITS), a programme to train and support care staff and reduce inappropriate use of antipsychotic medication. The programme showed a reduction of the use of the medication by 40% (Fossey *et al* 2006). The project was, however, a high cost and intensive programme, and although successful could not be scaled up across large numbers of care homes. (Fossey & James 2008).

The FITS Into Practice programme

Between 2012 and 2014, the University of Worcester worked with the Alzheimer's Society to design, implement and evaluate an intervention that would remain true to the FITS programme, but that could be delivered across numerous care homes. (Brooker *et al* 2014).

Two educators from the university were designated as Dementia Practice Development Coaches (DPDCs) and they delivered a nine-month education and supervision programme to staff who were called Dementia Care Coaches (DCC).

Lynne Phair is Professional Advisor, Milford Care & Independent Consultant Nurse. Kara Gratton is Senior Manager, Milford Care and Kirsty Swift is Dementia Care Coach, Milford Care.

Summary

This is the third of three articles on the Montessori approach and how it enables person-centred care to be integrated across a whole organisation.

The previous articles in the series discussed what Dementia the Montessori Way (DMW) is and how changing the culture of practice requires an organisation wide approach.

This article describes how Milford Care has adopted and implemented the Dementia Care Coach (DCC) training developed by the University of Worcester, how this is embraced across the company and how it is reinforcing the culture change and improved practice.

Dementia the Montessori Way is an ethos of practice that distils the work of Dr Maria Montessori's philosophy to four pillars of practice:

To enable the person:

- To be as independent as possible
- To have a meaningful place [in the care home] and feel they belong.
- To possess high self-esteem and a sense of achievement
- To have the chance to make a meaningful contribution and help others.

The outcome of the programme demonstrated that the DPDC could educate DCCs to be able to improve the care and support of people living with dementia and change the culture of practice; successfully decrease the need for anti-psychotic prescribing and improve person-centred care, providing their management and organisations are supportive of this role in practice. (Brooker *et al* 2014)

The university subsequently offered a one-year course, as part of the Post Graduate certificate in Dementia Studies, to become a Dementia Practice Development Coach and educate DCCs.

As part of the development of DMW across Milford Care, Lynne and Kara understood the need to have advanced practitioners, working directly with residents. Their role would not only improve care but would support



DCCs are given supernumerary time to uphold, reinforce and develop the DMW ethos

managers to uphold and improve practice standards. The DCC role would also enable staff, to obtain an additional qualification in the workplace, improving their knowledge, practice, confidence and self-esteem.

Lynne self-funded to do the DPDC course and worked with Milford Care. The DPDC course requires that the DCC course is developed, following criteria that were found to be effective. In addition to dementia care knowledge, the DCC course included coaching skills, bite size teaching, undertaking audits, observation skills and understanding how to motivate and learning styles.

Principles of the Dementia Care Coach role

- Uphold the philosophy and practice of the Montessori Way to continuously improve the wellbeing of residents
- Champion the reduction of inappropriate antipsychotic prescribing and other restrictive practices.
- Demonstrate enhanced knowledge and skills in dementia care
- Lead and educate others
- Lead by example
- Provide teaching, guiding and support sessions for staff
- Work with external professionals to ensure high standards of dementia care practice.

Staff were invited to apply for the course and were supported with time to attend and supernumerary time to carry out projects in the workplace. The DCC course has 10 study days plus activities in the workplace over five months.

Staff from all departments were invited to apply, and an interview and selection process was conducted. It was important to ensure staff wanted to attend, rather than being told to attend, and that they understood the commitment to

the training and the responsibilities the role of DCC would have after the course was completed. The course was adjusted to ensure that the ethos of DMW was taught throughout. Although the initial education programme developed by the University of Worcester focussed on reducing the use of antipsychotic medication, the Milford Care course was designed to ensure that the DCCs learned to review all types of restrictive practice. The course studied dementia and DMW in more depth together with supporting families, how to run a bite-size teaching session, the difference between coaching

and teaching and how the language and attitude of the DCC will assist staff to change their practice.

The DCCs had to complete workplace projects and discuss and unpick their practice as part of the course. They also learned to use the Sit & See Tool. This is an observation tool that highlights care and compassion in care settings. Learning how to stand back and observe practice was difficult at first, as staff were used to “doing” and not watching and reflecting. The DCCs also had to produce a video, either of a story and a resident and how their lives had been improved using DMW or a montage of images depicting the homes overall activity.

The DCC role in practice in Milford Care

The first cohort in 2022 of 11 care staff and one cook, from across all six care homes, completed the course. Some struggled at first as they had not had any formal education since leaving school with low academic achievement, and lacked self-confidence.

As the course progressed their confidence grew alongside their knowledge and skills. There were some difficulties in the workplace as a few other staff saw the DCCs as “special” or the “manager’s pet” and were very critical when the DCCs were carrying out observations or trying to support other staff. These negative attitudes were taken back to the managers and dealt with accordingly.

In 2023 a second cohort of DCCs, again from across the six care homes, completed the course. To date, 24 have been training, and due to two dropping off the course and some moving to new jobs, there are 14 currently working in the six care homes.

All DCCs are paid an enhanced rate on their overall wages, regardless of how many dedicated hours they do as a DCC. This is in line with Milford Care’s policy of funding all enhanced roles to recognise their extra qualifications, expertise and their additional responsibilities.

The role of DCC was initially only to be part of the normal role of the staff member, but it became evident that



DMW encourages each person to be as independent as possible, possess high self-esteem and a sense of achievement

lady to be so distressed. They observed the staff's approach while in her bedroom. Some staff had become quite fearful of this lady's responsive behaviour; at times she would hit staff and shout at them due to her being so unsettled. This reinforced their anxiety and approach to her. With the evidence of their observations, they created a bite-sized teaching session to educate, develop understanding and positively influence staff, to make the experience of personal care better and improve this lady's wellbeing.

there were benefits to it being a dedicated role. It is not possible to fund dedicated posts without reorganising structures or finding a larger budget.

Each home has two dedicated activity coordinators. Their roles were reviewed as part of the implementation of the DCC role and an opportunity arose when an activity coordinator vacancy occurred in one of the homes. Kirsty became the first full time DCC working in Milford House. There has since been another vacancy in another home, where there is also now a full time DCC.

Even in homes where the DCC works within their normal role, they are given supernumerary time to uphold, reinforce and develop the DMW ethos, to undertake in-depth observations of residents or undertake audits, bite-size teaching or buddying and coaching with staff.

Focussed assessment: a case example

Although it is everyone's responsibility to understand a person in detail, in reality, establishing why a person is responding in certain ways, or withdrawn quietly in the lounge, cannot always be unpacked with any degree of success by busy staff.

The team may identify a resident who needs focussed assessment, and the DCC will observe the person, the environment and the actions of the staff, as well as learning about the person from their family.

Once possible solutions are identified, that use the four pillars of DMW as the cornerstone of practice, the DCC will work with staff, and coach them, change the environment and educate staff and ensure the care plan reflects a positive approach to practice. The DCC may have to revisit the intervention or the staff several times to review and ensure the intervention is suitable for the person and make changes as required.

Kirsty is based in Milford House but also works across the company, supporting DCCs in other homes. She helps staff implement and improve the DMW ethos, observe practice and help to motivate the staff.

She recently visited one home, where staff had identified a lady who had not left her bedroom for a long time. The carer had reported that this lady would find it very distressing during any personal care and would get extremely upset.

Kirsty met with Janet, the homes DCC, to carry out a Sit & See. This enabled them to recognise what was causing this

Over the course of a week, two care assistants at a time were invited to observe Kirsty and the DCC to help the lady get ready. They also broke down all the component parts of how they were making the lady feel safe and less distressed, in order to teach the staff.

They began by asking her if she would like to listen to music, giving her a choice of CDs (Roger Whittaker was her favourite!). They gave her a choice of what she wanted to wear, informing her of the weather so that should make an appropriate decision of clothing. They slowly explained how they were going to help her get ready.

She was offered a flannel and invited her to wash her face; she then brushed her own hair and put her glasses on, this enabled her to regain some independence. She was invited to the dining room and enjoyed her breakfast, and was asked if she would help out in the laundry room helping to fold towels, which she enjoyed.

By continuing to support the staff in how to care for this lady, her quality of life is now so much better, and staff are less anxious, thus creating a calmer, more positive atmosphere. The lady has a sense of purpose, high self-esteem and independence, and her responsive behaviour has now considerably reduced. The work of Kirsty and Janet have enabled this lady to live her life again.

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Research into practice: the Living with Dementia Toolkit

Eleni Zerma and colleagues evaluated the Living with Dementia Toolkit, developed through the IDEAL study. They found that the Toolkit significantly benefits the well-being of people with dementia and their carers, and feedback pointed to improvements that could increase its accessibility and effectiveness.

Improving the population's well-being is a key pillar of the UK's health and social policy (NHS Long Term Plan 2019). It is argued that enhancing the well-being of people with dementia and family carers should be prioritized (Wilson *et al* 2023). Living well with chronic illness, such as dementia, has been defined as the best achievable state of health, involving all biopsychosocial life aspects (Harris & Wallace 2012). Dementia policy documents and research evidence indicate it should be possible to experience comfort and quality of life living with dementia (Department of Health 2009; Martyr *et al* 2018).

Identifying factors that enable people to live well with dementia is required to raise public awareness and provide effective care. Improving the experience of Dementia and Enhancing Active Life (IDEAL) was a nine-year longitudinal study which explored parameters affecting people with dementia and their primary carers across the UK to 'live well'. IDEAL specifically examined the constraints that people with mild to moderate dementia and their carers faced, along with the social, physical, and psychological resources that they employed and how these are related to the perceptions of being able to live well with dementia over time (Clare *et al* 2019). It was found that the perceptions of living well with dementia are strongly correlated with psychological health, followed by physical health condition, and to a lesser extent, social relations, ability to navigate everyday life, and access to resources.

As part of the IDEAL study, researchers collaborated with a group of people living with dementia and caregivers, the Action on Living Well: Asking You (ALWAYS) group and co-produced a comprehensive online resource of structured materials called 'Living with Dementia Toolkit' (Innovations in Dementia & University of Exeter 2021). The Toolkit aims to help people with dementia live as well as possible through regaining hope, focusing on what is important in their lives, finding encouragement from others living with dementia and developing coping and compensatory strategies. Caring for a person with

Eleni Zerma is Assistant Clinical Psychologist, Samira Ali and Jade Ngan are psychology students and Reinhard Guss is Consultant Clinical Psychologist, all at Bromley Memory Service, Oxleas NHS Foundation Trust, Bromley, UK. Toby Williamson is an independent health and social care consultant.

Summary

Enhancing the well-being of individuals with dementia and their carers is a crucial aspect of the UK's health and social policy. This research by Bromley Memory Service in London aimed to evaluate the effectiveness of the 'Living with Dementia Toolkit,' developed through the IDEAL study, in improving the quality of life for people with dementia and family carers. We conducted semi-structured telephone interviews with 41 participants, including people with dementia, family carers, and staff, to explore their experiences using the Toolkit. Data were analysed using thematic qualitative analysis.

Key findings revealed that the Toolkit fosters a sense of shared experience, reducing isolation, as users could relate to others' experiences. Practical advice and structured guidance were highly valued, empowering users to manage their condition and improve communication strategies. Opinions on the Toolkit's online accessibility varied, with some participants appreciating the flexibility and ease of use, while others struggled with complex content or technological aspects.

The positive tone and comprehensive information were praised for fostering hope and resilience, although careful curation of emotional content is necessary. Suggestions for improvements included the timing for Toolkit introduction, applicability for individuals living alone, including content on general health and lifestyle issues, and development of a mobile app. Overall, the Toolkit significantly benefits the well-being of people with dementia and their carers, but further improvements could increase its accessibility and effectiveness.

dementia can bring many challenges, including loss and grief, isolation and loneliness, depression, anxiety, and exhaustion (Merrilees 2016; Garzón-Maldonado *et al* 2017), and the Toolkit also provides support and positive information for carers via examples of real-life experiences.

Given the impact of the physical and cognitive constraints that people with dementia face and in the absence of the possibility of a full recovery, specialist memory services should deliver psychosocial interventions, expertise, and support to empower people with any dementia sub-type to live well with their condition

Key points

- The Living Well with Dementia Toolkit is a post-diagnostic resource for people living with dementia and family carers.
- The Bromley Memory Service included carers, people living with dementia, and staff in a project evaluating this Toolkit.
- 20 people diagnosed with dementia, 9 carers, and 12 staff members were interviewed by students and asked to provide feedback about the Toolkit.
- Feedback suggests that the Toolkit is a relatable, practical, and positive resource.
- Improvements to the Toolkit include adding information for people who live alone, accommodating people with limited understanding of technology, and creating a Toolkit app.

(MSNAP 2022). However, with specific dementia diagnostic targets that specialist memory services need to meet (66.7%) and within nationally defined timeframes, the increasing numbers of people being diagnosed due to the ageing population (Prince *et al* 2016), and stagnating funding for these services, this is often the ideal scenario rather than the norm. Specifically, ever more resources are directed at diagnosis, while post-diagnostic support remains fragmented and psycho-social programmes aimed at living well with dementia are moved from specialist services in health and social care to cheaper services in the voluntary sector (Frost *et al* 2020). Consequently, many services providing specialist adjustment to the diagnosis, developing coping strategies and maintaining a good quality of life are facing difficulties.

The Bromley Memory Service in London is part of Oxleas NHS Foundation Trust and provides assessment and diagnosis for people with dementia and other cognitive related difficulties. In line with service guidelines (MSNAP 2022), the Psychology Team offers individual therapy sessions and a carers' emotional support group to support carers' wellbeing. In our attempt to improve the service's post-diagnostic support pathways with our current staffing resources, the online and printed Toolkit materials of the IDEAL programme are utilized. Staff used Toolkit resources as a guide to develop two distinct Living Well With Dementia (LWWD) workshops for people with dementia and family carers. The service user LWWD workshop is an interactive, two-hour, face-to-face presentation, facilitated by assistant, trainee, and qualified clinical psychologists. Following the Toolkit's domains, it covers topics such as staying healthy, positive, active, and connected, as well as available support in the community. The carer LWWD workshop is an online one-hour psycho-education presentation, which aims to help family carers to support their loved ones to live as well as possible with a dementia diagnosis. The carer workshop adopts a multi-disciplinary team approach, facilitated by assistant and qualified clinical psychologists, and other professionals. Both workshops are used to collect feedback regarding the

benefits and challenges of using the Toolkit from participants' perspective. Memory service staff members also provided feedback. The Toolkit's weblink is also being added to diagnostic care plan letters and printed Toolkit booklets given to service users and carers in clinic appointments.

Methods

We recruited 41 participants in total: 20 people diagnosed with dementia, 9 family carers, and 12 staff members. All participants were invited to take part in a semi-structured telephone interview investigating their experiences of using the Toolkit and asked to sign a consent form. During the interview, our psychology students asked participants a series of open-ended questions examining the perceived benefits and challenges of using the Toolkit. The data was collected over a one-year period and analysed using thematic qualitative analysis. The project was delivered within existing service's resources, namely time, staff configuration, and funding.

Key findings

Relatability and connectivity

The thematic analysis identified the centrality of the theme *relatability* – feeling connected to others – in influencing how service users and carers engage with the Toolkit.

By seeing and connecting with reflections of their own experiences in others, users experienced a sense of shared reality which reduces feelings of isolation: “viewing footage of persons with dementia when using various Toolkit components makes them more relatable”. The richness of these personal accounts came with some challenges, as one person found, “reading other people's experiences also felt overwhelming”. A balance in the Toolkit's emotional content is essential to ensure it is both relatable and manageable for users.

Carers expressed that they could “relate to the feelings of carers [in the Toolkit] and felt like [they are] not alone in this fight against dementia”. It allowed them to “see what other carers have to say and how they are coping”. This inclusion fostered a community feeling, ensuring carers did not feel alone in their journey, helping to reduce carer burnout and emotional distress.

Staff felt that “the Dementia Toolkit provides a space for people who often feel undervalued like the carers, therefore watching and interacting with the toolkit makes such individuals feel better and connect with others”. For newly diagnosed clients, the Toolkit can mitigate feelings of shock and denial, and reassures the person they are not alone, helping them adjust to the diagnosis by hearing others' stories.

Practicality

The thematic analysis identified the theme of 'practicality' as pivotal in the utilisation of the Toolkit by both service users and carers. It encapsulates how practical steps and advice provided by the Toolkit facilitate a better quality of life for individuals with dementia and support for their carers. ▷

▷ *Implementation in real life*

Service users identified the Toolkit's structure and guidance as highly beneficial since it "allowed [the] client to reflect on his life accordingly, and that he has done activities under each to make sure he is living well with dementia". The Toolkit empowers users to take control over their condition by evaluating their current lifestyle and suggest adjustments to improve their well-being. However, it was noted that the effectiveness and practicality of the Toolkit depends hugely on the individual as "they need the discipline to do the actions".

Carers found the practical strategies for communication especially beneficial. The Toolkit's advice on reducing background noise, using visual aids like "I want to speak" cards, and engaging in one-on-one conversations rather than group settings, directly addresses common communication barriers faced by people with dementia.

Staff members also appreciated the actionable tips as "it gives clear guidance to incorporate the important aspects of living, which people often lose after being diagnosed". The Toolkit therefore appeared not only to help maintain mental and emotional health but also important practical advice.

Online accessibility

Service users provided mixed opinions about the Toolkit's online accessibility. One person expressed their gratitude for the Toolkit: "it is great to have resources that I can always look at in my own time at my own pace", because they "can hear other people's experiences without being in a group setting." However, a different person indicated their frustration understanding the information in the Toolkit because it has "enormously complicated content."

Carers gave mixed feedback about the online accessibility. Benefits of the Toolkit were that the website has a "user-friendly" appearance and they "can use it whenever they feel like it." However, one carer was less positive because, "the toolkit would be useless for his wife because of her inability to concentrate and the progression of her dementia."

Staff supported the views that the Toolkit is an understandable and accessible resource. They commented that the Toolkit is easy to understand due to the "different ways for delivering information, such as videos or text" and that it is "chronological and easy to navigate through."

Online accessibility is essential for the Toolkit because it gives people the freedom to use the information in the Toolkit whenever they wish. The Toolkit's simplicity allows people with dementia and their carers to receive clear information and support. Feedback indicated the Toolkit is perhaps not so accessible as a person's dementia progresses.

Style

Consideration was given to how the style of the website was helpful for people using the Toolkit. Carers found it appealing that all the information in the Toolkit was located on one website, illustrated in the statement "all information is collated in one piece." Service users and staff added information about the Toolkit's unique features. A service user noted that having "videos and top

recommendations might be very handy and interesting." Staff liked the "How are you feeling?" feature, commenting that "it is very innovative." Formatting the website in this way helps people with dementia because they are able to find information easily, and it is more engaging than plain text.

Emotional impact

The thematic analysis explored the 'emotional impact' of the Toolkit, emphasising the importance of tone and content in user experience.

Service users found the Toolkit "comprehensive and filled with positivity" and it "gives advice on how to stay positive and be hopeful for the future even on the bad days". This positive framing is essential as it counteracts the difficulties and emotional burdens of living with dementia. Encouraging and hopeful messages can play a crucial role in raising wellbeing and fostering resilience among users. However, one person did find that "some of the videos in the toolkit are depressing due to the negative tone". This suggests a need for careful content curation to ensure that the Toolkit serves to empower rather than contribute to feelings of despair.

A carer stated that "the videos are positive which is useful because it is nice to see that people with dementia can be positive and it is uplifting to see them being able to have conversations". This view was supported by staff members who pointed out that "as a guide, it is filled with hope, the Dementia Toolkit does not let the carers dwell on the bad aspects and gives a sense of purpose". By focusing on what individuals and carers can do—rather than what they can no longer manage—the Toolkit helps maintain motivation and engagement with life's activities.

Improvements

Feedback included several suggestions for improving the Toolkit. Comments emphasised the importance of timing the Toolkit's introduction, avoiding periods immediately after a diagnosis when users may be overwhelmed and less receptive. This underscores the need for strategic deployment to maximise effectiveness. Service users also raised concerns about the Toolkit's applicability to people who live alone who may lack support networks. This feedback points to a gap in the Toolkit's design, which might currently be more suited to those with active carer support, so additional resources could be added for people who might be managing their condition more independently. Improvements in online accessibility and the availability of physical copies were suggested to accommodate more digitally excluded users. Staff also suggested expanding the Toolkit's content to cover general health and life issues, making it more comprehensive and accessible for a broader audience. A suggestion to develop a mobile application for the Toolkit highlights the growing need for digital accessibility. An app could provide users with easier, quicker access that could make the Toolkit more user-friendly and engaging. These insights highlight areas for enhancing the Toolkit to better serve individuals with dementia, ensuring it is both practical and supportive in a variety of situations.

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Opening Doors to Brain Workout

Versha Sood and **Gabriel Mandal** describe how partnership designed and delivered a series of co-produced tailored engagements to connect with citizens deemed “hard to reach or under-represented”. The title of the series - Opening Doors to Brain Workout - was co-produced by all partners

Research suggests (Karia *et al* 2021) (Johnson *et al* 2019) that BAME communities often face delays in dementia diagnosis as well as barriers to accessing services, therefore engaging with these communities is essential in order to find a way to overcome such challenges. However, the BAME community is not a homogeneous group and no shoe will fit all. As the community is made up of such a variety of backgrounds, a tailored approach to engagement is crucial to understand specific challenges within each community. Cardiff and the Vale of Glamorgan’s population is rich, diverse and thoroughly multicultural; therefore, it is vital to sincerely engage with these communities in order to understand the perspective of



Key points

- Communities are not as hard to reach as many think; it is about taking information and advice and services into the community. It is important to raise awareness of services and be transparent about resources
- We need to reach communities to represent them in our work e.g. BAME communities, rural communities, economically deprived communities etc.
- Opening doors can support community-run infrastructure which can help people live healthier lives
- Engagement is an ongoing process and not a 'one stop shop' or 'tick box' exercise, we must continue to engage with communities. This builds long lasting relationships and trust
- True co-production is difficult, but we feel opening doors can begin to pave the way for true co-production by, with and for communities and services.

Versha Sood is Dementia Improvement and Development Manager for Cardiff and Vale Regional Partnership Board. Gabriel Mandal is Wellbeing Activity Manager, Mental Health Matters



Dementia Event Opening Doors to Brain Workout

How tailoring engagement to specific communities leads to more effective engagement.

Engaging with the public and communities helps us to understand the perspectives of people who access health and social care services and helps shape future services. In Cardiff and the Vale of Glamorgan there is an incredibly diverse population, with people from a variety of ethnic groups, socioeconomic circumstances and a wide age range. To engage due to diverse needs and beliefs of people.

Tailoring engagement events to specific communities within those communities. This can lead to a better understanding of the health and social care systems, cultural taboos, and different communities place value on.

For instance, research suggests that BAME communities face barriers to accessing services, therefore engaging with the 'why' and to overcome the challenges. However, in a group, with people from different ethnic backgrounds in each group is crucial to understand specific challenges



There was a lot of experience at the table, which added soul to the idea. We pooled resources which made it more cost and time effective. We had a small budget so partner organisations chipped in tea and coffee, and carry lunch was provided for everyone. People took ownership for the event and there was a real sense of pride. The India Centre offered the hall for free. They said they'd never had the opportunity and jumped at the chance.

Everyone had equal power, there was lots of flexibility and lots of ideas. The development of the event was a really good team building exercise in itself. People didn't know what other organisations were doing so it helped other organisations know what is available and they can share that information with others.

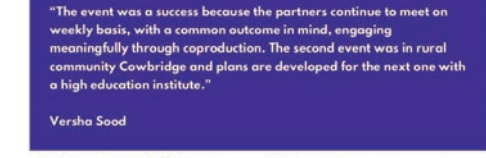
We invited people living with dementia, their carers and professionals to attend the event. Over 100 community members attended the event plus 30 service reps from health, social care and the third sector.

Different members of the community spoke, including a GP, a carer of someone with dementia, and we also did a group yoga session. People shared their perspectives and experience.

"An absolute joy to attend the 'Opening Doors to a Brain Workout' at the India Centre yesterday. Thank you for making us feel so welcome and thank you to Cardiff and Vale Regional Partnership Board and the many partner orgs for organising such a delightful event!"

Edward O'Leary - Researcher, Social Care

PhD in sexuality and people with learning disabilities



"The event was a success because the partners continue to meet on weekly basis, with a common outcome in mind, engaging meaningfully through coproduction. The second event was in rural community Cowbridge and plans are developed for the next one with a high education institute."

Versha Sood

dementia engagement events. The Dementia Programme also included professionals from research, education, clinical practice and leadership (Hubbard *et al* 2003), so that the programme would benefit from authentic contributions and experiences (Improvement Cymru Public Health Wales 2021-23). Together, it was agreed that each event should leave a legacy behind and "not just ticking boxes" (Anand & Dyson, 2023) - something which

would help drive change and would allow that community to remain connected to the Dementia Programme. Like so many events before, we did not want to simply visit a community once, gather information, 'raise awareness' and leave – this was about building lasting connections and having ongoing conversations, making a series. The title of the series, 'Opening Doors to Brain Workout' was co-produced with all partners as the brain continues to 'workout' and learn new things at all stages of life despite dementia. This signals inclusion for anyone with an agenda, from dementia prevention, to recently diagnosed, through to the advanced stages of dementia.

Hindu Cultural Association

The first event in the series, the pilot episode, focussed on the South Asian population of Cardiff. The Opening Doors to Brain Workout planning team met with the community leader of Hindu Cultural Association and discussed for several weeks what could and would not work for that community. The leader of this community welcomed the engagement opportunity and offered the community hall and its services free of cost. On the day, the stalls of the various organisations participating were set up, equipped with information and small activities, pooling resources for community members to engage with. Shortly before 11am, community members started to arrive at the India Centre, perusing the stalls and engaging in stimulating conversations about dementia. Versha Sood introduced the series to the community participants and set out an outline for the day.

After additional time for community members to access the stalls, a 'Yoga For All' session was delivered, discussing the importance of the effect yoga can have on mood, mental and physical health, and indeed dementia. ▷

Co-production from a personal perspective is the first rung on the ladder towards self-help. Co-designing services in equal relationships and shared power increases wellbeing, through valuing and respecting my experiences and my knowledge. Raising confidence, esteem and overall, increasing psychological, emotional and physical wellbeing. Co-production is more than improving services, it's about building relationships and improving culture that cannot be achieved in isolation. Nothing about us, without us.
Ceri Higgins, unpaid carer with lived experience

people who access health and social care services. What was needed was a better understanding of how communities experience the health and social care system, taking into consideration cultural taboos, differences in language and what individuals in different communities place value on. A greater understanding will in turn help shape the future services but the question remains – how does one achieve this?

It can be achieved through "co-production" (Bosco *et al* 2019) but the main question is **how**?

There were already many existing engagement events across the Cardiff and Vale region to which different communities from BAME backgrounds were invited, but the footfall hadn't been to the desired level. Noticeably, these events put a considerably greater emphasis on information and awareness, rather than engagement and co-production.

Co-production: a horizontal hierarchy

Having contributed to various engagement events, Dementia Improvement and Development Manager for Cardiff and Vale Regional Partnership Board, I collaborated with all partners to develop a new series of engagements. The guiding principle was to focus on those who are under-represented and 'hard to reach', including BAME, rural communities, LGBTQ+ and other communities, utilising their input and hearing their concerns to effectively enhance service provision throughout Cardiff and the Vale. Approximately thirty-five partners from the health and social care sector and charity sector were involved in the decision-making process regarding how best to structure and deliver a series of

▷ Everyone took part in the session – community members, guest speakers, organisers and those managing stalls. The yoga was accessible for all; the instructor stressed how participants could engage either by standing or sitting, whichever suited their need. The session was effective in conveying how yoga was indeed for all, regardless of weight, disability or other perceived barriers.

Later, Simran, a community member, spoke emotively to those present about her and her mother's experience with dementia. She spoke about how her mother began presenting with symptoms some years ago. At the time, some family members and friends were convinced that she was possessed and, in response, travelled to India to seek the support of spiritual leaders. When Simran's mother returned, she was different – insular, distant and fundamentally not herself – symptoms were worse. As the years progressed, friends and family kept their space from Simran's mother, referring to her as 'crazy'. This treatment could very well be a deterrent for assessment for subsequent diagnosis. Increasingly, more and more of the caring responsibilities fell to Simran to the point where she felt like she "no longer has a life" of her own. It was only relatively recently that Simran's mother got a formal diagnosis of dementia, so many years after initially presenting with symptoms. By that point, it was too late and the 'damage was done' – Simran's mother had internalised the experiences of what happened to her when she was taken to India and nothing could shake her conviction that she was possessed by demons. The manner in which Simran spoke was not scripted – it was raw, from the heart and deeply impactful. The sense of emotion coming from Simran cascaded across India Centre; there were tears in the eyes of some of those watching her speak. During the question-and-answer section of Simran's talk, solutions and remedies began to be crowdsourced; Simran was asking for specialised and social help for her mother and many of the organisations in the room answered.

One of the main takeaways from the event at Hindu Cultural Association was how community members expressed the need for regular engagement, especially those who had lost loved one or a partner during pandemic. For these people, losing a partner or loved one meant that they didn't feel like leaving the house and had therefore become isolated.
Mrs S Sharma (community member).

After a lunch of samosas and lentils so kindly provided by India Centre, there was an opportunity for community members to engage with stalls. Shortly after, a member of the community spoke openly to the room regarding the experiences her mother faced when diagnosed with dementia. In many ways, this individual felt let down by the medical model; from her perspective, medical practitioners made decisions without consulting those that know her mother best; they adhered too closely to a script and forgot about "the individual". This community member stressed the importance of not just seeing a diagnosis but truly seeing the person as well.

Opening Doors for Brain Workout has been such an incredible opportunity. Being able to connect with other third sector organisations to work towards the common goal of improving the lives of those living with dementia has been a privilege. The often-innovative ways in which we work together has been hugely inspiring and I have nothing but complete faith in this series - I sincerely believe that we are at the forefront of something radical.
Gabriel Mandal, Wellbeing Activity Manager, Mental Health Matters.

Members of the Ethnic Minority Research Advisory Group (EMRAG) at the University of South Wales (USW), Edward Oloidi and Juping Yu, spoke next. They discussed the importance of inclusive research and how it's essential to involve people, specifically from BAME communities, in an active manner in the research process. Edward spoke specifically about the use of language and how sometimes important content can be lost in a sea of academic language.

After a laughter yoga session led by Dr. Nathdwarwala, a 'Brain Workout' quiz created by MHM Wales about cognitive functions and memory was delivered – these two, enjoyable activities were an effective icebreaker in between sometimes solemn discussion. The event closed with a question & answer session directed to a panel of expert professionals working in dementia care – Dr. Biju Mohamad of Cardiff and Vale Memory Assessment Service; Ruth Cann, Consultant Nurse Older Vulnerable Adults; Natalie Robertson, a physiotherapist working on improvements in Dementia Care; Ceri Higgins of Lleisïau Dementia (Welsh lived experience forum); and Mrs. Niru Kumar, leader of India Centre. The panel was an opportunity to listen to the questions of the community, find ways of bridging any gaps and set realistic expectations. Advice was given by the panel regarding some community members' fears of losing their loved ones to care homes; Natalie Robertson(?) discussed how people can live longer in their own homes and be involved in the community with clinical and non-clinical support such as Social Prescribing. Also discussed was the subject of dementia care within the hospital setting and what could be expected from the *Dementia Friendly Hospital Charter*, supported by Welsh Government and *Improvement Cymru*. The *Dementia Learning and Development* team were advising people that training now was also offered to unpaid carers of someone living with dementia so that they could support the loved ones well informed there was discussions around joining the team being volunteer by supporting their own community and the next steps. ▷

Opening Doors is a fantastic initiative in which partners across Cardiff and Vale come together on a weekly basis, to co-produce community engagement activities that raise awareness of dementia to underrepresented communities. We have achieved and learnt so much by working together.
Sian Bidder, Alzheimer's Society.

The engagement was a success because the partners continue to meet on weekly basis, with a common outcome in mind, engaging meaningfully through coproduction. The second engagement was in rural community Cowbridge and plans are developed for the next one with a high education institute.

Versha Sood, Dementia Improvement and Development Manager, Cardiff and Vale.

▷ A lasting legacy

Part of the aim with the event was to let people know what to expect when accessing dementia services if they or a family member develops dementia and directing them to the services that are there for them. The event also provided a better understanding of the experience of people within that community when it comes to dementia care and attitudes towards dementia. Community members shared their thoughts, feelings and stories; the organisations present at the event are thoroughly taking that feedback onboard. Furthermore, organisations and community members present at the event collaborated organically as a result of being in the same room in an informal environment.

Following on from the event, groups such as *Platform*, Cardiff Local Authority's outreach work, *Alzheimer's Society*, *Ethnic Minority Research Advisory Group* and *WAST* have continued to connect with *Hindu Cultural Association*. The event has led to a variety of connections forming naturally which will, in turn, continue to build events in the future and created reciprocal relationships with the community. One clear example of this is that there are now plans for a defibrillator to be outside the *India Centre* and for training to be given.

As a result of these discussions, a regular partnership with *Hindu Cultural Association* was established and supported by Cardiff Local Authority, partnering with *Alzheimer's Society*, and volunteers from *Platform/Effro*. This partnership produced a group (*Chai Club*) which decided to meet on weekly basis with membership still increasing. The group went through some teething problems with regards to lack of resources and obtaining funding for hot beverages; however, regular funding through Cardiff Council was found to sustain the group. There were people who were unable to access *Chai Club* due to them not driving anymore or due to their partner living with dementia and therefore not being able to leave the house; further funding has been secured to combat this challenge and to extend the club to becoming a lunch club. This means that members of the community who may not feel confident discussing their challenges can instead participate in activities that promote fitness, health and dementia prevention. Three volunteers are currently undertaking training with Cardiff Local Authorities, so when Local Authority volunteers or members move onto the next of the series these three volunteers can continue to keep the *Chai club* and lunch club going.

After seeing the success of this work, many more charities and organisations are now getting in touch because they know that this engagement is not standalone. *Opening Doors for Brain Workout* is truly a platform to be

used to help communities uplift and strengthen themselves, to be more aware of the services that are around them. *Chai Club* offers opportunities on a week-to-week basis for professionals to visit and connect with community members, explaining the work they do and give advice on navigating through a complex health and social care system. Community members are now accessing the knowledge and awareness about the services that can help them to lead healthier lives and improve their well-being outcomes in the community.

There is a lot of discussion around 'hard to reach communities' but is any community sincerely 'hard to reach'? As we found with Hindu Cultural Association, once the door is opened, everything else will fall into place; and if you want to open the door, you have to first extend the hand. In future articles I will report on our work as we continue to open doors with other communities.

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Online support for South Asian dementia caregivers

Suman Kurana and colleagues describe the process of translating and culturally adapting the World Health Organisation's online intervention 'iSupport' for South Asian dementia caregivers in the UK.

Approximately 850,000 people live with dementia in the UK, projected to exceed two million by 2051. The number of new cases of dementia is expected to increase significantly in ethnic minority groups compared to the majority population (Prince *et al* 2014). South Asian individuals have an increased vulnerability to diabetes and cardiovascular disease, which are both risk factors for dementia (Sidhu *et al* 2016; van den Heuvel, Victor & Clare 2020). Additionally, South Asian migrants who arrived in the UK during the second half of the 20th century due to labour shortages are now ageing and susceptible to age-related conditions, including dementia (Giebel *et al* 2017; Sharma 2012).

Despite the increasing prevalence of dementia, South Asian families use services less frequently than other demographic groups (Parveen, Peltier & Oyebode 2017), and often only access support services in the advanced stages of dementia (Lin *et al* 2021). Multiple obstacles hinder access to services for South Asian older adults and their families. There can be a preference to rely on community support systems such as mosques and gurdwaras over specialised dementia services. This is potentially due to a perceived mismatch in cultural relevance (Baghirathan *et al* 2018). Notably, assumptions that South Asian individuals do not use post-diagnostic support services have led to disparities in recommendations provided by healthcare staff (Dodd *et al* 2020).

Additionally, stigma and a lack of understanding of dementia and mental health conditions further complicate access to care (Giebel *et al* 2015). Often, South Asian elders do not visit their GP about memory issues, as they frequently accept fate, or they may attribute their condition to "God's will" (Giebel *et al* 2015). Dementia can also be perceived as a normal part of ageing, with many South Asian dementia caregivers also believing that care is best performed by the family, which limits help-seeking (Blakemore *et al* 2018).

Caregivers are at an increased risk of developing depression (Collins & Kishita 2020), and caregiving

Summary

The rising prevalence of dementia among South Asian individuals in the UK highlights the critical need for culturally sensitive interventions and support services. South Asian dementia caregivers experience several barriers to accessing appropriate services, including limited awareness of dementia, stigma, and a lack of culturally tailored interventions. To address these challenges, we translated and culturally adapted the World Health Organization's 'iSupport' intervention, for South Asian dementia caregivers in the UK who speak Bengali, Punjabi and Urdu.

iSupport is an online self-guided programme for caregivers of people with dementia. We employed a co-design methodology, which involved discussions with 41 dementia caregivers and health and social care professionals to guide the initial cultural adaptations, followed up by feedback on the adapted online platform from 26 caregivers and professionals. Adaptations included clearly defining the role of a caregiver and recognising the impact of stigma. Culturally appropriate imagery and references to South Asian customs and traditions were incorporated into case studies. Additionally, an audio feature was implemented and summary posters for each module were created in all languages. iSupport and iSupport Lite for South Asian dementia caregivers is now available in four languages (Bengali, Punjabi, Urdu, and English).

burden has been linked to poorer psychological outcomes for people with dementia (Safavi, Wearden & Berry 2023).

Supporting caregivers through interventions is essential. Psychoeducational interventions offer information about dementia and how to respond to situations, which can enhance caregivers' self-efficacy and reduce levels of anxiety and depression (Frias *et al* 2019). Additionally, these interventions may benefit care recipients by decreasing overall neuropsychiatric symptoms and specifically addressing behavioural and mood disturbances. Furthermore, these interventions improve cognition and quality of life, delay institutionalisation and reduce mortality rates (Cheng *et al* 2022).

iSupport—an evidence-based programme

The World Health Organization's iSupport is one such intervention which can be translated and culturally adapted. iSupport is an evidence-based e-health training programme developed to support adult dementia caregivers in looking after themselves while providing quality care. ▷

Suman Kurana¹, Aimee Spector¹, Afra Azadi¹, Aziza Begum¹, Banika Ahuja¹, Danielle Proctor¹, Gill Windle², Greg Flynn², Gurmel Singh¹, Nuvera Mukaty¹, Patricia Masterson-Algar², Saleyha Mahmood¹, Joshua Stott¹, Emily Fisher¹

¹Department of Clinical, Educational and Health Psychology, University College London, ²School of Health Sciences, Bangor University

▷ iSupport incorporates information about dementia and caring, scenarios, and interactive activities with instant feedback (Pot *et al* 2019). Users can complete modules sequentially or choose parts based on their experiences. Importantly, as an online intervention, it allows caregivers to seek help in the privacy of their own homes without having to leave their family member or relative unattended.

iSupport consists of five modules:

1. Introduction to dementia
2. Being a carer
3. Caring for me
4. Providing everyday care
5. Dealing with behaviour changes.

This project aimed to collaborate with South Asian dementia caregivers, along with health and social care professionals and service providers, to translate and culturally adapt iSupport for South Asian dementia caregivers in three languages: Bengali, Punjabi and Urdu.

Methods

The process of translating and culturally adapting iSupport followed adaptation guidelines from the World Health Organization. Initially, the English version was translated into three different languages (Bengali, Punjabi, and Urdu) and checked by two expert reviewers for each language.

We collaborated with community organisations to engage with informal caregivers and dementia health and social care professionals proficient in either Bengali, Punjabi, or Urdu. Forty-one caregivers and healthcare professionals critically examined the intervention content, language, cultural appropriateness, design, and functionality, and provided recommendations for adaptation. The feedback received was implemented and following this, 26 caregivers and professionals were given access to the adapted online programmes to test out and provide additional feedback. The final versions were evaluated and approved by the World Health Organization before being released online.

Results

Several recommendations were made by caregivers and professionals to tailor the structure, language, content and design/functionality of iSupport for South Asian dementia caregivers. Many recommendations were language and culture-specific. Below we outline changes that were consistent across all languages.

Structure

- Simplifying the introduction by removing content intended primarily for researchers.
- Adding a conclusion with signposting to further information and support.
- Creating compact booklets/posters for each module to enhance accessibility and user-friendliness (an example of a poster from iSupport Lite Bengali pictured, right).

Language

- Adapting the language to make it more understandable and accessible for individuals with diverse literacy levels.
- Using common English words written in Bengali, Punjabi or Urdu to enhance readability, as certain words lack direct translations that are easily comprehensible, whereas English is more universally understood for certain words and phrases.
- Creating a culturally adapted English version of iSupport for South Asian dementia caregivers, which can be accessed by those who speak other languages or do not read Bengali, Punjabi or Urdu.


Adapted content

- Referencing culture-specific practices and traditions within case studies - for example leisure activities, food and eating habits, festive celebrations, and traditional attire.
- Incorporating culturally diverse illustrations to improve resonance and accessibility, for example, iSupport Punjabi includes illustrations of individuals sitting inside a Gurdwara (place of worship for Sikhs) and images of culturally recognisable food. ▷




ডিমেনশিয়া আক্রান্ত ব্যক্তির কোয়ার্টারদের জন্য দরকারী টিপস
ডিমেনশিয়া আক্রান্ত ব্যক্তির সাথে যোগাযোগ রক্ষা করা

ডিমেনশিয়া জন্য
iSupport




ডিমেনশিয়া আক্রান্ত ব্যক্তির সাথে যোগাযোগ রক্ষা করা

এটি আপনার যত্নে থাকা ব্যক্তির সাথে আপনার সম্পর্কের উপর প্রভাব ফেলতে পারে। এমনকি এটি তাদেরকে বা আপনাকে হতাশ, দুঃখিত বা রাগান্বিত করতে পারে।



ডিমেনশিয়া আক্রান্ত ব্যক্তির সাথে যোগাযোগ রক্ষা করা

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সম্বন্ধে ঠিক মতই বল

ডিমেনশিয়া আক্রান্ত ব্যক্তিকে একবারে একটি জিনিস জিজ্ঞাসা করুন বা বলুন। ছোট ছোট বাক্য এবং সহজ শব্দ ব্যবহার করুন যা ডিমেনশিয়া আক্রান্ত ব্যক্তি বুঝতে পারে। যতবার প্রয়োজন ততবার শান্তভাবে তথ্য পুনরাবৃত্তি করুন।

প্রয়োজন হলে, মুক্-প্রান্ত প্রসঙ্গলোকে বন্ধ-প্রান্ত প্রসঙ্গে পরিবর্তন করুন যার উত্তর শুধু হ্যাঁ বা না দিয়ে দেওয়া যেতে পারে।


নিশ্চিত করুন যে, ব্যাকগ্রাউন্ডে টেলিভিশন বা রেডিওর মতো কোনও মনোযোগ বিকর্ষককারী আওয়াজ নেই।



সম্মানজনকভাবে মনোযোগ আকর্ষণ করুন

আপনি যাকে দেখাওনা করেন তার সাথে স্পষ্টভাবে, ধীরে ধীরে এবং তাদের জন্য আরামদায়ক ডলিউমে কথা বলার মাধ্যমে তার মনোযোগ আকর্ষণ করুন। মনে রাখবেন, তাদের সামনাসামনি বসে এবং চোখে চোখে রেখে কথা বলা খুবই গুরুত্বপূর্ণ।

আপনি তাদের একটি হাত, বাহু বা কাঁধের সামনে হালকাভাবে টোকা দেওয়ার চেষ্টা করতে পারেন, যা ব্যক্তিকে তার নাম বা ডাকনামে ডাকতে পারেন যা তিনি চিনতে পারেন।





আপনার অনুভূতি নিয়ন্ত্রণে রাখার চেষ্টা করুন

মাঝে মাঝে, আপনি হয়তো বুঝতে পারবেন না যে আপনার যত্নে থাকা ব্যক্তি কি বলতে চাইছেন। এটি গুরুত্বপূর্ণ যে আপনি ব্যক্তিকে গুরুত্বের সাথে দেখছেন - তারা হয়তো আপনাকে কিছু বলার চেষ্টা করছে।

বৈধ ধরন এবং তাদেরকে নীজের কথা নীজে খুঁজে বের করার জন্য সময় দিন। তাদের মুখের অভিব্যক্তি এবং শরীরের ভাষা সহ তাদের প্রতিক্রিয়াগুলিতে মনোযোগ দিন।

ব্যক্তি যে অনুভূতি প্রকাশ করে সে সম্পর্কে সমবেদনা দেখান। মনে রাখবেন যে ইতিবাচক কিছু বলা বা ব্যক্তির প্রশংসা করা তাদের ভালো অনুভব করতে পারে।





আরও তথ্যের জন্য, iSupport মডিউল 2 দেখুন।
এই পোস্টারটি **Communicating information to the person with dementia** থেকে অভিযোজিত এবং অনুবাদ করা হয়েছে। এই অভিযোজনের বিষয়বস্তু বা সঠিকতার জন্য WHO দায়ী নয়।

UCL **NIHR** National Institute for Health and Care Research



New content

- Providing information to explain the role of a caregiver. Many individuals may not recognise themselves as a caregiver, and may simply perform caregiving duties without realising their role.
- Including information about stigma and its potential consequences of feeling unsupported and isolated.
- Highlighting that educating oneself and discovering available support resources can empower caregivers to better support the person with dementia.
- Including advice about finances and benefits, and signposting to further guidance and relevant helplines.

Design and functionality

- Implementing larger text sizes for better readability and accessibility.
- Using appropriate font for the different scripts.
- Integrating audio recordings to cater to diverse written literacy levels and considering caregivers' time constraints, enabling them to listen while multitasking.
- Incorporating audio to accompany wellbeing exercises to improve ease of use and engagement with the materials.

Discussion

The rising prevalence of dementia among South Asian individuals in the UK, underlines the urgent need for culturally sensitive interventions and support services. South Asian elders and their families face numerous barriers in accessing dementia services, including limited awareness about dementia and mental health conditions, stigma, preference for family-led care, and a lack of culturally representative services and interventions.

The adaptation of iSupport aimed to address the specific needs of South Asian dementia caregivers. Stakeholders highlighted the need for a clear definition of “carer” to help individuals recognise their role and access support. They recommended encouraging caregivers to seek help and framing this as a way of supporting the person with dementia. They also suggested signposting to financial guidance and benefit details, whilst reassuring caregivers that seeking financial assistance does not diminish their role.

Stakeholders emphasised the importance of simplifying language and incorporating culturally relevant references and imagery. Additionally, they suggested integrating an audio feature to support individuals with diverse literacy levels and enhance user experience. Summary posters outlining key points from each module have also been developed and are available in all languages. This aligns with stakeholders' views on providing a shorter information pack for those with limited time.

By following an authentic co-design approach, we have created tools tailored to the unique experiences of South Asian dementia caregivers. These adapted interventions can provide timely support, increase uptake, and enhance participant engagement and outcomes. They equip

Extracts from the introduction

If you support or look after a parent, relative, partner or friend living with dementia who would find it difficult to manage without you, then you might be described as ‘their carer’. You might feel you are doing what anyone else would do for a family member or friend, so the term ‘carer’ could feel uncomfortable. However, describing yourself as a carer may enable you to access the help and support you need for this role.

Self-care is important too. If you don’t look after yourself, then it is much harder to look after those around you. We hope that the information in this course will make you feel able to take time for yourself and get support if you need it.

caregivers with essential knowledge and skills to manage caregiving challenges effectively, while also improving their mental health and well-being.

There are a few limitations to consider. The number of caregivers and professionals participating in our study was limited and might not have comprehensively captured the diversity in the range of experiences. Additionally, despite allocating a generous amount of time for caregivers and professionals to review the iSupport material, it is important to note that this form of research demands a significant investment of time. This might have influenced the quality of the feedback, considering that participants were balancing their participation in the study with their responsibilities as caregivers and working individuals.

Future research could explore integrating iSupport within groups and community settings such as religious institutions or cultural or community centres. This may offer a familiar and culturally sensitive context for South Asian caregivers and can address digital exclusion. These settings are often embedded with shared cultural norms, values, and language, creating a supportive and comfortable atmosphere for caregivers to engage in discussions and activities related to dementia care. Additionally, through interactions with other caregivers, individuals can exchange practical advice, seek emotional support, and share coping strategies, thereby reducing feelings of isolation, stress, and stigma.

Accessing iSupport for South Asian dementia caregivers

iSupport Bengali, Punjabi, Urdu, English:
<https://www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/isupport-south-asian-dementia>

iSupport Lite – Bengali, Punjabi, Urdu, English:
<https://www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/isupport-south-asian-dementia-0>

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Key points

- South Asian dementia caregivers face barriers to accessing services, for reasons including limited awareness, stigma, and the absence of culturally tailored services and interventions.
- iSupport is a self-guided online intervention, developed by The World Health Organization for dementia caregivers.
- iSupport has been translated and culturally adapted for South Asian dementia caregivers using a co-design methodology.
- Adaptations include:
 - Including culturally relevant illustrations, names, and references to customs and traditions such as leisure activities, food habits, festivals, and traditional attire.
 - Defining the family member’s role as a caregiver and addressing the impact of stigma.
 - Simplifying the language and adding a read-aloud function.
 - Creating summary posters for each language.
- iSupport for South Asian dementia caregivers is available in Bengali, Punjabi, Urdu and English.

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Non-pharmacological prescribing in a care home liaison service

Joanna Marshall (left, below) and **Susannah Thwaites** describe their work and the results of a small-scale evaluation that showed improved quality of life and reduced distress for care home residents, following non-pharmacological interventions as part of behaviour support plans

The Care Home Liaison (CHL) Hub is an NHS multi-disciplinary service that provides support to 116 care homes in County Durham and Darlington. It is made up of several different professions: occupational therapy, psychology, speech and language therapy, dietetics, physiotherapy, pharmacy, and an advanced clinical practitioner focusing on physical health. The CHL Hub works in collaboration with care home liaison nurses and support workers based within five community mental health teams. The CHL Hub offers specialist assessment and intervention for care home residents living with dementia and/or complex mental health conditions presenting with distress or behaviour that challenges. The CHL Hub was originally developed in 2012 with one OT, one psychologist and one advanced nurse practitioner, then expanded in 2020. The aims of the service are to: increase use of non-pharmacological interventions as a first line intervention; avoid crisis situations, which may result in admission to mental health or acute hospital; improve access to direct specialist therapy provision; and offer training and support for care home staff.



Summary

This article shares the work of an NHS Care Home Liaison service that was given non-recurrent funding in 2021 to prescribe non-pharmacological interventions to patients referred to the service presenting with distress or behaviour that challenges. It includes case examples of patients with a range of presentations and needs. Interventions include personalised music 'Playlists for Life', robotic pets, HUG™, doll therapy, Namaste/sensory, and meaningful engagement items.

The article includes the results of a small-scale service evaluation project based on 12 months of routine outcome data, interviews with family members and care home staff, and feedback from patients. Care home residents showed improved quality of life and reduced distress/behaviour that challenges following the introduction of non-pharmacological interventions as part of Behaviour Support Plans.

At one month follow-up, 86% of care home placements were maintained, 10% of patients changed placement due to a change in the level of care they needed, 4% patients were admitted to hospital. The limitations of the service evaluation, practical challenges of implementing non-pharmacological interventions, and implications for practice are discussed.

The risks of antipsychotic medication

An influential review found that antipsychotic medications prescribed for behaviour that challenges in dementia are associated with significant risks to health and risks to life (Banerjee 2009). The British Psychological Society's Division of Clinical Psychology published a briefing paper on 'alternatives to antipsychotic medication', but a recent survey of professionals found that these guidelines were seen as lacking clarity about what might work for whom (Gray *et al* 2022). The authors highlight the importance of focusing on how non-pharmacological interventions may meet the needs of people living with dementia, rather than on simply targeting reductions in antipsychotic medication.

Dr Joanna Marshall is Consultant Clinical Psychologist, Tees, Esk and Wear Valleys NHS Foundation Trust. Susannah Thwaites is Advanced Clinical Practitioner Occupational Therapist & Certified PAC™ Trainer Tees, Esk and Wear Valleys NHS Foundation Trust.

Understanding needs

The 8-Needs Framework, which has been described in a previous edition of *JDC*, provides a model for understanding an individual's needs (Marshall 2022). The framework incorporates Kitwood's Flower and Maslow's Hierarchy of Needs, and is built on the principle that needs are universal, whether we are living with dementia or not. When a need is unmet, distress or behaviour that challenges will emerge. Eight fundamental needs are identified: physical comfort and freedom from pain; safety; positive touch; love and belonging; esteem; control over environment and possessions; occupation and exploration; and fun. The 8-Needs Framework also includes the needs of care home staff and family carers.

Why a person may be distressed or presenting with behaviour that challenges

The CHL Hub have been doing assessments and psychological formulations for the past decade to understand why a person may be distressed or presenting with behaviour that challenges, and to identify the unmet needs that may be driving this. The team develops

Key points

- The 8-Needs framework helps us understand the needs of people living with dementia and how non-pharmacological interventions may meet these needs.
- During the evaluation period in 2021/2022, the Care Home Liaison Hub prescribed 338 non-pharmacological interventions to 171 patients.
- Patients showed improved quality of life and reduced distress/behaviour that challenges following the introduction of non-pharmacological interventions.
- To reduce antipsychotic prescribing, mental health teams need to be able to prescribe a range of non-pharmacological interventions as well as medications.
- There are numerous practical barriers to overcome.

individualised Behaviour Support Plans, which include guidance on person-centred staff approaches and non-pharmacological interventions to meet the person's needs, improve their wellbeing and reduce their distress. However, until recently, it was left to family (if the patient had any and if the family could afford them) to pay for and provide these items. Often recommended interventions were not implemented and these patients were prescribed medication, admitted to hospital, moved to a higher (and more costly) category of care, or provided with one-to-one staffing.

Non-pharmacological prescriptions as part of Behaviour Support Plans

The CHL Hub received non-recurrent funding (£6000) in September 2021 to prescribe non-pharmacological interventions to patients referred to the service. Non-pharmacological prescriptions are the 'things' that mental health teams can prescribe apart from medication, including personalised music 'Playlist for Life' kits (Holden *et al* 2022), robotic pets (Koh *et al* 2021), HUGs™ (Treadaway *et al* 2023), Namaste/sensory items (Latham *et al* 2020), therapy dolls, DVDs, and meaningful engagement items. In our team, the interventions are prescribed following an OT/Psychology assessment and/or a psychological formulation meeting. The 'prescription' takes the form of a one-page Behaviour Support Plan, which gives specific details of how, why, and when to use an intervention. During the period 1 October 2021–31 December 2022, a total of 338 non-pharmacological interventions were prescribed to 171 patients in care homes on the Behaviours that Challenge Pathway.

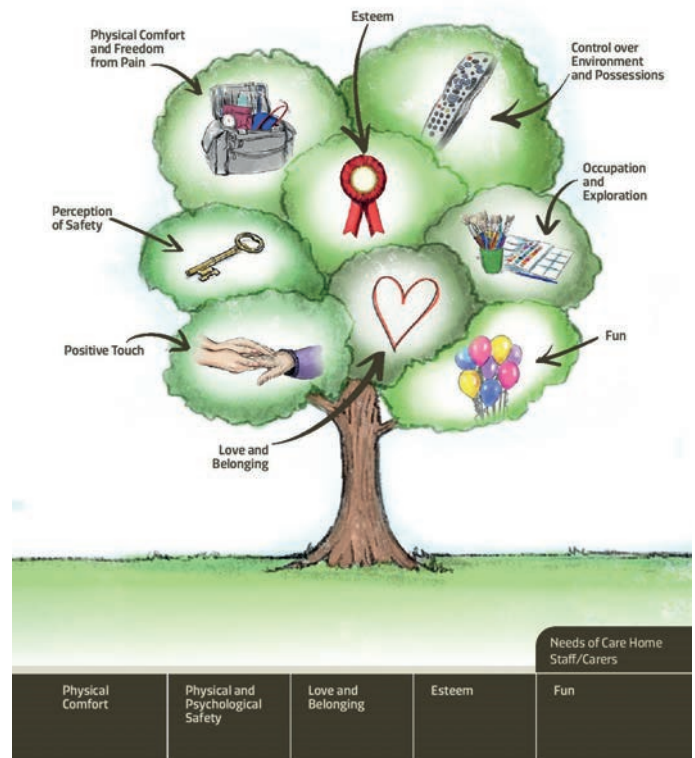
Personal and sensory biography

Our team has adopted the process of meeting with a close friend or family member to gain a detailed personal and sensory biography as part of our assessment. This was developed as part of a Namaste project in our trust and is crucial in selecting interventions that fit with a person's past roles, interests, and sensory preferences. Knowing what 'makes them *them*' leads to more effective, individualised

Fundamental Needs in Dementia Care

The 8-Needs Framework

Needs of the Person
Living with Dementia



interventions—for example that a particular smell or taste is associated with memories of a dear grandmother who made the person feel safe, or that they have always needed to do something active to cope with a stressful day.

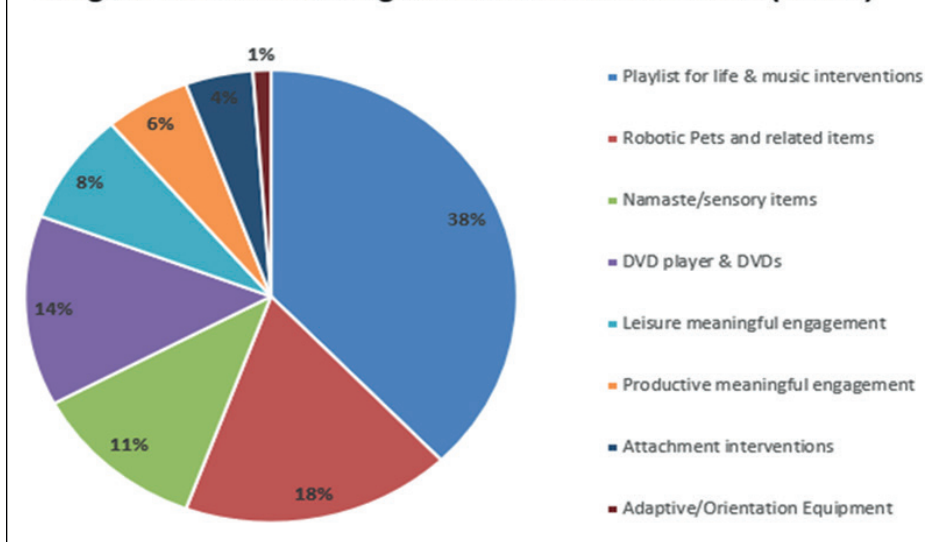
Current level of cognitive function

The occupational therapists in our team use the Allen Cognitive Levels to pinpoint the individual's cognitive abilities (Allen *et al* 2007). All staff also have knowledge of Teepa Snow's GEMS® model (Snow 2012), which is derived from this and helps to understand the person's limitations and abilities. A non-pharmacological intervention is more likely to 'hit the spot' if it fits with the person's current abilities. A person may reject a doll or robotic pet if they think it is childish, may disengage from a craft or work-like activity if they can no longer recognise the objects or there are too many steps, or become distressed if they cannot process lots of sensory information at once. Music spans all levels of ability and meets a variety of needs, so it is not surprising that this is our most frequently prescribed intervention.

Case example 1: Personalised Music Playlist

Mary was an 86-year-old lady with mixed Alzheimer's/vascular dementia presenting as very distressed, constantly walking around the unit asking to go home to see her parents. Other residents were concerned about her level of distress. Mary would not sit down long enough to eat and was losing weight. Care home staff had tried verbal reassurance and distraction, but these were not effective and Mary continued to be distressed. Prior to moving to the care

Range of Non-Pharmacological Interventions Prescribed (N=338)



at night, and takes it everywhere with her". Family reported "it was lovely to see her talking to the pet". There were no further incidences of Jane making advances to male residents. Jane died a few months later. The staff were pleased they had been able to maintain her placement.

Case example 3: HUG™

Jessie was referred to occupational therapy as she was very distressed on any form of touch, particularly personal care interventions. She was observed to tense her whole body, grimace, and push staff away even when a Hand under Hand™ technique was used (Snow 2012). However, Jessie responded well when a cushion was

home, Mary was cared for at home by her son. During the personal and sensory biography, he told us that when she was living at home, he would regularly play a particular song that reminded her of her father and had a soothing effect on her. Mary's identified needs were safety and familiarity, love and attachment, and a physical need for adequate nutrition. Mary was provided with a personalised music playlist on an MP3 player with a speaker, including the personally meaningful song. During our visit, we trialled the playlist with Mary. The Activity Co-ordinator was present, and observed:

There was a noticeable physical change in her presentation when a familiar song was played, which reminded her of her father. She appeared facially bright, smiling, tapped her foot and moved her body side to side. She sang along to the song using the correct words, in time with the music. After listening to the music, she stopped wandering the unit looking for her deceased parents and sat in the dining room to eat her lunch.

Case example 2: Robotic Pet

Jane was a 87-year-old lady with diagnosis of dementia in Alzheimer's disease. She was living on a mixed gender EMI residential unit, and the placement was at risk of breakdown. Jane had misidentified a male resident in the care home as her late husband (they had the same name) and was found undressed in his bedroom. This incident had been noted as a safeguarding issue. Both Jane and the male resident had been assessed by a social worker as lacking capacity to consent to a sexual relationship. Jane had recently made advances towards another male resident. During a formulation meeting with the care home staff, family and social worker, Jane's family shared that their mum had never liked being on her own, she had always liked male company, and had re-married after the death of her first two husbands, then had recently been widowed again. The family also shared that Jane had always loved dogs and had had several golden retrievers that she had treated like her children. Jane's identified needs were love, positive touch, occupation and exploration, and fun. We prescribed Jane a robotic dog, left it with her for a week for assessment, and she 'adopted' it. Care home staff reported that she "...absolutely loves it, keeps it on her bedside table

placed on her knee and some gentle deep pressure applied by pressing down on the cushion. She was also observed hugging the cushion to her. Jessie's identified needs were an increased sensitivity to touch, particularly in her hands, feet, mouth and genitalia, which alerted her fight or flight response, and a need for deep pressure touch to regulate this response. She also has a need for love and attachment, to hold and nurture something. A HUG™ (Treadaway *et al* 2023) is a soft comforter designed to be cuddled by people living with advanced dementia. It has weighted limbs and a soft body that contains a simulated beating heart. It was trialled with Jessie, and the OT who prescribed it noted:

I showed Jessie the HUG and after a couple of minutes I handed it to her, and she took the HUG and pulled it close. Jessie sat holding the HUG close to her with her arms wrapped around it and nestled her face into it.

On evaluation, care home staff reported:

Jessie has been champion, she absolutely loves the HUG and has it for most of the day. We have seen a big difference in her presentation, she seems far more settled. She still becomes distressed during personal care, but this is not as bad as it was before the intervention.

Case example 4: Namaste

James was referred to the team due to calling out for long periods across the day and night. In addition to having advanced dementia, James had a history of childhood trauma. He had witnessed domestic violence and experienced sexual abuse. James had been very close to his late brother. During assessment, the OT noted that James found processing lots of sensory information at once difficult. He was no longer able to walk independently, but could not retain this. He could drink independently and talk about the music he liked. His medical history suggested that he could be in pain, but he could not accurately communicate this. Pharmacological treatment had not been effective. James' needs were identified as feeling safe, physical comfort and freedom from pain, and sensory soothing opportunities. The main intervention implemented was Namaste, which is sensory-based comfort care for people with advanced dementia. This included planned short sessions across the day for 15 minutes at a time, an

intervention at night as part of his bed-time routine, and the option to use interventions ‘in the moment’ to provide reassurance and connection. Sessions included:

Therapeutic Touch – a warm flannel on his face or lotion rubbed into his feet or hands;

Sounds - listening to specific, meaningful music on an MP3 player with a speaker, including a local song that was played at his brother’s funeral;

Taste/Smells: cut up fruit to provide a variety of sensory experiences;

Visual: videos of Newcastle United football games. When the OT visited to introduce the interventions, James was unwell in bed with a chest infection and he had just been supported with personal care, which had left him tired and upset. The OT held his hand, rubbed some hand lotion in, and they listened to his Playlist together. When the song that reminded him of his brother came on, his breathing slowed and he visibly relaxed. There was no calling out and he drifted off to sleep shortly after. James died a few days after the visit, but the Namaste interventions prescribed helped care home staff and family to make James feel safe, calm and loved at the end of his life. Namaste interventions support Kathryn Mannix (palliative care consultant)’s work on ‘dying safely’ (Mannix 2022).

Therapeutic benefit of non-pharmacological interventions

Most patients had more than one need identified as part of assessment, so were prescribed more than one non-pharmacological intervention. Out of the 171 patients prescribed interventions, 152 (89%) received at least one intervention that was therapeutically beneficial (eg a robotic dog was not successful, but a personalised music playlist was). Following the assessment period (around a week), 19 patients (11%) did not have any successful interventions prescribed (i.e. patients did not engage with them). If interventions were not successful, they were collected, cleaned according to Infection Prevention and Control guidance, and prescribed to other patients.

Service evaluation project

A service evaluation project was conducted by a trainee psychologist from the Teesside Doctorate in Clinical Psychology, to evaluate the impact of non-pharmacological interventions by the CHL Hub. This included 12 months of routinely collected outcome data for patients receiving such interventions, interviews with family members and care home staff, and feedback from patients. This project was recently published in an academic journal (Bowers *et al* 2024). Proxy-rated measures of behaviour that challenges (Challenging Behaviour Scale, CBS, Moniz-Cook *et al* 2001) and Quality of Life in Dementia Scale (QUALID) (Weiner *et al* 2000) were completed as part of routine care pre and post intervention. Results showed a significant difference between pre- and post-intervention CBS and QUALID scores, with large effect sizes. Care home residents showed improved quality of life and reduced distress/behaviour that challenges following assessment, formulation, and the introduction of non-pharmacological interventions as part of Behaviour Support Plans. At one month follow-up, 86% of care home placements were

maintained, 10% of patients changed placement due to a change in the level of care they needed, 4% patients were admitted to hospital.

Limitations

This article reports on a small-scale service evaluation project completed by clinicians within an NHS service. It is not a research study with controlled variables. There are several limitations: outcome data was included from patients receiving different types of non-pharmacological intervention and many patients received more than one intervention, so it is not possible to tease apart effects relating to specific interventions; there is a lack of longitudinal follow-up of outcomes; and the sampling method to gather qualitative feedback from care home staff and family members was selective and lacks research rigour.

Practical barriers

The team encountered several practical barriers. Despite positive outcomes and feedback from patients, care home staff and families, there have been challenges in securing recurrent funding for non-pharmacological prescribing in the current economic climate. There has been a recent successful bid through the Better Care Fund, but there have been delays in getting this funding. It has also been a challenge to set up and maintain systems for ordering and purchasing items and delivering them to patients in a timely manner.

Implications for practice

The results of the service evaluation show promising findings for the impact of non-pharmacological interventions on distress/behaviour that challenges and quality of life for care home residents. However, due to ongoing practical barriers, antipsychotic medication is still often prescribed first. To reduce antipsychotic prescribing, mental health teams need to be able to prescribe a range of non-pharmacological interventions as well as medication.

The importance of language

Our final point is a reflection: we have both worked together for over a decade, but the language we use in our team and trust has not changed in that time. Recent co-produced good practice guidelines on how we talk about dementia were shared at the UK Dementia Congress 2023. The panel highlighted that many of the terms still used in health care settings, such as ‘behaviour that challenges’ and ‘behavioural and psychological symptoms of dementia/BPSD’ have the effect of ‘othering’ and de-humanising the person with dementia. The panel recommended that these terms should be avoided in favour of phrases or ways of looking at things, such as unmet needs. Clinicians need to listen to, and act on, the wisdom of our experts by experience.

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Reducing psychoactive medication use: Find the ‘why’

Katy Jenks, David Marshall and Graham Stokes describe and discuss a quality improvement project that focused on empowering staff to find the ‘why’ for behaviours that challenge

This project was prompted by our concerns about both the lack of timely clinical reviews and the high level of prescribing of sedating psychoactive medicines for people with dementia. These concerns predate the covid pandemic (Aldred *et al* 2007, British Geriatrics Society Joint Working Party Inquiry 2011, Ralph and Espinet 2019), but increased levels of antipsychotic prescribing were noted as we came out of its acute first phase (MacDonald *et al* 2023, McDermid *et al* 2022)

Similarly, ongoing difficulties for care homes seeking reviews in a timely manner for psychoactive medicines they felt were no longer effective have been noted (Care Inspectorate 2023). Care homes found they were caught between GP and mental health services when seeking reviews.

We also had concerns about some staff using sedating psychoactive medicines as a first line approach to manage stress and distress for people living with dementia in care homes, particularly if the staff member was less familiar with the resident. ▷

Katy Jenks is Dementia Care Manager, HC-One; David Marshall is Senior Improvement Advisor, Care Inspectorate, Scotland; Graham Stokes is Director of Dementia and Specialist Service Innovation, HC-One

Summary

The covid pandemic reinforced system-wide issues with the review and use of psychoactive medication for people with dementia living in care homes. These include a lack of timely review of medicines and staff using medicines as a first line approach to manage stress and distress.

We conducted a quality improvement project in eight care homes provided by HC-One that focused on frontline staff empowered to find solutions to improve dementia care relevant to their local context and reduce inappropriate use of psychoactive medicines for people with dementia.

Using the enriched person-centred approach to dementia care (Kitwood 1997; Stokes 2000) staff were supported to find the ‘why’ for stress and behaviours of concern and develop non-pharmacological approaches to manage this for specific residents. Homes received training in the basic principles of running a quality improvement project, with a focus on giving front line staff the psychological safety to test change ideas on small scale (initially 1-2 residents), fail, learn and try again. Homes gathered qualitative data from relatives, staff and clinicians as appropriate, while support with quantitative data was provided by the project team.

Change ideas related to the environment, activity and wellbeing, medicines reviews, personal care and staff practice.

All homes were able to demonstrate some improvement. Reductions were noted in the use of when required and/or regular psychoactive medicines, while case studies also showed positive quality of life benefits for residents and their families. Staff fed back that they felt empowered by the project and in some cases that the change ideas reduced administrative work and allowed more quality time with residents. We believe this approach can support sustainable changes to practice, enhance staff satisfaction, and lead to better outcomes for residents.

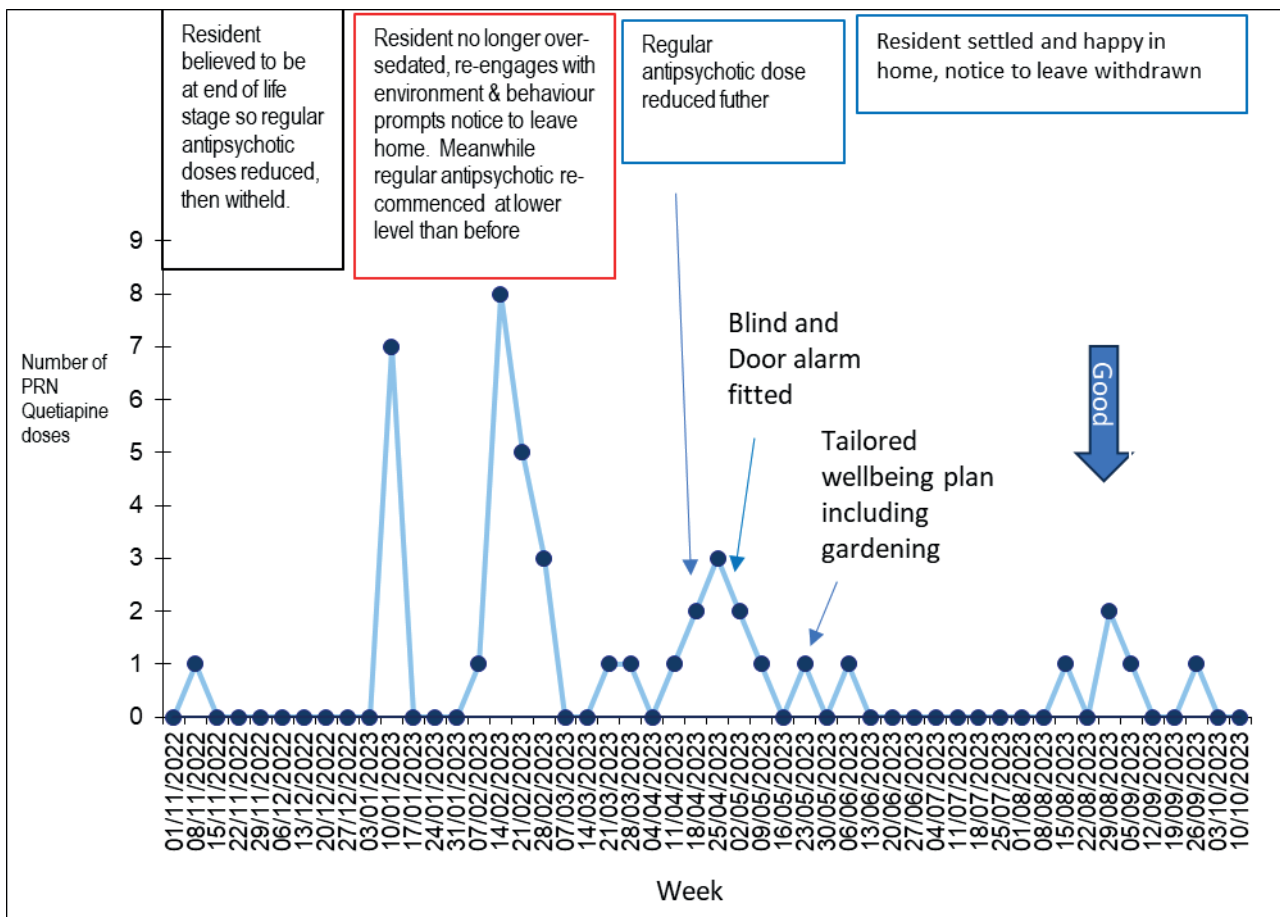


Figure 1: 'Finding the Why' Case Study

▷ The benefits of staff trained in “finding the why” for stress and distress behaviours and making adaptations to the physical and social environment are known (Casper *et al* 2018) and promoted in guidelines (SIGN 168, 2023).

An early case study acted as a trigger for our further work – see figure 1. The resident’s stress and distress were of a level such that they were served notice to leave the home, with one-to-one care in place until that time. However, following input from the HC-One Dementia Care Team, staff were able to *find the why* of the behaviours:

- Distress increased during sunset, with possible hallucinations caused by shadows in their room.
- The resident felt threatened by people following them or sitting outside their room.

Knowing this, the care home fitted a blind to the person’s room to reduce hallucinations, and a door alarm linked to the nurse call system was implemented so that the person could have private time in their room. These adaptations plus an activity plan tailored to the residents’ interest (gardening) resulted in a reduction in stress and distress incidents and facilitated a reduction in regular antipsychotic Quetiapine of 12.5 mg and anxiolytic Clonazepam 1 mg, as well as less need for when required (PRN) Quetiapine.

The resident now runs a gardening club in the care home, is now mobilising and independent with personal care and eating. The notice to leave the home has been withdrawn.

What we did next

We felt the current system needed to change as it was not serving residents well, and that we had to initiate that change. We developed a programme of work that had three specific principles behind it.

1. All teach all learn – the belief that no one person had all the answers to these complex problems and that we can all learn off each other. We wanted to create a community of learning.

2. Voluntary participation – this was not a mandated piece of work imposed on care staff, rather care homes self-referred into the programme. Our first cohort had eight care homes, all located in Scotland.

3. Frontline staff were given the power and psychological safety to identify local system issues, to develop and test new ideas, to fail, to learn and to try again. This was the most important principle as we felt this engendered ownership of practice and promoted sustainability.

The Learning Session and linked Action Period framework for our work is shown in figure 2. Before and during the project, homes had access to the HC-One Dementia Care Team for training on non-pharmacological approaches to dementia care – *finding the why*.

At Learning Session 1, homes received an overview of the project aims, and were provided with the basic principles of running a quality improvement project e.g. homes were encouraged to test change ideas on 1-2 residents rather than a whole unit/home approach. Staff were aided to develop change ideas relevant to their local context that they could test on return to the care home.

Learning session 2 focused on sharing learning from the

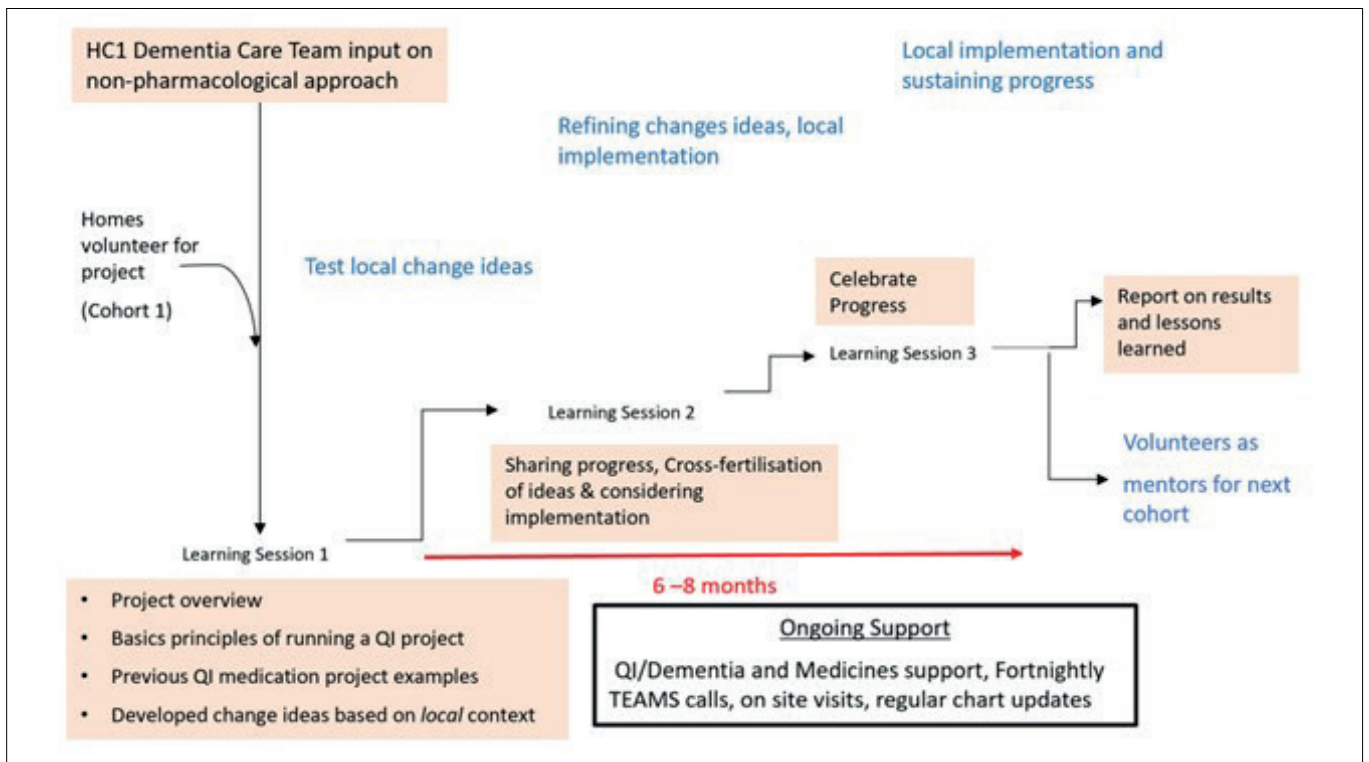


Figure 2: Framework for Quality Improvement Work

ideas developed in Learning session 1. These were refined to support the local implementation of change ideas.

Learning session 3 was a celebration of the progress made in the first 6 months and decisions needed to sustain implementation and spread of change.

Quality Improvement support

In addition to providing dementia and pharmacy advice as needed, the project team provided QI support, including collating of quantitative data, freeing up staff to focus on their role.

Our overall aim for residents who were part of the change ideas was a 40% reduction in the prescribing and use of psychoactive medicines (antipsychotics, anxiolytics, hypnotics, sedating antidepressants), i.e.

- Where a medicine was used on a when required basis, we were looking for a 40% reduction in use over baseline.
- Where a regular medicine was prescribed, and the dose deemed inappropriate, we were looking for a 40% reduction in that dose over baseline.

Sitting behind all of this was the desire to build a framework for sustainability and to change culture of practice. Staff ownership of change ideas was key to this in individual homes. However, we developed a spread plan for this work based on QI principles for subsequent cohorts. Staff from Cohort 1 have volunteered to act as mentors for staff in cohort 2.

Financial considerations

This work involved only time commitment from the people involved. Many of the changes ideas involved very little financial input but achieved significant outcome gains.

Examples of the project at work

The change ideas tested by the homes involved five themes.

Theme 1: Changes to the Environment

One staff member identified a resident watching care staff leave through the glass front door as a key trigger for the resident stress and distress. A frosted covering was then tested on the door resulting in less stress and distress for the resident, with a 60% reduction in use of ‘when required’ anxiolytics. The resident subsequently gained 1.4kg and now has a MUST (Malnutrition Universal Screening Tool) score of 0 and healthy BMI.

Another resident nearing end of life was prescribed and received regular and ‘when required’ psychotropic medicines. Care staff focused on the environment in her room to see if they could provide a familiar space resembling her own living room to make her feel safe and reduce her stress. This included familiar pictures, throws and cushions. In addition, staff purchased a reed diffuser and used this to provide the comforting smell of her husband’s aftershave.

The outcome was the resident was more settled and her psychoactive medicines were discontinued. This lady passed away a week later but because staff took an “*it’s never too late*” approach she was interacting with her family in that last week and had a meaningful and quality death:

Mum passed away peacefully not on any sedative medication. She was able to hold a conversation with us and share memories. I will never be able to thank the staff enough for never giving up and giving my mum a nice death.

Seeing the outcomes for the one resident, staff created a cosy lounge area with a kitchen area and free access to outside space. This allowed a space away from the main

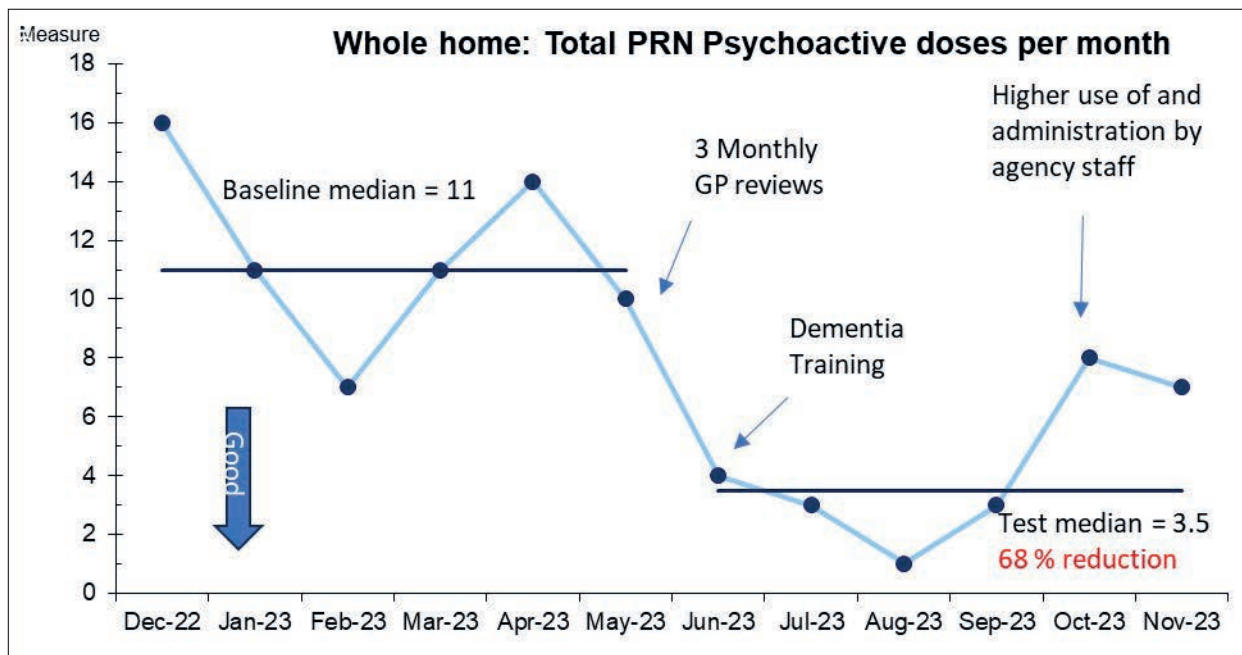


Figure 3: ‘When required’ psychoactive medication use

lounge that residents could go to if they wanted somewhere quieter to be and resulted in a reduction in use of whole unit ‘when required’ psychoactive medication.

Theme 2: Personal Care

A female resident in a care home was struggling to accept twice daily personal care. Desensitising the resident to the bathroom where personal care took place had limited effect. The service tried consistent staff, which had some effect, but gender of care staff had no effect. However, staff identified that height of care staff was a trigger factor for this person. Knowing this, they were able to achieve around 10-12 personal care sessions per week, compared to a baseline level of two per week.

Along with improved personal care, a successful reduction of regular Quetiapine medication is now in place of 100 mg reduction. This resident has also gained 2.25 kg, has a MUST score of 0 and healthy BMI, with staff reporting she now sits and enjoys her meal in the dining room, something she wouldn’t do before.

As with other homes staff report the project has reduced the time dealing with the administrative and concerning effects of behaviours that challenge.

Theme 3: Activity and Wellbeing

A resident was admitted to a care home with an expectation from social work that the placement would fail due to her behaviours of concern, with long term hospital care the next stage.

The staff recognised an area that hadn’t been explored was activity to provide a meaningful day. They worked with the resident and her family to find out things she liked and looked at ways to include these in tailored activity plans, along with opportunities for independent activity through life stations, settings that spark memories and give residents living with dementia purpose in their daily lives.

Throughout the day, the resident’s daily purpose was to support staff with folding towels and matching socks, organise the dressing table life station and engage with the

wellbeing staff to set up activity trolleys and dining tables, as well as organise cupboards.

The outcome was that the placement in the home was a success, with a complete reduction in stress and distress incidents, zero ‘when required’ anxiolytic use in the last 4 months of the project, and a 25% reduction in the regular Risperidone dose.

Staff approach of “*It’s never too late, you must always seek the why*” gave this resident the option to live their dementia journey in a homely environment.

Theme 4: Medication Reviews

One home noted that their GP surgery did not feel three-monthly reviews of psychoactive medicines for people with dementia was their remit. The manager signposted to the local NHS Board policy which called for three-monthly reviews plus a plan for reduction to be put in place if possible. The home and GP agreed a process for reviews to take place.

Of 11 residents prescribed psychoactive medications at start of project, eight had a psychoactive medication review by the end. Of these:

- five have an active reduction plan in place.
- two have had Risperidone discontinued.
- one has had Lorazepam discontinued.

GP reviews and staff training (from the HC-One Dementia Care Team) in this home resulted in an overall reduction in the level of ‘when required’ psychoactive medicines used (figure 3). The spike in use later in the project was driven primarily by agency staff, less familiar with residents, using medicines as a first line option.

This exercise has highlighted to the management of the home the need for closer oversight of medication when using agency staff.

Another home initially struggled to get GPs to engage when they phoned the surgery for medication reviews. They used the peer drop-in sessions to discuss these challenges with others on the project and gain feedback. Following this they decided to email the GP so

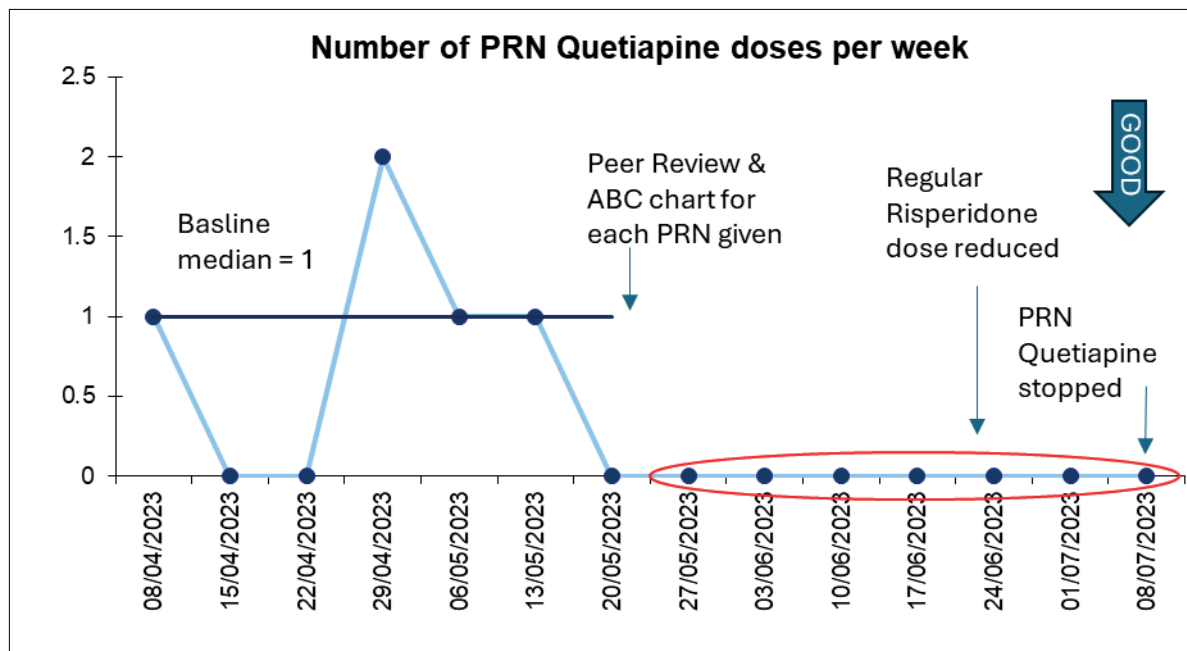


Figure 4: Reduction in resident 'when required' Quetiapine

there was evidence of requests made, along with asking the GPs to review individual residents at each visit and not a group. They found this approach more effective, and over the period of May-June the GP supported with one review a day and then changed to one a week when the majority of residents had had a meaningful review.

Through recognising changes in resident health and initiating reviews the home have seen an 87% reduction in whole unit prescribing of antipsychotic items .

The manager noticed a change in staff culture because of the project: previously the manager would have to initiate suggestions for review of residents' medicines; at the end of the project, staff were doing this.

A different home recognised that current reviews by the prescribers were ineffective because staff did not have the relevant information to hand when clinical discussions took place. To make reviews meaningful staff developed a form containing the necessary information pre review, such as how often PRN medicines are used, the number of distress incidents, resident presentation etc.

This form was developed using the QI approach of rapid change cycles where staff made small changes used it in practice and made any more changes identified when using it until a form was developed that met the need, with different staff members inputting at each cycle. Staff feedback was positive:

As a new nurse this form gave me the confidence that I could have the discussion to reduce medication, prompted me to have all the information I needed ahead of time, ready to present and discuss with the prescribing practitioner. Staff nurse, 2023.

Since implementation of the form, five residents have had a review with a reduction plan in place, and two residents have had psychotropic medication discontinued.

A relative of one of the residents noted the benefits of reduced use of medicine:

My wife has had her Risperidone and Trazadone medication stopped since moving into the care home and

staff working closely with her. I feel my wife has a better quality of life and she is now able to understand some of what is being said and is now managing to do things for herself that she couldn't do before when at home.

Feedback on the form has also been positive from clinicians, with one consultant psychiatrist noting: *It encouraged the process and benefit of not using medication.*

Theme 5: Staff Practice

In the next 2 examples, homes wanted to tackle staff using 'when required' psychoactive medication as a first approach, rather than a last resort for behaviours of concern. A psychological safe space was essential so staff could be honest about administration practices and ways to change this without fear of blame and repercussions.

These homes tested implementing Antecedent, Behaviour and Consequences (ABC) charts, and peer review of these, to show what steps were tried before any 'when required' psychoactive medication administration. An ABC chart is a tool that can be used to break behaviours into the above categories to allow for further analysis to find the 'Why' for the behaviours being shown. Training and support were given to staff, so they knew what to document on the charts, how to review behaviours, 'find the why' and implement strategies to meet residents' needs rather than use psychoactive medicines. The idea of the peer review was in case a second person could suggest anything that hadn't been tried. This gave staff the confidence that when medication was felt necessary, they had explored all non-pharmacological interventions and could evidence as such.

The results in both homes were a reduction in 'when required' psychoactive medication use. In the first home (figure 4) the change idea was tested on one resident and resulted in 'when required' Quetiapine being discontinued, along with a reduction in regular Risperidone of 75 mg daily. As well as medication reduction, the resident also had a reduction in falls and better QoL during their last three months. ▷

Key points

- Think big, start small
- Give power back to frontline staff and lead from a bottom-up approach
- Use data over time to track change and keep staff motivated
- Celebrate ‘smalls’ as you go, don’t wait until you achieve the desired goal
- It’s okay to fail as long as **you** learn from it.

▷ In the second home there was a 65% percent reduction in unit when required psychoactive medication administration. This included a period of disruption caused by opening up/merging of units in the home.

Implications for practice

We believe that sustained change is more likely when all voices are equal and part of the process, where staff know why they are doing something, rather than a hierarchical instruction.

Staff ownership of change has been a key cultural shift, taking some pressure off managers and promoting sustainability. During a recent scrutiny visit, when a home manager was on holiday, staff felt confident enough to share and discuss their test of changes data with Care Inspectors to good effect.

Another culture change has been the appreciation of data as a mechanism to chart the effects of change, positive *and* negative, and to use that data to drive forward improvements. While the project team charted data for this pilot, the homes involved have requested training on how to sustain this.

The pilot also highlighted the benefits of regular staff familiar with residents, trained in “finding the why” and using tailored non-pharmacological interventions to reduce stress and distress. It also raises concerns over the effects on resident care caused by a higher use agency staff in this area. Together with a reduction in behaviours of concern and subsequent psychoactive medication administration, homes reported a saving of staff time on administrative tasks and improved staff confidence enabling them to challenge the status quo within themselves and external professionals.

Lessons learned

In conclusion this project has highlighted key points that we are taking forward into cohort 2 of the project as we continue this learning journey. Taking a QI approach and implementing the theory of think big, start small and tracking data over time allowed homes not to become overwhelmed with trying to do everything at once. Instead, they could make small changes so that it didn’t require additional time and resources to make the changes—making it more likely that change would be sustainable and not just for the duration of the project. Tracking data over time allowed for homes to be able to see in real time the effect and impact of their changes.

This allowed homes to adapt their change idea if required or provided them with the encouragement to continue with their change idea. This data was shared with front line staff so they could see the impact of their change of practice to motivate them and again make the changes sustainable. The improvement journey focused on an all teach all learn and nurturing this theory of QI removed the hierarchy of change and allowed for all ideas to be brought to the table in a psychological safe way.

Psychological safety was fundamental as it allowed for frontline staff to be curious, courageous and creative when looking at change. Staff had to feel safe and supported to fail and learn from these failings so we can then try again until they found the solution. This approach also supported the sustainability of the programme, for when all staff were involved it didn’t matter if someone moved from the care home—the changes continued. If the project was led by one person you can see that change would not be sustained and there would be a return to previous practice. Along with this approach, celebrating small wins also supported the sustainability of change and kept motivation to drive change ideas. The greatest benefits reported by staff were that by making these changes both the quality of life of residents living with dementia and job satisfaction improved.

We have now established a format that will support future cohorts to deliver the programme in the same way, with staff from cohort 1 taking an active role in supporting and sustaining the programme.

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Serious games: how to improve motivation and satisfaction

Serious video games can help to improve and maintain cognitive skills for those living with dementia. **Rashmita Chatterjee, Kerstin Roger and Zahra Moussavi** explore ways to improve long-term engagement in these games

Game-based therapy has been shown to have more success than medication in improving and maintaining cognitive abilities of people living with dementia (Tárraga *et al.* 2006). These special video games, known as serious games, are aimed towards educating and learning rather than just entertainment.

Serious games began as traditional board games like puzzles. With the rise of video games, popular ones like Angry Birds were used for game therapy (Bing 2014). However, these games are designed by and for able-bodied, cognitively healthy individuals, making them challenging for people living with dementia. To offer effective game-based therapy, we need to customise games to accommodate the physical and cognitive limitations of the target audience.

Another significant challenge serious games face is *long-term engagement*. This means how willingly and regularly people living with dementia use the game over time. Regular play is required to improve and maintain cognitive abilities. Hence, long-term engagement is especially important for serious games. If people living with dementia are not satisfied with playing the game, they would not want to play it regularly, defeating the purpose. Our team considers this a worthwhile challenge.

This article explores ways to improve long-term engagement in serious games for dementia. We review current research and literature using two theoretical frameworks: the *Unified Theory of Acceptance and Use of Technology (UTAUT)* (Venkatesh *et al.*, 2003) and *Cognitive Evaluation theory (CET)* (Ryan *et al.* 2006).

UTAUT helps us understand how users perceive and accept technology. The UTAUT says a user's intention to use a technology is influenced by: performance expectancy, social influence and facilitating conditions. CET focuses on intrinsic motivation, which is the inherent satisfaction and excitement from doing an activity. It highlights four key principles: autonomy, competence, presence, and intuitive controls. (Ryan *et al.* 2006). These principles either boost or hinder a person's natural motivation to play games. By combining insights from these frameworks, our paper aims to provide recommendations to make serious games more engaging for people with dementia, ensuring they play regularly and benefit cognitively.

Rashmita Chatterjee, Department of Biomedical Engineering, University of Manitoba, Winnipeg, Canada. Kerstin Roger, Department of Community Health Sciences, University of Manitoba. Zahra Moussavi, Department of Electrical and Computer Engineering, University of Manitoba.

Summary

Game-based therapy for people living with dementia has become popular. These games fall under serious games. Making serious games for people living with dementia engaging can be challenging. If people living with dementia are not engaged and satisfied with playing the games, they would not want to play it regularly. This would defeat one of the primary purposes of cognitive rehabilitation, as regularity in playing serious games is crucial for sustaining and improving cognitive abilities. Utilizing existing theories of technology adoption and acceptance, as well as motivation for gameplay, we identified key elements influencing long-term engagement in gaming for people living with dementia. This discussion also draws upon our experience conducting dementia studies. Motivation and satisfaction to play serious games was found to be influenced by game design components and interaction with people living with dementia. We offer recommendations for the development and implementation of serious games for cognitive programs, emphasizing strategies to enhance long-term engagement.

Factors influencing long-term engagement and satisfaction for people living with dementia

Behavioural and social factors

The UTAUT theory outlines three main factors influencing the intention and continued use of technology: performance expectancy, social influence, and facilitating conditions.

1. *Performance expectancy* is the belief that using the technology will improve performance. For people living with dementia, believing that playing the game will enhance their cognitive abilities is crucial for motivation (Boot *et al.*, 2016).

2. *Social influence* helps increase motivation for all kinds of activity. Playing serious games can be more enjoyable and motivating if done in social settings such as part of senior centre activities or with family members.

3. *Facilitating conditions* can help a user believe that the technology can support them effectively. Asking for preferences like volume and screen brightness and allowing the user to explore the game environment before playing the game could help them get comfortable with the technology.

Environment and game design factors

According to Cognitive Evaluation Theory (CET), four key principles—autonomy, competence, presence, and intuitive controls—affect intrinsic motivation and engagement: ▷

▷ *Autonomy*

Feeling free to make your own choices increases motivation (Ryan & Deci 2000). Games should provide non-controlling instructions and choices (Ryan *et al* 2006). It is also important to respect a person living with dementia's decision if they do not want to play regularly. It is better for long-term engagement if they play it only once or twice a week when they want to rather than holding them to a regular schedule.

Competence

This is the feeling of effectively interacting with the environment (White 1959). Games should have intuitive controls, gradually increasing difficulty, and provide positive feedback. Early feedback should be encouraging, while later feedback should be constructive and specific.

Positively pointing out errors while praising their specific achievements is an effective way for them to feel motivated. However, always keep in mind the attitude of the person living with dementia and interact accordingly. Interaction is a key aspect that we will discuss later in the paper.

Presence

Presence in the context of gaming, is the sense of feeling part of the game world (Rigby, 2004). A game in which a player feels more present is a game that they will enjoy coming back to, and hence presence improves long-term engagement and satisfaction. Presence can be increased by providing user-friendly and intuitive controls, having an engaging storyline and appealing visuals within the game.

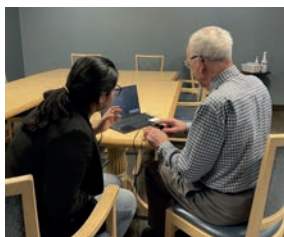
Intuitive controls

Easy-to-use controls improve satisfaction (Ryan *et al* 2006). It is difficult for people living with dementia to multi-task, so keyboard arrows and mouse are not intuitive for them. Using a single thumb stick on a gaming controller instead of the traditionally used two, can make navigation easier for people with dementia. When someone is unable to use a technology, attributing it to their dementia and giving up is not fair to them. In most cases there will be a solution that will work.

Improving motivation and satisfaction

Customizing the game and gadgets

Serious games should accommodate the cognitive and motor impairments of people living with dementia. Ben-Sadoun *et al's* recommendations (2018) offer valuable insights in this regard. To avoid multi-tasking, actions should be fewer in number, simple and easy to learn. To ensure that the game remains engaging and appropriately challenging for users at different stages of dementia, varying difficulty levels should be offered. Finally, due to impairments in memory, older adults living with dementia (depending on the severity of dementia) might not be able to retain all the information they require to achieve the goals within the game. Hence, beyond



Older adults playing a navigation-based serious game.

Key points for practice

- **Tailored game design:** Customize serious games by incorporating larger font sizes, intuitive controls, and simplified tasks to accommodate cognitive and motor impairments.
- **Positive interaction:** Foster positive engagement by using encouraging language, avoiding elderspeak, and building rapport with people living with dementia to create a supportive and enjoyable gaming environment.
- **Autonomy and choice:** Respect the autonomy of people living with dementia by offering choices within the game and allowing them to play at their own pace, ensuring a sense of control and empowerment.
- **Continuous feedback:** Provide constructive feedback tailored to the individual's level of competence, focusing on specific achievements and areas for improvement to maintain motivation and engagement.
- **Awareness building:** Educate caregivers, researchers, and long-term care staff about the capabilities of people living with dementia and the benefits of serious gaming interventions.

in-game instruction guidance, they need tutors to guide them regularly on what needs to be done in the game and to provide positive feedback on where they went wrong and how performance can be improved.

Promoting positive interaction

The quality of interaction between tutors and the people living with dementia is vital for game enjoyment. A tutor can be anyone guiding them to play the game, like a caregiver at home, a student in a research environment, a care practitioner in a long-term care environment, senior centre staff members in the community. Interaction needs to be positive while playing the game, otherwise they will not want to play the game regularly (Williams *et al* 2016), which would defeat the purpose of the game.

Use positive language

Positive language makes people living with dementia feel more comfortable and engaged (Schack *et al* 2021). As a tutor, being encouraging and positive creates a safe space where people will want to work on improving their performance. However, it is important to reiterate here, that positive feedback does not mean superlatives. People usually want to know mistakes they made. Feedback should be framed constructively.

Reduce elderspeak

Elderspeak is a speech style like baby talk often used to different extents by younger adults to talk down to older adults living with dementia. Elderspeak can imply incompetence that could decrease self-esteem and engagement. Older adults living with dementia react negatively to elderspeak (Kemper & Harden, 1999). As a tutor it is important to make a conscious effort not to use elderspeak. ▷

▷ Get to know the person living with dementia

For a tutor it is key to build rapport with the older adult living with dementia they are guiding to play the game. This increases the level of comfort, well-being and long-term engagement in the game. In cases where a tutor has continuous one-on-one interaction like a caregiver or a student researcher, it is easier to form a relationship. In situations where the tutor is a long-term care or a senior centre staff, it is more difficult, but important.

Build awareness about strengths of people living with dementia

Staff perceptions about capabilities of people living with dementia is one of the biggest barriers to gaming technology adoption (Hicks *et al* 2019). A lot of the time, staff do not attempt to use the technology with people with advanced cognitive impairments because they think it might be disorienting (Hayden *et al* 2022).

People who will be tutors for the serious games need to be made aware of the strengths and capabilities of people living with dementia. Awareness sessions and demonstration videos showing people living with dementia playing serious games can help change perceptions.

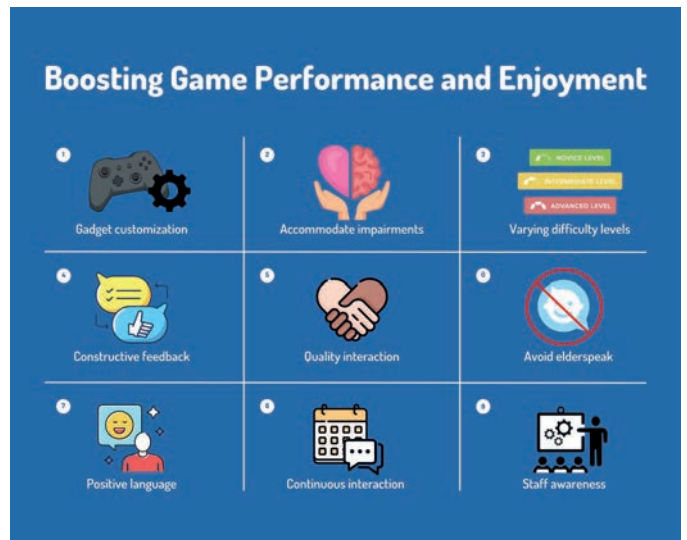
Conclusion

Serious games can be a valuable recreational activity for older adults living with dementia, providing both enjoyment and cognitive benefits. When played regularly, these games can help maintain and even improve cognitive abilities. However, finding enjoyment in these games and maintaining the motivation to play regularly can be challenging. It is essential for game designers to create games that are enjoyable and accessible for people living with dementia. Tutors also play a crucial role in making game sessions interactive and engaging, helping to foster regular participation. Our paper has outlined practical solutions for improving game design and interactions. Quality of interaction with the person assisting is an overarching influence on the other elements discussed and hence it is important to focus attention on this for future research.

A key takeaway is the importance of respecting the autonomy of individuals with dementia. They should have the freedom to choose activities that enhance their quality of life and should not be forced to play games if they do not enjoy them. While playing serious games can provide cognitive benefits, any improvement is an added bonus rather than a necessity. As the population ages and technology continues to advance, future generations of older adults will likely be more familiar with gaming. This familiarity is likely to lead to a greater acceptance and enjoyment of game-based therapies, making them an even more effective tool for supporting people living with dementia.

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Evidence for practice/Research news

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

We welcome contributions such as:

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

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

Dementia prevention: Nutrition update

Appropriate nutrition represents a potential strategy to mitigate dementia risk and this review offers a clinician-focused update on the current state of the knowledge on nutrition and dementia prevention. It concludes that strong evidence exists to support the consumption of healthy, plant-based dietary patterns (e.g. Mediterranean) for maintaining cognitive function and reducing dementia risk in later life; this is supported by dementia prevention guidelines from leading public health bodies (e.g. World Health Organization). Emerging evidence suggests potential cognitive benefits of consuming specific nutrients/foods (e.g. n-3 fatty acids or fish) and multi-nutrient compounds (e.g. Fortasyn Connect). The paper highlights challenges and opportunities for integrating nutritional/dietary interventions for dementia prevention into clinical practice.

Townsend R, Fairley A, Gregory S et al. Nutrition for dementia prevention: a state of the art update for clinicians. *Age and Ageing*, Volume 53, Issue Supplement 2, Pages ii30–ii38, Published May 15 2024. <https://doi.org/10.1093/ageing/afae030>. Restricted access.

Intimate and sexual needs

Person-centred care emphasizes close care relations regardless of gender. However, when residents with dementia express intimate or sexual needs, nurses may struggle with their own emotions. This survey in Dutch nursing homes showed that while positive nurturing sentiments towards residents prevail, residents expressing intimate needs elicit higher levels of positive-nurturing and lower levels of negative emotions than those with sexual needs. Male residents, who expressed more pronounced sexual needs, received less affection and interest from female nurses who felt especially close to female residents with intimate needs. The authors conclude that close care relations established through nurses' personal emotions inadvertently introduce gender-sensitive and differing emotions towards residents. They highlight that nurses'

capability to include personal boundaries benefits the relationship and well-being of both parties.

Waterschoot K, Roelofs TSM, van Dam A, Luijkx KG. Exploring the gender-sensitive feelings of nurses towards residents with intimate and sexual needs in dementia care. *Geriatric Nursing* 59, Sept-Oct 2024. 312-320. <https://doi.org/10.1016/j.gerinurse.2024.07.025>. Open access

Music and social connections in young-onset dementia

This mixed methods pilot study aimed to assess the feasibility and acceptability of an online group program for people with young-onset dementia and their care-partners living at home in Australia. The program involved six weekly two-hour sessions co-facilitated by a psychologist and music therapist, and a private Facebook group. Qualitative findings supported acceptability of the program with four emergent themes: (1) being connected to others with shared experiences; (2) reframing thoughts and feelings about dementia; (3) music as a therapeutic tool; and (4) benefits of the Music and Psychology and Social Connections (MAPS) intervention. The high retention rate and positive evaluation suggest that the programme is a promising, feasible and acceptable for couples affected by young-onset dementia.

Loi SM, Cadwallader CJ, Stretton-Smith PA. et al. A mixed methods evaluation of the music and psychology and social connections (MAPS) pilot – A dyadic intervention for couples affected by young-onset dementia. *Dementia*. Published June 21 2024. <https://doi.org/10.1177/14713012241263151>. Restricted access.

Montessori approaches

This paper examined staff impressions of Montessori-based program training and implementation at Veterans Affairs Community Living Centres in USA. Qualitative interview data from staff trained in Montessori supported three themes: (1) an understanding of the program and the benefits of Montessori compared to previous routines; (2) positive feelings about Montessori principles/applications and a willingness to try the Montessori approach, and (3)

making sense of the new intervention through early rehearsal of Montessori principles/practices. The authors conclude that Montessori virtual training resulted in high levels of coherence and cognitive participation among multidisciplinary staff, evidenced by high knowledge, self-efficacy, and readiness to act. The trainings were evaluated as accessible, relevant, and supportive of diverse learners. Kennedy KA, Lynn Snow A, Mills EL et al. Implementing Montessori approaches after training: A mixed methods study of examine staff understanding and movement toward action. *Dementia*. Published July 22 2024. <https://doi.org/10.1177/14713012241263712>. Restricted access.

Stimulating leisure-time activities and dementia risk

This study investigated the association of stimulating leisure-time activity in late adulthood with the risk of dementia across up to two decades' follow-up in Finland and Sweden. The authors conclude that stimulating leisure-time activities are associated with a reduced risk of dementia in short-term but not long-term follow-up. Heikkilä K, Pentti J, Dekhtyar S et al. Stimulating leisure-time activities and the risk of dementia. A multi-cohort study. *Age and Ageing*, 53(7). Afac141. Published July 2024. <https://doi.org/10.1093/ageing/afac141>. Open access.

Hospital admission to single rooms

This scoping review aimed to identify, explore and conceptually map the literature reporting on what older people with dementia and their families experienced during admission to a hospital with single room accommodation. It concluded that it is not merely the room design and hospital environment that determine what the patients and families experience as important; the exposure to sensorial stimulation and the presence of well-trained staff taking a dignified patient-centred approach are also crucial for their experience of high-quality nursing care. Søndergaard SF, Skow T, Andersen AB et al. The experiences of hospital admission in a single room for older persons with dementia and their families: A scoping review. *International Journal of Older People Nursing* e12626. Published July 6 2024. <https://doi.org/10.1111/ijn.12626>. Open access.

Domestic model of residential care

In New Zealand, one provider of aged residential care developed a village inspired by de Hogeweyk in the Netherlands, where resident engagement in valued activities supports continuing lifelong identities. The study aimed to explain the transition from a traditional Aged Residential Care facility to a clustered domestic model of care. The authors emphasise that, while a domestic-scale environment provides cues to normal living, staff who know residents and what is important to them enable participation in community and valued activities. The authors conclude that workplace culture change is an essential part of such a transition. Shannon K, Cook C, Neville S. Realising person-centredness: Transitioning to a clustered domestic model of aged residential care for people with and without dementia. *International Journal of Older People Nursing* 19(5) e12632. Published July 31 2024. <https://doi.org/10.1111/ijn.12632>. Open access.

Also:

Donadey M, Broc G, Erkes J et al. Application, understanding, and appropriation of the Montessori method for persons with dementia: A qualitative pilot study. *Dementia*. Published July 25 2024. doi:[10.1177/14713012241264910](https://doi.org/10.1177/14713012241264910). Restricted access.

Interventions to prevent abuse in community settings

The abuse of older adults is a societal and legal issue, and a person living with dementia is at high risk for abuse. This literature review examined the evidence for interventions to prevent the abuse of people living with dementia in the community but it found very few studies and was not able to draw conclusions on the effectiveness of interventions. The authors conclude that, given the paucity of research, there is a clear need to identify how to overcome the challenges faced in elder abuse research. Peter AS, Probhu MM, Devi ES et al. Effectiveness of interventions to prevent abuse in people living with dementia in community settings: A systematic review. *Dementia*. Published June 21 2024. <https://doi.org/10.1177/14713012241260476>. Restricted access.

Place of death in advanced dementia

This comprehensive literature review highlights the profound challenges of advanced dementia end-of-life care. It concludes that place of death in advanced dementia is influenced by 10 individual (age, gender and ethnicity), illness-related (pneumonia, Chronic Obstructive Pulmonary Disease, cancer and functional status) and environmental factors (marital status, urbanisation level and funding mechanism). It concludes that shifting end-of-life care from the hospital to the community in advanced dementia involves more than increasing/decreasing nursing home/hospital bed capacity. To meet the specific needs and preferences of the increasing number of people with advanced dementia and their families appropriately while ensuring sustainability, integrating palliative care into the healthcare system, with a funding mechanism that incentivises care coordination such as capitation, is recommended.

Tay RY, Tan JYS, Preston N et al. Factors associated with the place of death of persons with advanced dementia: A systematic review of international literature with meta-analysis. *Palliative Medicine*. Published online Aug 2 2024. <https://doi.org/10.1177/02692163241265231>. Open access.

Nature-based activities

These researchers interviewed people living with dementia and family carers to explore how they frame their everyday experiences of nature and how these are shaped by any cognitive challenges and/or other comorbidities affecting physical health. The findings reveal how the participants framed their experiences through three interlinked themes of: (1) 'bodily feelings and emotions'; (2) 'sense of self and identity' and (3) 'connectivity to others'. The paper contributes to current knowledge by examining through the lens of embodiment the neglected dimension of everyday leisure: how nature is encountered, negotiated and enjoyed. The paper illustrates how nature and the outdoors may help people living with dementia to continue to enjoy prior leisure pursuits and thus achieve a degree of continuity in their everyday lives.

Owen S, Page S, Clare L et al. Embodied leisure experiences of nature-based activities for people living with dementia. *Dementia*. Published July 26 2024. <https://doi.org/10.1177/14713012241262384>. Open access.

Also:

Jiang H, Eaglestone G, McCrone P et al. [How are nature-based interventions defined in mild cognitive impairment and dementia studies? A conceptual systematic review and novel taxonomy.](https://doi.org/10.1177/14713012241261788) *Dementia*. Published July 22 2024. <https://doi.org/10.1177/14713012241261788>. Open access

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