

# The Journal of DementiaCare



For all who work with people with dementia

Vol 32 No 1 January/February 2024



## The Photobook Project: Empowerment through creativity

Also inside  
this issue:

- Dementia care in mixed ethnicity families
- Reducing fire risks
- Digital life stories



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

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



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Cover photographs: Sincere thanks to Ellie Robinson-Carter, David Truswell and all involved in the Photobook Project described on pages 23-25.

**NEW FOR 2024**

The Journal of  
**DementiaCare**  
**WEBINARS**



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

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

**30 January 2024**

### **Innovations in care and culture: The Montessori Way using Dementia Care Coaches**

**Presenter:** **Lynne Phair**, independent nurse and expert witness, and a colleague from Milford Care.

**Description:** This webinar will describe how the University of Worcester FITS into Practice Dementia Care Coach programme was implemented in Milford Care to ensure cross-organisation shift of culture using the Montessori ethos. At Milford Care the programme is open to all staff and all are encouraged and trained—whatever their role, job title, abilities or background – to embrace residents as equals and use their strengths and abilities in the care setting.

**27 February 2024**

### **Non-pharmacological Prescribing in a Care Home Liaison service**

**Presenters:** **Joanna Marshall** and **Susannah Thwaites**

**Description:** This webinar will share the innovative work of a Care Home Liaison service that was given non-recurrent funding to prescribe non-pharmacological interventions to patients living with dementia who were referred to the service presenting with distress or behaviours that challenge. We will share case examples, discuss the practical challenges of implementing non-pharmacological interventions and how these were overcome. Interventions include personalised music 'Playlists for Life', robotic pets, HUGs, doll therapy, Namaste and meaningful engagement items.

**11 March 2024**

### **Cognitive Stimulation Therapy**

**Speakers:** **Emily Fisher** and colleagues, University College London

**26 March 2024**

### **Understanding Equality, Diversity and Inclusion in dementia care**

**Presenters:** **Karan Juttla**, University of Wolverhampton, **David Truswell**, Dementia Alliance for Culture and Ethnicity, and (tbc) **Jagdish Brar-Orgill**, activist and former carer.

**22 April 2024**

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

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

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

**21 May 2024**

### **Can lie telling be used to support personhood?**

**Presenter:** **Dr Jane Murray**, University of Northumbria

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



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**Hilary Woodhead**, NAPA

**The Dementia Engagement and Empowerment Project** –  
people living with dementia (with Nathan Bolton)

**The 3 Nations Dementia Working Group** –  
Alzheimer's Society (with Allison Garoghan)

**David Truswell** – Dementia Alliance for Culture and Ethnicity

**Dr Nadia Wahid** – Dementia Primary Care Clinical Lead,  
Birmingham

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

# New year brings change

by Sue Benson



**W**elcome to this first issue of 2024, a year in which we hope the journal and our Dementia Community will grow and thrive. The energy and warmth we felt at last year's UK Dementia Congress gives us hope that we can work together to improve services and the experience of all involved in dementia care, despite inescapable difficulties ahead.

The new year brings some changes. Mark Ivory, who has been a sensitive and expert editor of JDC for the last nine years, has retired. We are all very sad to lose him, and wish him many happy years ahead to pursue his absorbing interests. Other wonderful people are retiring too, sadly for me. Firstly Jackie Pool: Jackie has been closely involved in JDC and all our activities from the very beginning, shaping the direction of the journal and a constant inspiration to us all, and her Pool Activity Level tool is a lasting legacy of her important work. Tessa Gutteridge, retiring too, has nurtured the Young Dementia Network and seen it grow in strength and influence over many years. Philly Hare and Rachel Niblock have stepped down from their roles at Innovations in Dementia. Philly and Rachel supported people living with dementia to have a pivotal role in the UK Dementia Congress over many years. In 2011, Philly set up the 'Dementia without Walls' programme for the Joseph Rowntree Foundation which was pioneering work that explored new ways of framing dementia. Before Rachel's work with Innovations in Dementia, she worked with the National Dementia Action Alliance through the launch of their Carers' Call to Action. We will miss them all but wish them the very best for the future.

In with the new: we are delighted that Kellyn Lee, Kate White, Kritika Samsi and Jan Oyebode have recently joined our advisory group.

I am moving back into the role of editor, to where I began at the launch of JDC in 1993. I've been deeply touched over the years by the terrific work and inspiring ideas described in so many wonderful articles, as well as UK Dementia Congress presentations and National Dementia Care Awards entries, and I'm very much encouraged by the quality and variety of articles, and proposals for articles, that are coming in to me now, promising some excellent issues of the journal ahead. Please keep it up: send me your ideas for articles, whether descriptions of projects and services, evaluations and accounts of research projects, viewpoint or opinion pieces or just letters to the editor – I would like them all, all kinds and all lengths of contribution. Guidelines are on our website, but don't hesitate to email me to discuss your ideas.

Significant articles in this issue include an evaluation of SPECAL Practitioner training (pp26-29). SPECAL is a controversial approach that has provoked strong feelings over many years now; this evaluation showed some significant benefits. The development of specialised training for carers of people with a learning disability and dementia is recounted on pp30-33. The Photobook Project described by Ellie Robinson-Carter (pp23-25) and work with mixed ethnicity families (described by Mary Tilki and Mohammed Rauf on pp16-18), are accounts of important work with marginalised communities in the UK. Both JDC and the board of Dementia Community are strongly committed to the principles of equality and inclusion in dementia care. We will be working hard to make significant progress in 2024, and we welcome all who can help us along the road. ■

**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 and resources round-up

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

## Young onset dementia risk

A major study, published by the JAMA Neurological Journal, has provided greater insight into the risk factors associated with developing young onset dementia (dementia under the age of 65). The study challenges the concept that genetics are the sole cause of young onset dementia, and lists factors not previously associated with developing dementia, including vitamin D deficiency and levels of proteins, called C-reactive proteins, in the blood. <https://www.alzheimersresearchuk.org/risk-of-young-onset-dementia-linked-to-health-and-lifestyle-factors-as-well-as-genetics/>

## New Year's Honour's List 2024

*Kate Lee*, Chief Executive of the Alzheimer's Society, has been honoured with an OBE for her services to charity. Alongside Kate, five more people have been recognised for their work with people who have dementia. They are: *Karen Spiers*, Senior Charge Nurse, NHS Lanarkshire. For services to Dementia Care in Hospital.

*Joanne Williams*, Chief Executive Officer, Forget-me-not Chorus. For services to people with dementia and their families.

*David Mynott*, Volunteer, Torfaen Dementia Group. For services to people with dementia and their carers.

*Versha Sood Mahindra*, Lately Dementia Lead, BUPA. For services to community cohesion and to people with dementia in Cardiff.

*Debra Veigas*, End of Life Care Admiral Nurse, Wakefield Hospice and Dementia UK. For services to people with dementia and to end of life care in Wakefield, West Yorkshire.

Full New Year 2024 honours list here: <https://www.gov.uk/government/publications/new-year-honours-list-2024>

## Validation pioneer, Naomi Feil

Pioneer of the validation method for supporting people with dementia, Naomi Feil, died on Christmas Eve 2023 at the age of 91 at her home in Oregon, USA. Naomi's work continues thanks to the Validation Training Center, which she set up in 1982, now led by her daughter Vicki.

<https://www.legacy.com/us/obituaries/legacyremembers/naomi-feil-obituary?id=53938156>

## Call to share digital technology experiences

The Ageing and Dementia Research Centre at Bournemouth University are looking for care home managers, staff and volunteers to share their experiences of using digital technology to interact with people who have dementia and are living in care homes. The definition list of technology for this survey is broad and includes using tablets, smartphones, apps, Alexa, virtual reality (VR) and artificial intelligence (AI).

[https://bournemouthpsych.eu.qualtrics.com/jfe/form/SV\\_5dsIRgZVke4BSg6](https://bournemouthpsych.eu.qualtrics.com/jfe/form/SV_5dsIRgZVke4BSg6)



## Two dementia care home nurses honoured

Two nurses from a specialist dementia care home, Wren Hall in Nottinghamshire, have attended Buckingham Palace for an event held by King Charles II to recognise and celebrate the contribution of international nurses and midwives working in the UK's health and social care sector. Jincy and Rose Antony (pictured above) have worked at Wren Hall for over 20 years after arriving from India in 2003. A YouTube film showing highlights of the event is here: <https://youtu.be/Nlrax2tvYOU?si=Mez4Jt7kAGPS3ZWS>

## Professor Clare Surr to chair new NIHR Panel

Professor Claire Surr, who leads Leeds Beckett University's Centre for Dementia Research, has been chosen to chair the brand-new National Institute for Health and Care Research (NIHR) Research Programme for Social Care Funding Panel. Professor Surr said: "I'm excited to be part of this new programme and I'm looking forward to working with the NIHR on commissioning research that will make a real difference to those accessing and providing social care. The Research Programme for Social Care funding will hopefully increase the volume of social care research currently being conducted in the UK as well as growing the numbers of social care organisations that take part in and benefit from this research."


## Using AI to innovate for people with dementia

A Cambridgeshire start-up, Supersense technologies, has hit the headlines with its use of cutting-edge technology. Matt Ash, co-founder of Supersense Technologies and an electronics engineer, was inspired to begin his work for people with dementia after becoming a long-distance carer for his mum with dementia. Alongside his Supersense Technologies co-founder James Brown, Matt used Artificial Intelligence (AI) to produce a device that can monitor a home and the person living there without cameras or microphones. They believe that by installing it early in someone's life with dementia, their device can 'learn' the person's regular behaviour and alert family carers to problems or changes in patterns, while enabling the person with dementia to remain independent for longer. <https://www.bbc.co.uk/news/uk-england-cambridgeshire-67264900>

James and Matt are hoping to make the final shortlist for the Longitude Prize on Dementia (see below).

**Social care for people living with young onset dementia:**


**The DYNAMIC study**



Do you have a role in or an awareness of adult social care planning, provision, management or commissioning?  
Would you like to help to develop recommendations to improve social care for people with young onset dementia?  
**If so, please complete this short survey. Click here to access [the DYNAMIC survey](https://bradford.onlinesurveys.ac.uk/social-care-planning-and-provision-for-people-with-young-o-2)**

<https://bradford.onlinesurveys.ac.uk/social-care-planning-and-provision-for-people-with-young-o-2>

If you want to find out more before taking part or would like a paper/telephone version of the survey, please contact:  
Helen Young Email: [h\\_young@bradford.ac.uk](mailto:h_young@bradford.ac.uk); Tel: 07584 368525



DYNAMIC Work-package 2 flier v201082023

### **DYNAMIC study: social care for young onset dementia**

The DYNAMIC study aims to better understand current social care planning and provision for people with young onset dementia. They are looking for people who have a role in or an awareness of adult social care planning, provision, management or commissioning to complete a quick online survey (will take no more than 10 minutes). The information from the survey will be used to create recommendations and resources for improving social care provision for people living with young-onset dementia. <https://bradford.onlinesurveys.ac.uk/social-care-planning-and-provision-for-people-with-young-o-2>

### **Hearing tests**

Alzheimer's Research UK (ARUK) have called for more to be done to detect mid-life hearing loss. Dr Leah Mursaleen, Head of Clinical Research at ARUK, said: "Like dementia, losing your hearing is not an inevitable part of ageing and early intervention is crucial. We are urging the government to include a hearing check in the NHS Health Check for those over 40. This could help millions identify hearing issues sooner, and potentially reduce the risk of dementia." <https://www.alzheimersresearchuk.org/hearing-aids-may-prevent-or-delay-the-onset-and-progression-of-dementia-study-suggests/>

### **Thrive Winter Wellbeing Calendar launched**

Thrive, the gardening for health charity, have launched a Winter Wellbeing Calendar. The four-week calendar features a mix of practical, passive, active and creative activities. Some can be done indoors, others outdoors, most need little to no equipment, and you can take part if you have a huge garden or no garden at all. The aim is to support people to increase their time in nature and enjoy the well-known benefits of this. <https://www.thrive.org.uk/get-gardening/winter-wellbeing-calendar>

### **App launched to help detect UTIs**

Newfoundland Diagnostics have collaborated with the Rightdose Self-Test and Treat App to provide an at-home test and treat service for those who test positive for urinary tract infections (UTIs). The process for patients involves ordering a UTI test, then using the QR code on the box to download and register with the Rightdose Test and Treat App. Patients perform the test, verify the results and, if positive, update the App, select medication and pay, with

medication expected to arrive to the person's door in 24 hours. This service, in addition to what GP surgeries and high street pharmacies offer, is designed to alleviate pressure on the NHS <https://www.rightdose.co.uk/medications/uti-self-test-and-treat-kit/> (cost from £15).

### **Music Can is launched**

Music Can is a new, inclusive digital platform, spearheaded by Universal Music UK, that is designed to empower families, caregivers and musicians to integrate music as a fundamental part of dementia care. It includes a directory of support, playlists, music activities and advice and is a joint endeavour by the music industry, technology providers and cross-sector groups. Grace Meadows from Music Can said: "The Power of Music report <https://exxfmt5ydc6.exactdn.com/wp-content/uploads/2022/04/Power-of-Music-Report-Final-Pages.pdf> called for a re-imagining of health and social care. Music Can is part of how we do that and help provide more personalised, meaningful care for those living with long term conditions, such as dementia, to lead the best possible quality of life." Find out more here: <https://www.musiccan.co.uk>

### **Skills for Care strategy expert groups**

People living with dementia and carers who are drawing on social care support or thinking about it, and who would be interested in informing the work of Skills for Care as they lead the development of a workforce strategy for adult social care in England, are being sought to form expert groups. The strategy will identify the adult social care workforce needs over the next 15 years and set out a plan for ensuring the sector has enough of the right people with the right skills. Find out more via Innovations in Dementia: <https://www.dementiavoices.org.uk/deep-groups-news/skills-for-care-want-to-know-what-people-living-with-dementia-want-from-social-care-over-the-next-15-years/> or contacting Jane Brightman directly: [jane.brightman@skillsforcare.org.uk](mailto:jane.brightman@skillsforcare.org.uk)

### **VR technology for care home residents**

Alzheimer's Society's Accelerator Programme, that supports dementia innovation, has been hailing the success of Recreo VR.

Recreo's virtual reality headsets are being used in care homes to enable residents to experience environments that reflect their own personal histories, hobbies they've enjoyed and topics of interest from the past. Founders of Recreo VR, Sam and Alex, were inspired to create their product after seeing the transformation a journey to a beach had on Sam's grandmother towards the end of her life. Joyce, who lived with dementia and had struggled with verbal communication for a long time, began to smile and engage in conversation during the trip. Sam and Alex have aimed to replicate Joyce's experience on that beach using VR technology. Details at: <https://www.recreovr.co.uk>

Find out more about Alzheimer's Society's Accelerator Programme partners, including how they've worked with Recreo VR, here: <https://www.alzheimers.org.uk/blog/innovative-products-support-people-affected-dementia>



**Nellsar Care Homes, which operates 13 homes across Kent, Surrey and Essex, has trained 40 members of staff to effectively deliver a Namaste Care Programme (pictured left)**

### **Social care workforce**

The Department of Health and Social Care (DHSC) has announced plans to provide new accredited qualifications, digital training and funded apprenticeships to support careers in social care under the umbrella of a new Care Workforce Pathway. Alongside this, the DHSC has also relaunched its 'Made with Care' recruitment campaign for social care.  
<https://www.gov.uk/government/news/government-sets-out-plans-to-develop-the-domestic-care-workforce>

### **New report on Memory Services from MSNAP**

The Royal College of Psychiatrists Memory Services National Accreditation Programme (MSNAP) have published their 2023 report which highlights data they've collected from memory clinics who are current members MSNAP. The report includes both quantitative and thematic analysis, noting that the number of new admissions taken on by memory clinics per week has risen by 130% since 2009.  
[https://www.repsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-national-report-\(2023\)2400cc4f-9e00-46ee-a132-5e834740f770.pdf](https://www.repsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-national-report-(2023)2400cc4f-9e00-46ee-a132-5e834740f770.pdf)

### **'Invisible' – report into carers' experiences**

Dementia Carers Count have published a stark report about dementia carers' experiences based on responses to a survey of 1,314 dementia carers aged over 18 from across the UK undertaken between June and September 2023. The report details many findings, including that 9 in 10 dementia carers are reaching crisis points. Frances Lawrence, CEO Dementia Carers Count said: "Dementia carers are in desperate need of emotional and practical support to help them cope with the complexities of caring for someone living with dementia. However, carers have told us that they feel "invisible" to health and social care services and like they "don't matter". Only a quarter of dementia carers say that they have been able to access support when they have needed it and almost half have struggled to get advice from their local authority about how to pay for and organise any support."  
<https://dementiacarers.org.uk/wp-content/uploads/2022/05/Invisible-2023-Report.pdf>

### **Guidance for care environment**

The Dementia Services Development Centre (DSDC) has published a blog exploring the topic of Trompe l'oeil (French for 'deceive the eye'). This is an artistic term, often associated with painting, that tricks the viewer into perceiving painted objects or spaces as real.

DSDC highlights this technique as inappropriate within care home environments for people with dementia. Read the full blog here: <https://www.dementia.stir.ac.uk/newsblog/trompe-loeil>

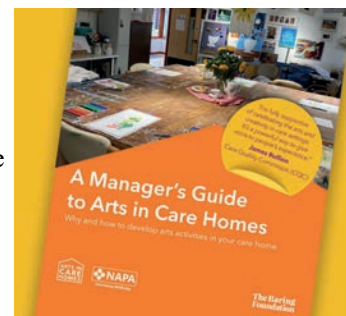
### **Longitude Prize on Dementia partners with the Social Tech Trust**

The Longitude Prize on Dementia, which is driving the creation of personalised, technology-based tools co-created with people living with dementia, has announced a partnership with social innovation charity Social Tech Trust. This partnership will support The Longitude Prize on Dementia by enabling their 24 International Discovery Award Teams to develop working prototypes of new assistive technologies to help people living with dementia remain independent for longer.

The Longitude Prize on Dementia has been running since September 2022. The next phase will be the announcement of five finalists in 2024, with the overall winner announced in February 2026. The winner will receive a grant of 1,000,000.  
<https://dementia.longitudeprize.org/news/longitude-prize-on-dementia-partners-with-social-tech-trust/>

### **A Manager's Guide to Arts in Care Homes**

NAPA (National Activity Providers Association) has created a user-friendly guide to help care home managers develop exciting person-centred arts offers involving all their staff teams, artists and the local community.



See article on p13 of this issue, and access the guide here: <https://artsincarehomes.org.uk/2023/11/20/a-managers-guide-to-arts-in-care-homes/>

### **Guidance on management of diabetes and dementia**

New guidance has been published by Trend Diabetes on the practical management of diabetes and dementia. It includes a series of recommendations to promote a consistent, high-quality approach towards caring for people with both conditions. Trend Diabetes plans to release a podcast episode dedicated to the guideline.  
[https://trenddiabetes.online/wp-content/uploads/2023/11/HCP\\_Dementia\\_TREND\\_2023\\_FINAL.pdf](https://trenddiabetes.online/wp-content/uploads/2023/11/HCP_Dementia_TREND_2023_FINAL.pdf)

### **NHS preparations for new treatments**

Ann Jarvis, the Programme Director for NHS England's 'Alzheimer's Disease Modifying Treatments programme', has been sharing how the UK health service is preparing for the roll out of two potential new treatments for Alzheimer's disease (for which the manufacturers are seeking regulatory approval). She describes planning to secure additional diagnostic resources, work on strengthening workforce capacity and the need to raise awareness of symptoms as the proposed treatments are best suited to people in the early stages.  
<https://www.england.nhs.uk/blog/preparing-for-a-new-chapter-disease-modifying-treatments-for-early-alzheimers-disease/>



### **‘This is our dementia – seven dementia stories’**

Alzheimer’s Society have released a new film where carers and people living with dementia - Beverly, Mark, Eugenie, Alma, Trevor, Liz and Errol - share their experiences of daily life with dementia. The film has been made to highlight that, unless you have dementia yourself or care for someone that does, it can be difficult to understand what the reality of day-to-day life is like. To watch the film, and find out more from the participants, go to: <https://www.alzheimers.org.uk/blog/this-is-our-dementia>

### **Dementia Commission 2023 report published**

The Dementia Commission’s 2023 report has been published. The report is the result of a collaboration between a panel of commissioners with a specialism in neurodegeneration and a research team from Curia. Together they examined case studies on neurodegenerative conditions and examples of best practice found through a series of inquiry sessions. The report looks at prevalence, future technologies, population health and engagement, and patients, carers and service design.

<https://chamberuk.com/wp-content/uploads/2023/12/231127-Dementia-Commission-Report->

### **Creative Health Review Report**

The National Centre for Creative Health (NCCH) and the All-Party Parliamentary Group on Arts, Health and Wellbeing (APPG AHW) have launched the Creative Health Review Report. The review highlights the potential for creative health to help tackle issues in health and social care, including health inequalities and the additional challenges faced following Covid-19. The review has gathered evidence that shows the benefits of creative health in relation to major current challenges, and examples of where this is already working in practice. It says:

“There is a very strong body of evidence detailing the benefits of creative health for people living with dementia, and in preventing cognitive decline.”

Dementia is mentioned throughout the report, and extensively on pages 76-77. Details including case studies here: <https://ncch.org.uk/creative-health-review>

### **Lewy Body Society new website and ‘Living with Lewy’ podcast**

The Lewy Body Society have launched a new website and podcast to help communicate more clearly about the condition with people who are living with dementia, their families and carers, researchers and health and care professionals. The website is at <https://www.lewybody.org>, and the podcast ‘Living with Lewy’ (Parts 1 and 2) here: <https://www.lewybody.org/information-and-support/podcast/>

### **NAPA launches Dementia Strategy**

The National Activity Providers Association (NAPA) has launched its new Dementia Strategy, intended to be a blueprint for activity provision. NAPA want to enable people living with dementia to experience support, understanding and joy through their key focus areas:

**Empowering** activity providers with the necessary knowledge and skills required to adapt activity programmes for individuals affected by dementia.

**Elevating** awareness and understanding of dementia for



### **Painting project**

Angela Thorn, a healthcare assistant at Colten Care’s Fernhill, has engaged nine residents on what she plans to be the first in a series of creative works (above). Starting with a blank canvas and using brushes, sponges and acrylic paint, Angela led the group through the production of a giant landscape scene featuring a woodland walk, river and mountains. Angela said: “We started with the canvas flat on a table and four people working on it at the same time. I brought in some leaves and pieces of bark so the residents could see and touch them and have a sense of being outdoors. I made a background wash and then we built up the layers of paint, the contrasts in the sky and on the ground, the perspective and the shapes of features. I showed them various techniques in how to paint bark and leaves with sponges. It was lovely to step back and watch them begin to dab on their first touches of paint and take it from there in the directions they wanted.”

more inclusive activity and engagement.

**Embracing** innovative approaches to enhance quality of life for individuals living with dementia.

**Enabling** a supportive network that promotes connection, empathy and shared experiences.

<https://digital.napa-activities.co.uk/view/264524976/>

### **Enabling Research in Care Homes**

ENRICH (Enabling Research in Care Homes) is a resource developed by the National Institute for Health Research (NIHR) including CRED talks to participate in at the time or view afterwards, as at the link below for a session on mouth care and health:

<https://www.arc-wx.nihr.ac.uk/event-details/cred-talk-knowing-how-to-support-mouth-care-and-health-for-older-people-living-in-care-homes>

### **NAPA – New toolkit resources**

The National Activity Providers Association (NAPA) have launched two comprehensive, free toolkits aimed at supporting activity providers and friends and family to provide meaningful visits. These toolkits, supported by the National Lottery Community Fund, have been created from

the collaborative efforts of activity providers, social care leaders, family members, and individuals with lived experience.

The Activity Providers Toolkit offers tailored guidance and engaging activity ideas specifically designed for Activity Providers operating in care homes.

<https://digital.napa-activities.co.uk/view/10457780/>

The Friends and Family Toolkit provides support to enrich visits for friends and family members in care homes.

<https://digital.napa-activities.co.uk/view/9974620/>

### **New guidance for care homes on alcohol management**

A new guide has been created for care homes on alcohol management by the University of Bedfordshire in collaboration with the Care Quality Commission (CQC). This guide aims to help care staff deliver a high standard of care in relation to alcohol, and is based on the findings of a research study which gathered the views and experiences of care staff, people living in care homes, their families and CQC inspectors. It takes account of legislation, standards for care set out by CQC and codes of conduct for adult social care workers and nurses. There is a specific section relating to people with dementia and cognitive impairment. The guidance for care staff can be found here: <https://www.beds.ac.uk/iasr/about/research/smart>, plus a link to a guide for care home residents and the general public.

### **House of Lords Committee calls for healthcare reform**

A report published by the House of Lords Integration of Primary and Community Care Committee has highlighted a lack of coordination between the everyday primary and community services relied on by people using the NHS. This is leading to sub-standard care, missed opportunities for home or community-based treatments, and undue strain on hospitals. It recommends reforms to include better staff training, improved data-sharing, flexible healthcare structures and collaboration across different professions in the healthcare system. You can read the report, 'Patients at the centre: integrating primary and community care' here: <https://committees.parliament.uk/publications/42610/documents/211770/default/>

### **Grey Matter—BRACE collaboration**

A new film about dementia has premiered at London film week. Starring Stephanie Beacham as Peg, W4 Films 'Grey Matter' explores the challenges and triumphs of living with dementia and the changing relationship between a grandmother and her teenage granddaughter.

Dementia research charity, BRACE, is being supported by W4 Films <https://www.w4films.co.uk>. Director, Arabella Burfitt-Dons, says of this collaboration:

*Partnering with BRACE Dementia Research was a natural fit for the film, as we recognize the urgency of supporting research initiatives that can make a tangible impact on individuals and families affected by dementia.*

Stephanie Beacham has also lent her personal support to BRACE – Find out more here: <https://www.alzheimers-brace.org/stephanie-beacham-joins-brace/>.

Grey Matter is available to watch at various venues. The trailer is here: <https://youtu.be/FFvbIK4YWmg?si=jx8Dt2Gk174hQM9C>.



**Members of the cast and audience for a dementia-inclusive panto in Malvern, Worcestershire**

### **Dementia-inclusive panto brings festive joy**

The Coach House Theatre in Malvern have showcased a dementia-inclusive performance of their Snow White pantomime for people in the Malvern area living with dementia. The dementia-inclusive show was staged by students from Drama Studios London who are managed locally by professional director and producer, Kirsty Cubberley of The Phoenix Collective. Chris Bassett, Executive Trustee of The Coach House Theatre, explained how the performance was made inclusive for people with dementia: "The volume of music was reduced, the house lights dimmed so the auditorium still had ambient lighting, the cast were fully briefed on how some of the audience may react during the show and there were additional staff on hand to offer support if needed. This created a relaxed, friendly, comfortable and safe environment."

Shirley Bradley, Friends of the Elderly's Head of Day Care Services, supported clients who attend her Day Care alongside residents from Friends of the Elderly's Bradbury Court dementia care home and members of the Malvern Dementia Action Alliance to attend the panto. Shirley said: "The day care clients and Bradbury Court residents who attended had a wonderful time and laughed at the traditional panto gags."

You can find out more about The Coach House Theatre here: <https://www.coachhousetheatre.co.uk>

### **House of Memories App updated to include Liverpool Football Club history**

House of Memories have worked with Forever Reds and Liverpool FC Foundation to create a new app package for Liverpool Football Club fans. Through capturing the sights and sounds of iconic matches, the 'Liverpool FC Memories' package in the My House of Memories app aims to connect fans with their sporting history. The team behind the app worked with local care homes to ensure the package they've put together represents a collaboration with the wider dementia community.

Katie Ellis Carrigg, Head of Partnerships at LFC

You can find out more and download the app here: <https://www.liverpoolmuseums.org.uk/house-of-memories/my-house-of-memories-app/liverpool-football-club-memories>

# JDC Asks Challenge: Equality, Diversity and Inclusion

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

In the September/October 2023 *Journal of Dementia Care*, a special issue on Equality, Diversity and Inclusion in dementia care, we invited readers to send us examples of excellent initiatives which are helping to make dementia services more inclusive. **The invitation is still open! We know there are lots of other brilliant projects going on, and we would like to hear about them.**

Are you, as a practitioner or researcher, or the organisation you work for, making an effort to reach out and co-create

opportunities for effective support to individuals and communities who tend to be under-represented and under-served in dementia services? You might have made a small change that made a big difference, undertaken a stand-alone project, or you might have been involved in a major initiative to refocus your organisation's vision and mission. What challenges have you faced, and what have you achieved? Please write to Sue Benson at [sue@dementiapublishing.community](mailto:sue@dementiapublishing.community)

### **Dementia United, Greater Manchester Integrated Care's programme for dementia**

Amal Morsi got in touch to tell us about this service. He or his colleagues will write for JDC in future; meanwhile the service is described here:

<https://dementia-united.org.uk/active-inclusion-of-marginalised-communities/>

*A specific aim of the service and the progress made so far is set out on the website, as below:*

#### **Active inclusion of marginalised communities**

**Our aims:** To establish a network with engagement partners from across our underserved, diverse communities locally and with partners nationally. This will enable us to share best practice, resources and will support us to take forward priorities for Greater Manchester wide projects.

We'll take forward lessons learned from the Greater Manchester wide projects that are already up and running eg: Greater Manchester's LGBTQ+ Dementia Online Support group . The development of this group has been evaluated and the report contains a set of clear system wide recommendations

Our work to translate the Greater Manchester delirium leaflet into 16 languages is an example of co-development with diverse community groups and co-production with lived experience. Further aims are to:

- collate and review evidence based public facing resources and ensure that all resources are available within our Greater Manchester Dementia Care Pathway and shared widely
- scope out a model to engage with marginalised community groups and looking for opportunities where we can be harnessing Greater Manchester's partnership working across all ten localities
- scope out work taking place nationally that's looking at collecting accurate data and work with locality partners to consider if there's any learning that's useful for our work in Greater Manchester.

#### **What we've achieved so far**

We established the Dementia United's Greater Manchester LGBTQ+ online dementia support group for people affected by dementia, family members and care partners.

We also commissioned LGBT Foundation one day a week to support and promote the group and to evaluate its development. The evaluation report demonstrates that we've been able to meet our objectives in establishing the group with excellent partnership working across all ten localities.

We commissioned the African Caribbean Care Group to complete an appreciative inquiry to look at the needs of Black, African, and Caribbean communities. The appreciative inquiry highlighted the need for culturally appropriate care, training, and the importance of Ethnicity Data capture.

We commissioned the translation of the delirium public facing leaflet into 16 languages Making delirium information more accessible in Greater Manchester

The lived experience groups and networks which are at the heart of the Dementia United programme reflect some of the diverse communities across Greater Manchester. These groups ensure that we hear from people's lived experiences.

We funded partners in the Manchester locality partners to develop resources for the South Asian community in order to raise awareness.

**Martha P** emailed to say:

*I am a researcher and studying for a prof doc. To make my practice more more dementia inclusive, my prof doc research is being co-produced with a group of five people with dementia and we are investigating how to provide peer support groups to give people with dementia a voice in planning their future care.*

**Nancy**, who works in and around Lyndhurst, Hampshire as an activity provider in people's own homes, has a "passion is to help people live a fulfilled life" :

*One thing I do is help a lady who lives with dementia to cook her husband and grown-up son a meal for when they come back from bowls. She had told me she felt sad that she could no longer could do this, so I explained I could be her instruction manual and cook book combined, helping her when she got stuck and just being her back up. She cooked a lovely meal which she enjoyed with her husband and son upon their return.*

# Dementia Diaries

Many readers will be familiar with the efforts over recent years to recast dementia as a disability. One of the main drivers behind this is an attempt to establish a conversation about applying a social model of disability to dementia.

In brief, the social model of disability describes how a person is disabled, not just by any specific impairment they may have, but also by their environment.

That environment obviously includes the physical space in which we live our lives, but also the psycho-social environment, the attitudes of others, both individually, and as a culture, which shape our lives.

Listen to this diary from Keith Oliver, in which he explains the frustrations of trying to live positively with dementia against a backdrop of limitations and expectations from others:



*“What is a good role model for someone with dementia?” I ask myself. A person frail, scared, old, immobile? Is that a good role model? Something to aspire to or celebrate, or something to be fearful of? No wonder that dementia is, in so many surveys, the most feared health condition amongst the over 40s. I do wish this wasn’t the case, it need not be.*

<https://dementiadiaries.org/entry/18111/what-is-the-one-thing-i-wish-other-people-knew-about-my-experience-of-dementia-asks-keith/>

And of course, it’s not just the media that promote an image of dementia that casts people as vulnerable and dependent.

In this diary from Clive, he describes his encounter with a similarly disabling attitude from a service he was keen to be involved with:



*I said “oh, I’ll come on my own, I’m quite capable” and their response was amazing. They said “You can’t come alone, you’ve got to come with a carer”. This really annoyed me as however much I tried to tell them I was quite capable they wouldn’t listen. All I got was it’s our policy. I find that really frustrating and I was so angry.*

<https://dementiadiaries.org/entry/11869/clive-expresses-frustration-at-the-attitude-of-others-2/>

This is far from the only dementia diary in which people with dementia, describe how they have encountered assumptions that they lack capacity by definition of their diagnosis. In this diary, Dory relates an encounter which suggests a mindset that excludes people with dementia from their rights to participate at the most fundamental level.



*“Well, I thought with you having dementia, you wouldn’t be allowed to vote – because of your capacity to make that decision.” Which I replied to, “well, I wouldn’t vote for you, if it was you standing for election.”*

<https://dementiadiaries.org/entry/18801/teresa-is-slightly-gobsmacked-at-the-suggestion-that-she-shouldnt-vote-because-of-her-dementia-quite-right-too-people-with-dementia-have-every-right-to-vote/>

A lot of work has gone into changing and challenging these perceptions of dementia over the last decade, and beyond. This conversation, which includes diarists Nigel and Howard shows just how far we have come.

<https://www.youtube.com/watch?v=X0MC4TuXjfk&t=485s>

It’s also true to say that people with dementia are increasingly conscious that they DO have rights, that their diagnosis does not mean that they immediately take a back seat and become passive recipients of care and dependent upon the goodwill of others.

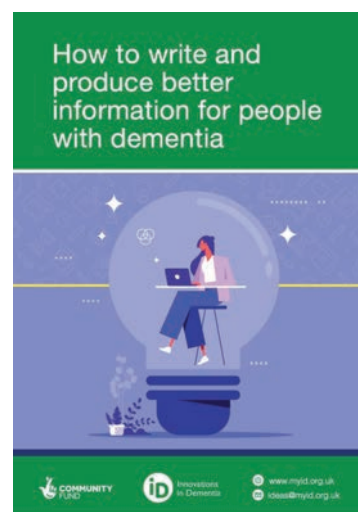
Jacqui has a very strong sense of her own rights as a disabled person, and this comes through in many of her diaries. This diary shows that in spades.



<https://dementiadiaries.org/entry/21937/clearly-written-information-is-akin-to-a-cognitive-ramp-for-people-with-dementia-and-more-people-with-dementia-like-jacqui-are-starting-to-see-the-right-to-accessible-information-as-a-right/>

It is because the provision of accessible information is so fundamental to our engagement in the world around us, that we have been working with dementia diarists and others to produce these new guidelines. We hope very much they will help those producing information to make life easier for everyone.

You can find the new guidelines here:



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

Steve Milton, director, Innovations in Dementia



Left: Appleby House (Care UK) Art Studio (photo by NAPA Arts in Care Homes). Centre and right: Oskar Design

# A manager's guide to arts in care homes

**Alison Teader** describes a new resource from NAPA, created to inform and inspire managers and activity and care teams

Throughout 2023, as programme director of the National Activity Providers Association (NAPA) Arts in Care Homes programme, I worked on a project with three care home managers who are doing interesting work involving the arts, cultural participation and creative approaches to care provision. The result of this collaboration is an innovative resource empowering care home managers in arts engagement: *A Manager's Guide to Arts in Care Homes*.

Intended as a user-friendly resource to inform and inspire managers and activity and care teams, the guide includes insights from the three registered managers – Shona Bradbury, Fatma Makalo, and Marlene Kelly, who played a pivotal role in its development. You can watch the launch event, featuring them chatting to Alison about the guide and their homes here: <https://www.youtube.com/live/P1hdzsdssXU?si=eecso7vPEYP59t7T>.

The report also features valuable insights from arts organisations including Magic Me, The Spitz and Live Music Now and experienced individuals doing related work, which further enriched the content. The resource emphasises how evidence of arts engagement can bolster the six key evidence categories for Care Quality Commission (CQC) inspections. It addresses potential barriers to developing arts in care homes and provides ideas and inspiration based on successful care home projects and activities.

Funded by The Baring Foundation, this resource was developed in response to a recommendation in the Baring Foundation's *Every Care Home a Creative Home* report (2022). The report advocates a systematic approach

*We have known for a long time that whether or not a care home resident has access to creative opportunities is entirely a lottery and therefore inequitable. A systems approach could help change this but requires the input of all stakeholders, including the regulator. We hope this new guide for managers is useful for those homes taking their first steps into developing an arts offer and supports them to demonstrate how this offer supports the quality of care they provide.*

David Cutler, Director of The Baring Foundation

*Art is not limited to paint and a brush; it involves anything creative that expresses your imagination. Our art activities provide opportunities to learn something new and encourage a sense of achievement and pride. We believe the atmosphere created by art helped us achieve an 'Outstanding' rating by CQC. Shona Bradbury, Registered Manager, Appleby House Care Home*

involving various stakeholders, aligning with residents, staff, relatives, care providers, regulators, social care and arts funders, training providers, arts organisations, and the local community.

NAPA, a membership organisation and charity, is a leader in the field of promoting the importance of meaningful activities in care homes and the need for training and support for care staff. Arts in Care Homes and the National Day of Arts in Care Homes is an initiative by NAPA and funded for five years by The Baring Foundation and The Rayne Foundation. Now in the fifth year, it acts as a central hub for delivery of arts and creative activities in care homes with sector research, user friendly resources and 'How To' guides for care staff.

NAPA will be announcing plans for the next stage of Arts in Care Homes, including the campaign for The National Day of Arts in Care Homes 2024 soon. Sign up to NAPA's weekly E-Newsletter and look out for social media updates. Download a copy of 'A Manager's Guide to Arts in Care Homes' and a summary version here:

<https://artsincarehomes.org.uk/2023/11/20/a-managers-guide-to-arts-in-care-homes/>

NAPA website: [www.napa-activities.co.uk](http://www.napa-activities.co.uk)

Arts in Care Homes website:

[www.artsincarehomes.org.uk](http://www.artsincarehomes.org.uk)

*At NAPA, we believe in creating environments that celebrate creativity, enhance wellbeing, and elevate the quality of care provided. This resource is a testament to the importance of meaningful creative activities in care homes and the invaluable contributions of dedicated care and activity teams."*

Hilary Woodhead, Executive Director NAPA

# Reducing fire risks in vulnerable groups: a partnership approach

**Emma Murdoch** and **Matthew Height** describe a successful project to equip health and social care staff with skills and confidence to include fire risk in their assessments, and promote partnership with fire and rescue services

With the general population of the UK overall living longer, the number of people diagnosed with dementia is expected to exceed 1 million by 2030. Statistics from Alzheimer's Research UK suggest that the Cardiff and Vale of Glamorgan region has one of the highest prevalences of people with a known diagnosis within one geographical area. In 2021, this number was estimated to be between 3.2 and 4.3k.

Health and social care agencies aim to support people to stay in their preferred place of residence for as long as possible; this may be the person's own home or the home of an unpaid carer. Although dementia presents challenges for the person, their families and support networks and services, people living with dementia do function better in their own home environment, where familiarity and routine can reduce the impact of the disease and reduce stress and distress. However, as the disease progresses, risk factors can increase.

## Significant risk of fire

One significant risk factor that may well be overlooked is that of fire. Although most households in the UK have smoke alarms, these may not be in full working order, and the person with dementia may not know what to do in the event of a fire emergency.

Over the past 20 years fire services have invested in fire prevention, resulting in a sizable decrease in accidental dwelling fires (ADFs). However, ADFs still occur, causing psychological and physical trauma, loss of home and contents, financial and social problems. In other words, it is a life changing event.

Data from South Wales Fire and Rescue Service shows that older people living alone are at high risk. Although the number of deaths from these fires is low, most are avoidable, so prevention is important. South Wales Fire and Rescue Service (SWFRS) completes approximately 12,000 Home Fire Safety Checks yearly, relying heavily on health and social care agencies to refer high risk households. In our view, fire risk should be an integral part of these agencies' assessment of a person's circumstances and level of function in the home environment.

*Matthew Height is a Highly Specialised Occupational Therapist, South Wales Fire and Rescue Service. Emma Murdoch is a Registered Mental Health Nurse, PGCert Health Education, Cardiff and the Vale Regional Partnership Board, Dementia Learning and Development Team Lead.*

## Key points

- People with dementia are living longer in their own homes, many alone, and they can be at high risk of house fires.
- Fire risk should be an integral part of health and social care agencies' assessment of a person's circumstances and level of function in the home environment.
- Our project to raise awareness of our services has been widely welcomed and led to 100% increase in referrals from the health board in the first six months.
- Promoting fire safety should be everybody's business. Everyone needs to be aware of fire risks, and to know where and how to access specialist support.

The Fire and Rescue Service Act (2004) emphasised a statutory duty to prevent fires and resulting death or injury. *Good Work: a Dementia Learning Framework for Wales* (Social Care Wales 2016) identifies a collection of learning outcomes that highlight the need to provide early support and access to services for both people with dementia and unpaid carers. In 2022, Wales introduced the Dementia Care Pathway of Standards to ensure equitable and accessible services for people diagnosed with dementia. There is a strong rationale for teams that support



'How safe is your home' leaflets in both Welsh and English

people living with dementia to incorporate fire risk as standard procedure during assessments. There is a clear necessity to promote effective partnerships and referral pathways enabled by well-informed, confident staff.

### Collaborative project

With this vision SWFRS, in collaboration with Cardiff and Vale University Health Board, Dementia Learning and Development Team, embarked on a project aimed at raising awareness of potential fire risks to vulnerable people and supporting the integration of fire risks into holistic person and situation assessment of people living with dementia in their homes.

*The learning objectives of the sessions were:*

- To enable participants to identify common causes of accidental dwelling fires ▷
- To raise awareness of potential interventions to mitigate fire risk in people’s homes
- To raise awareness of referral pathways to SWFRS for home safety checks and high-risk groups.

*Aims of the sessions*

Reduce fire deaths, injuries and hospital admissions.

### Work undertaken

A PDSA (Plan, Do, Study, Act) improvement model was engaged to provide the health and social care workforce with interactive awareness training that explored risk profiles, and the person-centred approach of a Home Fire Safety Check .

We provided information leading to greater understanding of the range of ‘fire’ interventions that can be offered, such as fire-retardant bedding, hard of hearing smoke alarms and electrical safety.

A partnership referral pathway, that supports people living with dementia to maintain independence and well-being, was promoted throughout.

Since beginning the project in January 2023, several face-to-face training sessions have been delivered to staff who routinely support people with dementia across the regional partnership board.

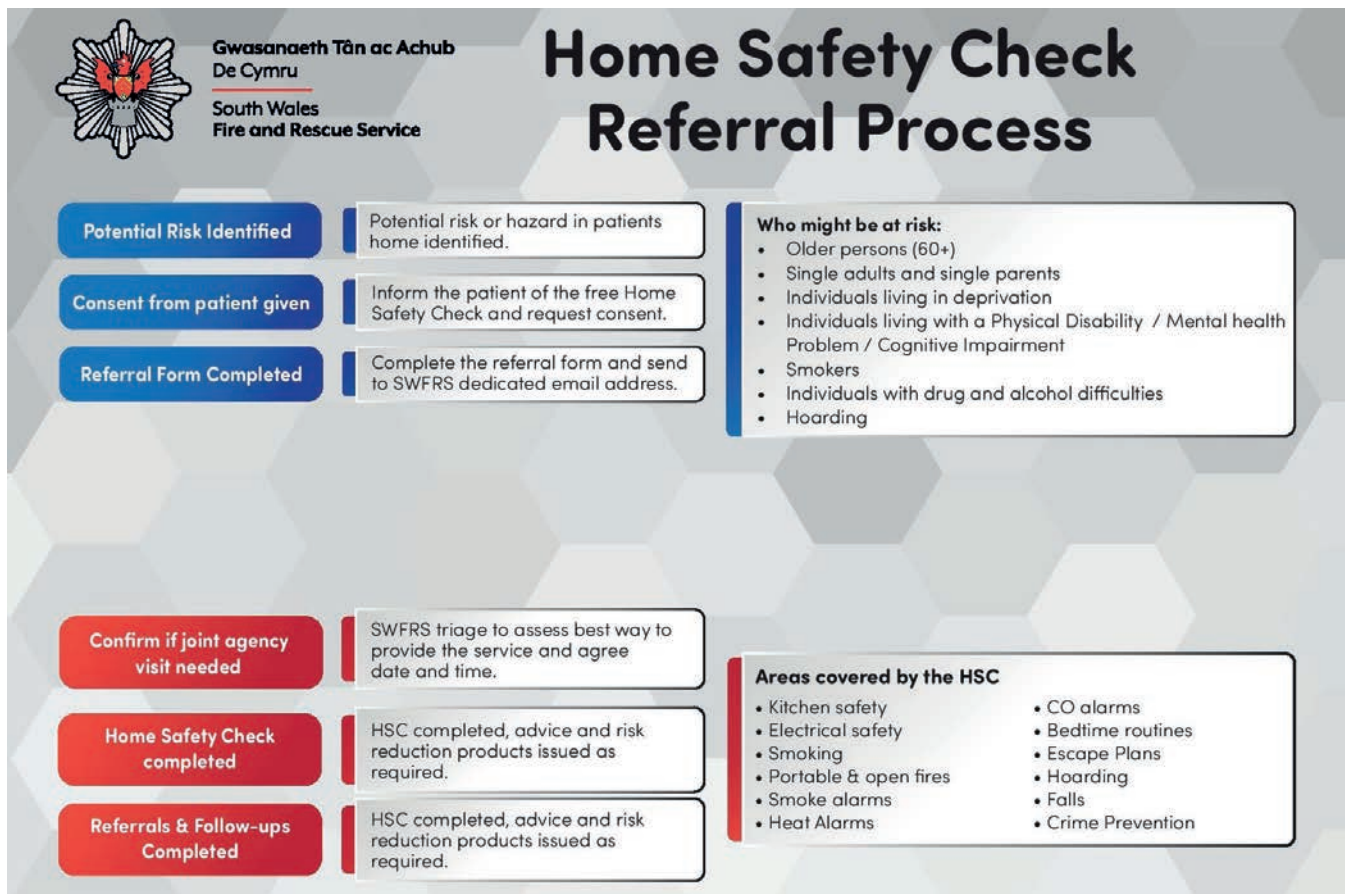
Of the sessions that have been delivered, attendance data currently shows that 89% of staff who attended were from the NHS and 11% were from local authority (social care). The majority of the workforce were clinical staff with direct person contact; other staff who attended had non-clinical (administration) and managerial roles.

Staff were asked to complete pre-training session self-assessments; this was to identify their current practice and measure their awareness of partnership agencies that provide specific support and intervention around reducing fire risk, such as SWFRS home safety checks.

Noticeably, pre-session assessment of those attending the training demonstrated that attendees had either never referred into SWFRS or that referral into SWFRS was not part of their current practice when assessing a person on admission or in readiness for discharge from hospital. Almost all staff were not aware of the full extent of the interventions that are available to support fire risk support and management.

### Implications for practice:

Results so far have justified the benefits of contextual Fire Awareness Training to the extent that it has changed clinical practice, promoted positive risk taking and systemic working that reduces risks in homes. Following training, 89% of staff who attended have either considered or completed referral to SWFRS and 100% of people who attended shared the training information and referral



process with other team members and wider services.

**One significant outcome of the project has been to support memory assessment services (MAS) to review and adapt their six-month patient review paperwork to include consideration of potential fire risk and provide signposting to SWFRS when necessary.**

Significantly, early indications from SWFRS data highlight a 100% increase in referrals from the health board during the first six months of the project.

### Future plans

Following review of the initial outcome of the training, our ambition is to expand the offering out to social care staff, particularly those who work in domiciliary care.

The review also raised the question of how we could improve fire data collection—capturing relatable ‘fire and dementia’ risks and incidents to inform future work.

We are exploring how we can embrace smart technology for potential solutions to notifying emergency services, as

not everybody living with dementia will be able to respond safely or perceive the audio alarm from a smoke detector as a warning or threat of fire.

The aim will continue to be to ensure health and social care staff have access to evidence-based training that embeds a partnership approach to fire management, enabling people to stay in their own homes. There is an evident need to enhance models of best practice to include fire risk awareness as part of routine home assessments and risk assessments. This is particularly important for those who live alone and have a diagnosis of dementia. Promoting fire safety should be everybody’s business. Everyone needs to be aware of fire risks, and to know where and how to access specialist support.

Social care Wales (2016) [Good Work: a Dementia Learning Framework for Wales](https://socialcare.wales/cms-assets/documents/Good-Work-Dementia-Learning-And-Development-Framework.pdf). Care Council for Wales. Link - <https://socialcare.wales/cms-assets/documents/Good-Work-Dementia-Learning-And-Development-Framework.pdf>

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# Dementia care in mixed ethnicity families

A fast-growing minority community in the UK is that of mixed ethnicity families, leading to more and more partners or younger family members caring for relatives whose culture and language they largely do not understand. **Mary Tilki** and **Mohammed Rauf** highlight the issues and consider our current knowledge about family care for people with dementia from minority ethnic groups

There is growing evidence that the numbers of people with dementia from minority ethnic communities in the UK is increasing and will continue to do so (APPG 2013). We know that minority communities are less knowledgeable about dementia, seek help later (often in crisis) and are less likely to be offered external help (Parveen & Oyebo 2018, REF 2022, APPG 2013). While awareness of this pattern is improving, there is another group that receives little or no mention. Recent census data demonstrates that the fastest growing ethnicity group in the UK are those who identify with the mixed or multiple ethnic group category. For simplicity, this article will use the term mixed ethnicity families.

Although the profile of this group is younger, their parents (and possibly grandparents) from different ethnic backgrounds belong in the older age groups. Our concern was driven initially by work with the Irish community in Britain, where in past decades women married men from many different parts of the world. They are now growing older and are caring for partners with dementia whose culture and language they largely do not understand. This is not unique to the Irish community and the children of mixed ethnicity partnerships or second-generation cultures are likely to find themselves in a similar situation.

This paper aims to raise awareness of the issue, encourage debate and consider what can be learned from

what we already know about family care for people with dementia from minority ethnic groups. We want professionals to understand the complexities of family care and the conflicting expectations families can be faced with. The article poses more questions than answers and explores some of the difficulties which may be experienced with a view to helping family carers anticipate and prepare for their caring roles. Without reinventing the wheel, it may be possible to highlight sources of information and support and navigate services which are sensitive to people from ethnically diverse cultures.

Aside from ageing, people from Asian, Caribbean, African and Irish communities in Britain carry additional risks for dementia. There is also evidence that the numbers of people in minority ethnic groups with Young Onset Dementia (under 65) are growing (Dementia UK, undated). We know that minority ethnic families either do not know about or choose not to access external help until later in the illness or in a crisis (NHS/Alzheimer Europe 2022). While this may reflect lack of knowledge, it may also be out of respect for the person with dementia, reluctance to disrespect their wishes or to challenge family hierarchies. ▷

*Dr Mary Tilki is Patron, Irish in Britain, Cuimhne Memory Loss Alliance. Dr Mohammed A Rauf MBE is founder and director of Meri Yaadain CIC, Bradford UK*





**Ann from Ireland and Gautam from India tell their story “The Colour of Love” as part of Irish in Britain’s Cuimhne Carers, Thoughtful Thursday dementia resources series. Ann and Gautam are also Cuimhne volunteers.**

▷ Families newly faced with dementia may not understand what is causing changes in their loved one’s personality, memory or behaviour. In particular, those caring for somebody from a different culture are unable to understand changes which reflect the person’s earlier life and experiences. Parents may never have spoken about the pain of leaving home or the abuse and hostility experienced in the new country, especially in a mixed cultural relationship. Carers may have limited understanding of customs which might explain “unusual” behaviour or experiences which reflect past hostilities or traumas.

People with dementia often have problems with communication. However, loss of the second (acquired) language is a known feature of dementia, and family carers may not understand the language their loved one reverts to. This may be subtle at first but becomes frustrating for both parties when the person with dementia only communicates in their mother tongue. Some elders, particularly women, may never have become proficient in the second language. For socio-economic reasons, migrants were forced to work in particular sections of the economy, often with people from their homeland, and they therefore had few opportunities to learn or improve English. While every effort was made to use family language in the home, this was difficult particularly if the mother did not speak the same language. Even where both parents spoke the mother tongue, once children started school, they were under pressure to speak English. Although some families attended Saturday classes to learn the parental language and culture, many still feel ill-equipped and lacking in confidence. Many families could not afford holidays in the homeland which would have helped improve language skills and cultural understanding as well as opportunities for conversation, comfort or reminiscence later.

Changes in behaviour in dementia can often be explained by habits, customs and mores from an earlier period in life. These may be unknown to partners or family carers. For

## Key points

- As the number of people of mixed ethnicity grow in Britain, the numbers of families caring for a loved one with dementia from another culture will also increase.
- People with dementia often lose the ability to communicate in their second, acquired language, making communication and care difficult for family carers who don’t speak the same language.
- Carers may not understand the experiences and cultural customs which can explain changes in memory or behaviour in their loved one and they can struggle to provide quality care
- The lack of cultural knowledge and/or language precludes opportunities for reminiscence, comfort or enjoyment as well as ways of reducing or coping with “unusual” behaviour
- Different beliefs about dementia, attitudes to external help and traditional family roles impact on carers, causing lateness or failure to access support and professional services, potentially damaging the health of family carers and/or the person with dementia

example, carers may not understand why the person who has always eaten and enjoyed western food refuses to eat the same food as the family or begins to eat with their fingers. They may not understand religious rules about using the left or right hand which have suddenly become more important to an elder. Family carers may be confused by a parent who becomes more religious. Personal care for a spouse or parent is invariably difficult and embarrassing, but carers from a different culture may not appreciate religious washing and toilet rituals, which were previously a private matter for the individual. Carers can have additional problems with skin and hair care, clothing or head coverings which were always a personal matter.

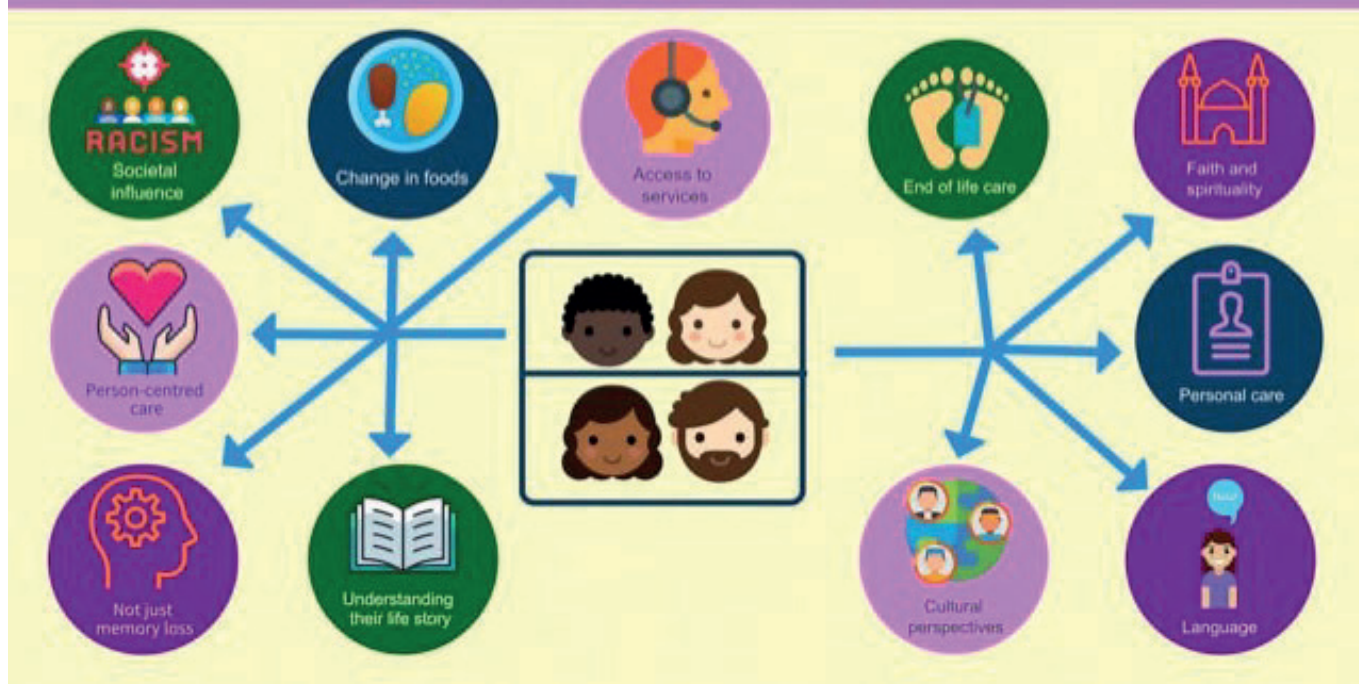
### The wider family

Apart from the day-to-day care, family carers have to deal with the beliefs and values of the wider family. There may be reluctance from relatives on either side to accept that there is a problem, believing that memory loss or behavioural changes are just signs of old age. Beliefs about mental illness and stigma may prevent or delay worn out carers from getting help. Some families may see symptoms of dementia as a result of mental illness, spirit possession, a test of faith or punishment from a higher being and as such, something to be tolerated or about which nothing can be done (Regan 2013). Even when they are sceptical about differing beliefs, the younger generation may be reluctant to challenge family hierarchy or upset the older generation.

Negotiating the health and care system is a minefield for any family affected by dementia. However, minority ethnic families in particular may feel that the changes in their loved one cannot be helped by doctors or other professionals. Some will be reluctant to ‘waste’ the

# Mixed ethnicity families and caring for dementia

## Factors to take into consideration



doctor's time while others believe they will be dismissed, rushed, prescribed medication or institutionalised. ▷

▷ Additionally, minority ethnic families (among others) often have a fear of social services while their elders in particular worry about being “put away” in a care home.

There are differing views on duty and responsibility and minority ethnic groups have high expectations of wives, daughters and daughters-in-law. There is evidence that families from minority ethnic groups feel culturally more obliged to care for elderly relatives and therefore they are less likely to be offered services (Parveen & Oyebode 2018). The idea of a large supportive extended family can be a myth at the best of times but especially if either wider family is reluctant to support the person who has “married out” or who is still seen as an outsider. In addition, traditional expectations of family support and negative discourse around benefits, can make seeking external help or claiming entitlements difficult. However, lack of awareness or other reasons for reluctance to seek external help may conflict with the best interests of the person with dementia or the carer. Asking for help in the home or residential care is fraught with anxiety and guilt for all families but the expectation of care and support “from the cradle to the grave” may make it easier for UK families to seek help and claim entitlements.

The authors recognise that while the experience of every family caring for a loved one with dementia is unique, some difficulties are common to all families. We are cognisant of the heterogeneity within any ethnic, faith or linguistic group but acknowledge the additional problems faced by minority ethnic communities when caring for a loved one with dementia. However with growing numbers of mixed ethnicity families, there is a need to consider

carers who lack the language and cultural knowledge to optimise the quality of life of the one they care for. There is clearly a need for research to hear the voices of mixed families, but meanwhile we must try to prepare them for the issues they may face. There is a particular need to reach out to carers who feel that either mainstream or a culturally specific service is not for them and they have to go it alone. While we need to know more, it is highly probable that existing cultural information and resources will be helpful to mixed ethnic family carers if tweaked or tailored to meet individual family needs. Meanwhile it is important to keep the needs of mixed ethnicity families and the people they care for on the agenda.

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# Sailing into uncharted waters

## The story behind Admiral Nursing

In this beautifully produced book, Jane Jason tells the story of Admiral Nursing and what is now Dementia UK. It is a personal story and also the story of a changing world and changing attitudes to dementia over those years, taking us back through what were also the early years of the Journal of Dementia Care and the UK Dementia Congress.

What was to be a long, eventful journey began when Jane's father Joseph Levy (Joe) developed dementia from the late 1970s onwards. The family found there was very little support or even information to help his wife (Jane's mother) Ninot. Stigma and negativity were widespread; Jane was furious when her parents' GP bluntly informed Ninot that nothing could be done. She recommended her own GP, Stuart Sanders, who gave kind and patient support, and referred her father to Dr Monica Greenwood, consultant psychiatrist at the Middlesex Hospital, London and a great force for positive change in old age services at the time. Through Monica they then met Margaret Butterworth, another remarkable figure determined to improve services and the lives of all affected by dementia. Margaret formed the active carer support group CRAC Dementia; both she and Monica were founder trustees and solid supporters as the charity Dementia Relief Trust was conceived and began to take shape. Everyone involved felt strongly that the greatest need was for information and support for family carers, and that this focus would lead to better health and quality of life for the person living with dementia too.

At the time, and over the following years as the concept of Admiral Nurses developed, this focus was challenged, as was the belief – strongly supported by the family carers involved - that this specialist role required the solid grounding of a professional nursing qualification as well as expert knowledge and experience of dementia care. Jane also remembers the cool reception other organisations gave to a new dementia charity, something she had not anticipated. Thankfully, she and the board pressed on, and have been rewarded in the high standing and influence of Dementia UK and its Admiral Nurses today.

Backing for the charity came from the Joseph Levy Foundation, a charitable trust set up by Jane's father some years before. The name Admiral Nurse came from Joe's nickname 'the Admiral' (he was a keen sailor).

Among the engaging personal stories in the book is that of the very first Admiral Nurse, Mark Lawton. He was the only one of two appointees who turned up on the first day (the post, being a three-year pilot project, was a career risk that deterred many). From the Derbyshire dales, Mark was excited to be in London and persevered despite having to improvise desk space in a storeroom, with no phone... (in 1990, before mobile phones). The story also includes the setting up of the first multi-disciplinary course on



**Above left: Jane Jason's parents Ninot and Joe at Buckingham Palace, where Joe was awarded a CBE. Above right: 'Time for a cuppa', launched in 2010, became a regular fund-raising event**

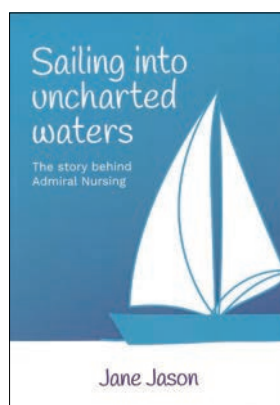
dementing illnesses ENB N11 with input from family carers. Course tutor was Ron Isaacs, an early contributor to *JDC*, and Admiral Nurse Dave Bell one of the first students. The English National Board (ENB) has since been disbanded, and dementia care is still not a mandatory part of nurse training today – something that urgently needs to change, as Paul Edwards, Dementia UK's director of clinical services, stressed when speaking at last year's UKDC.

Barbara Stephens became chief executive in 1999 and led the charity through years of growth, many memorable fundraising events, the launch of Admiral Nursing Direct and two rebrands - to *for dementia* then Dementia UK. She stood down from the role in 2013, when the board decided to align the charity exclusively with Admiral Nurses, feeling that the helm should be taken by an effective nurse leader. Hilda Hayo was appointed and remains in that role today.

Just about all Admiral Nurses past and present are featured in the book, adding their memories and thoughts on what makes the role so special and valuable. It is a lovely record of a fascinating story and great achievement.

*Sue Benson*

On page 20 of this issue, Jane Jason describes how this book, *Sailing into Uncharted Waters, the Story behind*



*Admiral Nursing* came to be written. More details can be found on Jane Jason's Honorary President's page on the Dementia UK website

[www.dementiauk.org](http://www.dementiauk.org) The book is currently being distributed through the Joseph Levy Foundation. Please send details of your postal address to [info@jlf.org.uk](mailto:info@jlf.org.uk). A suggested donation of £10 to Dementia UK is requested.

# Milestones, achievements and a strong ‘family’ bond

Researching *Sailing into uncharted waters: The story behind Admiral Nursing* was an emotional and rewarding journey, as its author **Jane Jason** relates

The idea of writing a book evolved from a suggestion made to me some time ago that I should record my story and the early development of the charity that is now Dementia UK. I was being interviewed by a member of the charity’s fundraising team for the tenth anniversary of the charity’s now annual fundraising event ‘Time for a Cuppa’, which I launched back in 2010. The young person questioning me knew little about the background of the charity and suggested very sincerely that it might be helpful if I would record my memories. I thought about it for some time, beginning early planning in the summer of 2019. By the time I got started in earnest in early 2020, the country was shortly to head into lockdown. Each interview seemed to lead to yet another, hence the length of time it took to complete the story.

Initially I had thought to merely record some of the key dates and events so that there would be an accurate table of events for the future. It was never envisaged to be an official record of the charity’s history, just my own personal recollections. After I had drawn up a list of people to interview from the most formative years of the charity, it soon became evident that the strict restrictions imposed on us all meant most were unusually available and willing to speak at length. It was an informative, yet emotional journey, talking to old friends, reliving so many of the charity’s important events and milestones.

Detailed research was time consuming as there were no digital records available from those early years. Many hours were spent trawling through old emails and checking committee minutes to retrieve valuable evidence as I was determined anything recorded in the book must be accurate. Barbara Stephens, the charity’s former CEO and Hilary Leslie, who worked with me to launch the charity in 1995, were an invaluable information resource; original articles and other memorabilia collected from Admiral Nurses helped piece more of the jigsaw together. I was unable to hide myself away in an isolated cottage in the country like some authors, although I can now see the benefit of doing this, but time was spent with ex-CEO Barbara Stephens recalling, in detail, many of the events which had taken place over the 14 years we worked together.

The book correctly acknowledges some of the genuine unsung heroes of the original project, without whom Admiral Nurses would not exist today. Many of these were family carers who recognised it was time for change and



were prepared to meet the challenge; others were the original Admiral Nurses, those intrepid pioneers who never gave up, in spite of the opposition faced during the early development of Admiral Nursing. We were regularly questioned about the speed of the service’s growth, so I felt justified in explaining the importance of maintaining standards to retain the quality of support provided.

I wanted to illustrate that despite the many challenges encountered there were also many good times. Admiral Nurses

formed a united bond which in turn led to the creation of today’s unique ‘Admiral Nurse Family’. As I interviewed individual nurses it very soon became clear how much each of them valued their role. Many, now retired from the NHS, still work part time on Dementia UK’s Admiral Nurse dementia helpline where families receive support and advice from these highly experienced and professionally qualified nurses. I am humbled when they thank me, telling me how privileged they feel to have been offered the the role they love.

Among the charity milestones mentioned in the book are many successful fundraising events often attended by our loyal celebrity and medical patrons. Their support was truly invaluable, particularly when over time some felt able to share their personal experiences of dementia. People really began to listen. Probably the most challenging but one of the most memorable was George Melly’s last concert, held in June 2007 at the famous 100 Club in Oxford Street, arranged with the support of his wife Diana, who later became a patron of the charity. Not everyone managed tickets for this prestigious event, but those who did enjoyed a highly emotional, nostalgic evening of jazz , miraculously organised in just six short weeks!

Towards the end of my time on the charity’s board I accepted the time had come to move on. The results achieved since the new regime, led by David Croisdale-Appleby and Hilda Hayo, took over the helm have been exceptional, far outreaching my wildest dreams. I sincerely hope this was adequately acknowledged in the book, I will, however, never forget the important part played by so many others in building the foundations of this important charity which now focuses support on Admiral Nursing.

*See page 19 for details of how to obtain a copy of the book.*  
Photo of Jane at the launch party (above): Ingrid Weel Photography.

# A duck out of water: dementia and care home life

**Helen Johns** shares her and her mother's experience of care home life, reflecting especially on how residents spend their day. Relatives and friends must be better supported, she argues, and enabled to become true partners in care

On the last day of 2012 my mum moved into a care home after a rapid decline and a diagnosis of dementia. My emotionally fragile mum had become so confused and agitated that it became increasingly difficult to look after her at home. We were advised that she needed 24-hour care so found a lovely home (rated as 'Good' by the inspectorate) and we thought that our worries about Mum were over.



However, the reality of care home life was very different from what we expected. The home was run with fixed routines and tasks, and despite a homely décor sometimes felt more like a hospital. Carers seemed to treat residents as patients, and although they were kind and polite, it all felt quite oppressive. At that time there were few smiles around from staff or residents to comfort my bewildered mum.

Most worrying was the lack of anything remotely interesting happening in the home. The cliché of 'God's waiting room' – the care home lounge with residents sitting dolefully around the perimeter of the room – was now Mum's reality. Busy carers kept strictly to their care tasks and over time, I learned of the uneasy stand-off between care staff and the activity team. Each thought the other should be doing more. The Lonely Lounge didn't appeal to Mum, so she isolated herself in her bedroom and became increasingly confused and distressed. This went on for over a year, despite my frequent trips to the manager's office to ask for help. I couldn't understand how Mum could be more bored, lonely and afraid in a *care environment* than when she had lived alone in her flat.

## A daughter on a mission

Observing Mum's experience forced me to learn quickly about dementia – initially just to soothe her distress. However, the more I learned the more I was fascinated by dementia and particularly in learning how to support people to live well with the disease. This curiosity (born of years as an education consultant), led me to do more research into dementia care, the role of meaningful activity and care home standards. That, in turn, led to a career change that

*Helen Johns is the author of A Duck Out of Water: Mum, dementia and care home life*

## Key points

- Writing the book allowed me to take a step back and reflect on what I have learnt as a daughter and as a professional.
- A false dichotomy has emerged in many care homes leading staff to feel they have to choose between providing 'care' or an 'activity'.
- A misunderstanding of what constitutes meaningful activity still exists which reinforces the misconception that activity is a bonus not an essential part of care.
- Care teams need training, support and permission to turn care tasks into a shared care experience with the resident.
- Relatives can provide an additional resource to complement the specialist work of care teams.
- Care teams, commissioners and the inspectorates need to place a greater value and focus on:
  - How a person spends their day
  - How relatives/friends are supported as partners in care

saw me working with activity coordinators, care teams and inspection professionals on a variety of projects.

But back then, I was just a daughter who wanted to use my skills to improve day to day life in the care home - not only for Mum but for her fellow residents. Over the next few years, some of my efforts were welcomed (e.g. those that offered an extra pair of hands to provide activities) but others received a lukewarm response.

Successive managers gave me permission to embark on each project but didn't empower staff to make the changes necessary. Despite my boundless enthusiasm, it became apparent that there was a limit to what I, as Mum's daughter, could achieve within the culture of the home. Carers were polite and friendly, but were no doubt bewildered by this relative who was stepping outside of their usual role. I realised that the home's culture created a barrier rooted in their perception of two aspects of care:

- The role of meaningful activity in care, and
- The role and value of relatives in the care partnership. ▷



### Meaningful activity in care

In Mum's home the division between care staff and activity coordinators was longstanding. Both 'sides' had become entrenched in what I considered to be a false dichotomy: having to choose between providing 'care' or an 'activity'.

Overstretched carers, faced with either performing care tasks or offering meaningful activity stuck to what they knew. They hadn't been trained to recognise that care tasks *could also be* a meaningful activity or a shared care experience with the resident. Neither had they been given the permission (or the time) to take a few moments to simply 'be with' a person for an informal chat or a quiet moment together.

Conversely, activity coordinators saw their role as providing entertainment events such as games, sing-alongs, movie afternoons or a very rare outing. The few activities that took place seemed only to cater for the more sociable residents or those who were most able. There didn't seem to be an understanding that everyday tasks and low-key experiences could be considered meaningful and enrich a person's day – irrespective of their abilities.

Such a limited view of what constitutes meaningful activity led to a general consensus that activity was a bonus element - not an essential part – of care. This meant there were huge stretches of the day where nothing happened leaving residents bored and confused. In my work with other care homes since, I've seen numerous similar examples of how this type of stalemate can make care home life quite dull.

I've also observed homes where they, in principle, support the concept that 'activity is everyone's responsibility' and do not employ activity coordinators. However, I've found that unless the correct structures and training are in place, this is a fragile concept. When times are tough and the pressure is on, busy carers revert to what they know, and all too easily it becomes 'no-one's responsibility.'

### The relative's role in the care partnership

For me, my involvement became much more than simply a 'daughter on a mission' and ultimately led to a career change - but that is not for everyone. I know that different relatives will vary in their capacity (or willingness) to be involved in their loved one's life.

However, I also know that many relatives do not want to be resigned to the role of 'just' a visitor. They want to continue to care for their loved ones and to be part of care home life. They often see the pressure that care teams are under and want to assist in some way. That could be lending a hand with personal care for their loved one or helping out with generic tasks across the home. It is wonderful where this happens naturally and easily but increasingly, I hear of strained relationships where relatives feel excluded from being a true care partner and are afraid to make too much of a fuss. Once again it is the perception that is at fault. If relatives are considered as just an interested onlooker, that can automatically create assumptions about what they are 'allowed' to do and leads to 'them and us' thinking.

The pandemic showed us the devastating impact on a

### Why did I write a book?

Over the course of our journey, I read a lot about dementia and caring for people living with the disease. However, all the accounts stopped at the door of the care home - nothing told the story of what it might be like to live in one.

I wanted to chronicle, through Mum's experience and her words (many are taken directly from notes that I made at the time), exactly how she felt and why she felt it.

I also wanted to illustrate how a relative might feel in this position. To explore the power dynamic between the care home and the relative and how that could be improved.

**A Duck Out of Water: Mum, dementia and care home life** is available at [www.hmjconsultancy.co.uk/bookstore](http://www.hmjconsultancy.co.uk/bookstore) and at [www.amazon.co.uk](http://www.amazon.co.uk)

person's wellbeing when they are deprived of contact with relatives and friends or lack regular stimulation. Given our heightened awareness, it seems logical that we should embrace this often-willing army of relatives who can provide an additional resource and contribute to meaningful activity in the home. Not to replace the specialist work of care teams but to complement it.

### What can be done?

In a sector that is often described as at breaking point, there are many debates about what is needed to fix social care – a seemingly insurmountable task. However, an improvement can be made by placing a greater emphasis *on the things that, the pandemic showed us, affect a person most*. Care commissioners, inspectors, care home owners, managers and care teams need to increase their focus on:

- How a person spends their day
- How relatives and friends are supported to be true and active partners in care.

If we consider that good care is a series of shared meaningful experiences between the carer and the cared for, there is the scope for each person in their caring role (paid and unpaid) to play their part. This takes away the fixed distinction between what is a care task and what is a meaningful activity and allows teams to work collaboratively towards a more authentic caring experience for everyone. Relatives can be included in this partnership by taking into account the manner and the extent that they would like to be involved.

To conclude Mum's story—things did improve but we went through many cycles of highs and lows over the next six and a half years. In 2019 we made the decision to move her to a different care home based on the Butterfly Care model developed by David Sheard where meaningful activity is part of everyday life and where (in his words) 'feelings matter most'. She lived there happily until she died in April 2021.

*Note: I use the term 'relative' throughout this article, but recognise that essential support is provided by relatives, partners, friends and others connected to the person living in a care home.*

# The Photobook Project: Empowerment through creativity

**Ellie Robinson-Carter** describes the Photobook Project: how creativity and the arts empower people living with dementia in global majority communities living in the UK

*I've been allowed to be part of the conversation.  
This situation becomes my example of what is possible.*  
(A project participant)

## Creativity and dementia

Creativity is defined as the tendency to generate or recognise ideas, alternatives, or possibilities that may be useful in solving problems, communicating with others, and entertaining ourselves and others (CSUN 2023). With the recent launch of the National Centre for Creative Health, there is more evidence of the benefits of creative health interventions - including visual arts, sculpture, theatre, literature and more (Arts Well 2022).

For people living with dementia, there are specific benefits to be gained from engaging in creative activity: As a non-pharmacological intervention, the arts provide a valuable opportunity for self-exploration, adventure, experimentation and a way of connecting with others (Robinson-Carter 2020). Provided with well designed creative frameworks, individuals are offered the space and opportunity to process their feelings and thoughts and to go on a journey of self-discovery in a way that is unique to them (Robinson-Carter 2020). Also, there are studies which not only reflect a slowing of cognitive decline but a reversal (Memory Matters 2015). At present such services are often not prioritised nor made widespread for people with dementia (Robinson-Carter & Wolverson 2023).



Some examples of photobooks

## The Photobook Project CIC

The Photobook Project empowers people living with dementia through creative practice and research [www.the-photobook-project.com](http://www.the-photobook-project.com). The project uses single-use cameras to invite people with dementia and their carers to document their current experiences, from their perspective, under themes they decide upon. For example, looking up, light or a colour. The project has been delivered across the globe, with internationally-renowned intergenerational home Humanitas Deventer (Holland), intergenerational relay race Run Tomo (Japan), Dementia Dogs (Bulgaria) and across the UK. Photography used in this way as a qualitative research tool - termed 'photovoice' - has often been used as an engaging and empowering research tool for older people (Myssyuk & Huisman 2019). It enables us to see an experience from the person's own perspective - since the person makes a decision to press the button and document a specific moment, object or environment.

Single-use cameras are more accessible and user-friendly than digital equivalents - with a lens to look through, a simple wheel to wind on and button to press, which older people and those with dementia find more familiar and easier to use.

## Photobook Collection 10: "My Dementia Life Matters"

In summer 2020, The Photobook Project collaborated with David Truswell of Dementia Alliance for Culture and Ethnicity and Ronald Amanze, a musician and record producer living with dementia, to widen access and raise awareness of the unique stories and experiences of people living with dementia with ethnically diverse heritage. With funding from the Race and Equality Foundation, Collection 10 of The Photobook Project was created, titled at Ronald's suggestion, "My Dementia Life Matters". The project invited 13 people living with dementia and their families to take part in the project remotely, by creating an accessible activity pack and building relationships with community group leaders at Chinese Wellbeing (Liverpool), Nubian Life (London) and the African Caribbean Society (Manchester). ▷

*Ellie Robinson-Carter is Founding Artistic Director of  
The Photobook Project ©  
[www.the-photobook-project.com](http://www.the-photobook-project.com)*

▷ The participants were invited to take one photograph a day over four weeks to capture their experience of their lived environments over the summer of 2020, during the lockdown due to Covid-19. They were also invited to answer four questions:

- What is your story?
- What are your favourite things to do?
- If you could tell the world anything about living with dementia, what would it be?
- Is there anything else you would like to share?

When the participants had completed their photography and answered the questions, they returned their work to The Photobook Project team who curated these into photobooks. Each participant had their own photobook made with their images and text. The images were kept in the order they were taken in, to preserve the narrative captured by the individual, with the text scanned and made into booklets attached at the centre of their respective books. At the end of the project, the books were sent back to the participants and a copy kept at The Photobook Project archive.

### Participant feedback

#### *Feelings of empowerment*

On receiving the photobooks, participants reported feelings of happiness and enjoyment in seeing themselves, their families, special objects and environments in their books. A carer of one participant shared that her husband had “loved seeing his garden in full bloom”. A group leader said: “I do believe they and their families will love the photobooks because it would be a good memory for them”. One participant said, “Looking at it again, loads of memories came flooding back to me... it’s about capturing the beautiful moments, the enjoyable moments that we want to hold on to”.



**Mr Richards with his wife, sharing his photobook**

### Hints and tips for practitioners

#### *Be open to how the project evolves*

The Photobook Project is always looking for new ways of capturing and sharing the stories and experiences of people living with dementia. Working with Ronald opened up an opportunity to create our first moving-image photobook, capturing his story and how the project had supported him. This process taught us the importance of leaving room for the project to evolve, and the value of funders being open to this process.

#### *Designing creative frameworks*

Designing socially engaged projects requires a unique approach and skillset. It is important that people taking part are clear about what is expected of them, and that space is created for them to make a project their own. This can be a hard balance to strike, but finding it is often where the magic happens. The framework may have elements that can be tweaked - for example, in the case of the Photobook Project, it can be delivered in group settings as well as remotely. The questions asked can change, and can even be replaced with other activities, leaving the overall framework in place and making the parameters clear for both the practitioners and participants.

#### *Don't worry if things don't quite go how you anticipated/hoped*

Working in a truly inclusive, co-creative way means hurdles or unexpected factors can come into play, which is often when the best learning happens. Communication is really important, as is being open to how the project may change you as a practitioner, and inform your future delivery.

#### *Be clear about the start, middle and end (as much as possible)*

Sharing the steps of the project, even if there is some ambiguity at play, can be really helpful for participants and group leaders/carers supporting involvement. If things need to change, keep people in the loop so expectations are managed.

#### *Unique insight*

One participant felt that he didn't feel he would have much to share, since he spends a lot of time in bed, but his book was really striking as it reflected the day-to-day experience of being in the same space and the small changes that take place in his environment. Another participant reflected that the books are a “unique piece that everyone produces... simply them”.

#### *Importance of journey and destination*

We received feedback from most participants that having their work presented in a professional book created feelings of achievement and increased feelings of confidence. This highlighted the importance of sharing back the images created, and each participant having their



## A case study: Ronald Amanze

“I always felt silenced by the circumstances I was involved in. People don’t give them a voice. You guys gave me a voice. If it wasn’t for the way you encouraged me, I wouldn’t have found it. I found a means and a way to do it.”



From the beginning of the project, Ronald took the role of Co-Producer, shaping its delivery and outcome. As someone of Jamaican heritage and as a music producer, radio DJ and poet, Ronald is passionate about sharing the benefits of creative engagement and widening access to everyone living with dementia.

Ronald created his own photobook, combining this with his poems. Ronald introduced the idea of creating a film highlighting the importance of creative arts for people living with dementia, his story and his



involvement in the project. This resulted in the creation of Amanze—A Portrait of a Pirate, a multi-award winning short film created in collaboration with Lucy Hawes Productions: <http://tinyurl.com/bdfef2xb> Ronald feels that the project is the “perfect example of cooperation and how inclusion can be meaningful and possible”.

own copies. One participant reported, “I went through it again and again, and again, I had the feeling”.

### Universality of images

Over the course of the project, we learned that people with dementia often lose the ability to speak second/additional languages, and revert back to their native language. For many of our participants, this meant that understanding English (both written and spoken) wasn’t possible. Using our funding to have the packs translated for the individuals taking part highlighted how much of a barrier this is for ethnic diverse communities living in the UK. Moreover, one participant commented on the importance of translated materials, “Having to translate in my head back to English becomes harder, which can be conceived as cognitive decline”.

### Postcode lottery

Support services for people with dementia of particular heritage are not widespread/accessible across the UK. For example, for those living in the Liverpool vicinity, there is Chinese Wellbeing to support them, but this specific support wasn’t available for every person of Chinese heritage in the UK.

### Cultural differences

We were struck by the different cultural experience shared across the group. For example, participants through Chinese Wellbeing opted to not have their faces included in the images of the books which were shared more widely. There was also a strong culture of families being the main, and often sole, support system for the person with dementia. We were struck by how many participants were in their later stages of dementia, and all living at home.

### Future plans

The Photobook Project, Dementia Alliance of Culture & Ethnicity and Ronald Amanze are currently delivering the

second iteration of the project (2023), thanks to funding from Giving Tuesday.

The project offers consultancy around socially engaged projects, especially those which engage people with dementia and intergenerational groups. Get in touch if you would like to find out more: [info@the-photobook-project.com](mailto:info@the-photobook-project.com)

*Huge thanks to David Truswell - a fellow ‘enabler’, as Ronald likes to call us - and to Ronald Amanze for his passion, insight and poetry.*

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# SPECAL: a blueprint for sensitive communication

**Zoe Elkins** and **Di Trinder** describe an independent evaluation of a change in approach for a day centre service. The study found that a small investment in SPECAL Practitioner training led to significantly greater contentment and raised self-esteem for service users, and less stress and anxiety for their families

In 2018, Age UK Notts started to train staff in the SPECAL method in order to transform the previously mainstream Sybil Levin day service into a SPECAL-informed specialist dementia service.

The SPECAL method is an innovative dementia management method developed by Contented Dementia Trust, that can be learned and used by anyone involved in the care of a person with dementia. It is based on a particular understanding of the experience of the disability, called the SPECAL Photograph Album analogy.

## The SPECAL Photograph Album

The SPECAL Photograph Album offers a simple and practical analogy to explain how memory works, what happens to all of us as we age, and the single dramatic change which occurs with the onset of dementia.

Normal memory provides us with a continuous record of what has just been happening in our life, in terms of both facts and associated feelings. Common sense, which we use all the time in our life, is predicated on our being able to access this recent information as we move from moment to moment. Dementia introduces a change to the normal storage of everything that has just been happening. With dementia, new factual information becomes less and less reliably stored, while feelings continue to store in the normal way. Feelings become more of a reference point than facts. This is a single change, and the person with dementia has a natural ability to adapt to the new situation in which they find themselves.

However, unless the rest of us understand what the person with dementia is experiencing, and exactly how they are coping, we can unwittingly trip them up. In other words, the single change has the potential to disrupt just about everything to do with the person's life unless we adapt our own actions and reactions to take proper account of what is actually going on. It follows that once dementia is present, common sense is guaranteed to become less and less useful as a starting point.

## SPECAL sense—the golden rules

The Trust has developed SPECAL sense, which provides a method of managing the dementia. SPECAL sense begins with Three Golden Rules:

- Avoid asking questions
- Listen to the expert – the person with dementia – and learn from them
- Don't contradict.

## Summary — key points

Age UK Nottingham teamed up with the Contented Dementia Trust to transform a mainstream day service into a SPECAL-informed dementia service.

An independent study was commissioned on the impact of the SPECAL method. The results showed:

- Users were more content in a SPECAL-Informed service.
- Family carers commented on loved ones being less anxious and more relaxed.
- Staff noticed immediate improvements in user anxiety levels and engagement.

Each of SPECAL's Golden Rules is, by definition, counter-intuitive, and each rule has an associated tool. The use of these tools immediately reduces stress not only for the person with dementia, but also everyone else involved. Confusion gives way to confidence, and with the confidence comes a level of competence and wellbeing which is very different from that usually seen along the dementia journey.

## Service design

To become a SPECAL-Informed service, Age UK Notts adopted a number of service design features:

- All staff and volunteers attended a SPECAL Photograph Album introductory presentation
- At least one team leader qualified as a SPECAL Practitioner, with at least one more actively engaged in the SPECAL Professional Pathway
- Key SPECAL service features were adopted, including a small core team, many props and activities centred on users, music playing, refreshments available throughout the day, a 'restaurant style' food service and an absence of queuing and name badges. ▷

*Zoe Elkins is a Trustee for the Contented Dementia Trust, and Di Trinder is CEO of Age UK Notts.*

▷ Bath & Main Associates were commissioned to study the impact of the SPECAL approach. This study builds on previous research into the SPECAL method, most notably the ‘SPECAL Evaluation Project’ (Pritchard & Dewing 1999) and the ‘SPECAL method of caring for people with dementia’ (McCrae *et al* 2019, Kings College, London).

### Approach

During their review of day service provision in 2018, it was agreed that Age UK Notts would concentrate on the provision of specialist dementia day service support. This began the search for a method of service delivery which had positive outcomes for people with dementia and reflected the ethos of Age UK Notts.

The Age UK Notts dementia lead was tasked by the Board of Trustees to review existing dementia service provision and theoretical perspectives and present findings to the Board of Trustees. The Board found an immediate resonance with the SPECAL method and Age UK Notts’ values. Approval was given; a new dementia strategy was developed identifying the SPECAL method as the preferred model for the delivery of a specialist dementia day service.

The COVID-19 pandemic led to the closure of the existing day service until February 2022. During this time, the Age UK Notts dementia lead completed the SPECAL Practitioner course and a second staff member commenced SPECAL Practitioner training.

The centre began with a planned slow start of 6 users, with a new user starting every 2-3 weeks until a total of 20 people was reached. The centre opened for 3 days a week initially, moving to 5 days. Users were either self-funders or people funded by local authorities. The charge for users was in line with the Framework Agreement in place with Nottingham City Council.

### The study

The goal was to identify whether there is any impact on the day-to-day stress levels of the carers and service users as a result of using the SPECAL method at a day service. The qualitative study would achieve this through:

- Observational visits, including studies of how a typical day is carefully run and choreographed to achieve a high level of person-centred care, and the reactions of attendees to activities.
- Collecting individual responses via online surveys, telephone interviews, in-person interviews
- A focus group with staff, volunteers and family carers.

A four-phase, iterative, action research approach to the study was agreed with the study’s Steering Group (see below) covering a period of approximately nine months. This required a degree of flexibility; the process used was adapted as the study progressed.

Phases 1 and 2 enabled a level of baseline information to be established and then revisited, re-examined, and assessed in phases 3 and 4. This phased approach was viewed as effective and less stressful for the stakeholders as they become more engaged and involved in the study process; the aim was to create opportunities for constant review and improvement as the pilot service developed.

The four phases were:

- November 2021-February 2022 - a pre-day centre launch phase
- February-March 2022
- April-June 2022
- July-August 2022 – including analysing the data and findings and writing the final report.

Though the focus of the study used qualitative approaches, quantitative approaches were also put into place from the beginning of the study.

The first phase of the study was pre-Sybil Levin opening. It centred on:

- Planning and preparing
- Desk-based research to gather comparative research into dementia day care within a UK setting and the effect of day care on carers (notably their stress levels)

The key elements of phase 2, 3 and 4 of the study activities are outlined in the table on page 28.

### Findings

- Users who had previously attended the conventional Sybil Levin day centre (2+ years ago) showed signs of being more content in a specialist dementia day service using the SPECAL-Informed approach.
- Family carers have commented on loved ones being less anxious and more relaxed after attending the day service, compared to before the centre opened and/or when attending other mainstream day centres.
- Staff and volunteers have noticed immediate improvements in anxiety levels and engagement of users.

Observations included attendees playing the piano, singing, dancing or playing snooker after years of not doing so and feeling surprised and happy as everyone congratulates them.

An initial online survey of family members included the following comments:

- “The difference is huge. Mood is better, loved one always on my mind in the past. The anguish (her) mum was in was exhausting and (the) change is huge.”
- “Still early days, but yes feels positive. Never get very stressed but get a feeling of reassurance when Mum goes to Sybils”.

When asked “Thinking back to when the person you care for first started at Sybil Levin, compared with then, how stressed and/or anxious on a day-to-day basis do you feel now?” 100% of family members stated they felt less stressed and anxious.

One daughter reported that visits to her father had dropped from twice daily to three times a week, with phone calls from him now only when he goes to bed. ▷

Date	Activity
February 2022	<b>Online survey</b> – sent to all staff, volunteers and family carers at this time. There were 8 responses (4 staff, 2 volunteers and 2 family carers).
21 February 2022	Attended a <b>staff and volunteers briefing meeting</b> to learn about the SPECAL method at the Sybil Levin Centre.
23 February 2022	<b>Family carers Introductory Meeting</b>
24 Feb 2022	Second visit to <b>Staff/Volunteers briefing / induction</b>
16 and 30 March 2022	<b>Two full day observation visits</b> - two full day observation visits were made to the Sybil Levin Centre with one researcher at each.
24 March 2022	<b>Structured first interviews</b> – interviews started on 24 March by phone or online.
24 March - 26 May 2022	<b>Telephone or online interviews</b> – 17 structured interviews were undertaken. Interviewees were a mix of staff, volunteers and family carers.
28 April 2022	<b>Family carer training</b> – attended a second training session for family carers on the SPECAL method. Both researchers joined online via Teams.
6 June 2022	<b>Interim Report</b> submitted
8 and 13 June 2022	<b>Observation visits</b> – a second full day observation visit was made by each researcher to Sybil Levin.
27 June – 27 July	<b>Telephone or online interviews</b> – 18 structured interviews were undertaken with a mix of staff, volunteers and family carers.
July 2022	<b>Second online survey</b> – sent to all carers. 7 responses received - 6 from family carers and 1 who stated that they shared the caring responsibility.
12 August 2022	<b>Observation visit</b> – a fifth observation visit was made by one of the researchers.
25 August 2022	A <b>Focus Group</b> was held at Sybil Levin with staff, a volunteer and a family carer attending with the main aim of discussing the draft Final Report findings.



- “My dad was a lot more relaxed after his first session and for the first time in months I didn’t have the constant questioning I usually get in the evening. This lasted a couple of days.”
- “He seemed calmer, content and there was less questioning. He seemed to accept what I spoke to him about, without constant repeating and questions”

**The following was taken from the study authors’ observations:**

We have seen examples where staff have boosted the sense of self-worth and confidence in the users purely by observing their body language. Staff and volunteers become familiar with past interests and expertise of individual users and are able to emphasise personal achievement by dropping into the conversation references such as a ‘demon at dominoes’, a ‘wizz at snooker’ or ‘fantastic at repairing bicycles’.

Invariably, the user will respond, even if non-verbally. Their body language changes (standing or sitting a bit straighter), a smile happens or a modest comment or a confirmation is made. It is enjoyable to see the pleasure this gives users as they feel or sense a level of happiness and greater wellbeing.

It also provides great satisfaction to the staff and volunteers, who can see the SPECAL method is working and making a difference to the lives of the users.

One user who attended the previous conventional day centre (pre-Covid) was known by some of the staff. He displayed signs of anxiety when there and was constantly tapping his foot. He rarely engaged in any activities.

Two years later, he now attends the SPECAL-informed day centre, the same physical space, but with a different approach. There have been no signs of tapping. He listens to conversations around him and smiles to himself when he hears something that amuses him. When asked by a fellow user over lunch “where did you go to school?”, he stated where and the fact he has a degree. This information about him is now mentioned by the staff within his hearing, to boost his well-being.

**Implications for practice**

The success of implementing SPECAL in the day service shows that with a small initial investment in SPECAL Practitioner training, it is possible to significantly improve the well-being of service users living with dementia without increasing overall cost-base.

The SPECAL Photograph Album offers a simple and practical analogy to explain how memory works, and the single dramatic change which occurs with the onset of dementia. With dementia, new factual information

becomes less and less reliably stored, while feelings continue to store in the normal way. Feelings become a greater reference point than facts. The person with dementia has a natural ability to adapt to the new situation in which they find themselves.

However, unless the rest of us understand what the person with dementia is experiencing, and exactly how they are coping, we can unwittingly trip them up. The single change has the potential to disrupt just about everything to do with the person's life unless we adapt our own actions and reactions to take proper account of what is actually going on. It follows that once dementia is present, common sense is guaranteed to become less and less useful as a starting point.

SPECAL provides a blueprint for communication which does not rely on common sense, but instead takes account of this single change to the way memory works. SPECAL training is cost-effective, easy to implement and provides paid staff, volunteers, and family members with a raft of simple skills which promote well-being and avoid unwittingly triggering anxiety for people with dementia.

#### Future plans

The SPECAL-Informed Specialist Dementia Day Support model has the potential to be replicated in other parts of the UK. The SPECAL training and tools can work well in a day centre setting and can be used and applied in multiple day settings. Both AGE UK NOTTS and the Contented Dementia Trust are happy to be contacted by any organisation wishing to find out more.

[www.contenteddementiastrust.org](http://www.contenteddementiastrust.org)

[info@contenteddementiastrust.org](mailto:info@contenteddementiastrust.org)

[www.ageuknotts.org.uk](http://www.ageuknotts.org.uk)

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# Preparing to care: Training for carers of people with dementia and a learning disability

People with learning disabilities are at high risk of developing dementia, and they will face different and additional challenges. Care partners who know the person well play a vital role, and expert support for all involved is vital. **Saff Davies** and **Teresa Atkinson** describe the development of a specialised training package

It is reported that between 78-79% of adults with learning disabilities in the UK live in their own home or with their family (Nuffield Trust & The Health Foundation 2023). Gates (1997) defines a learning disability as ‘a term used to describe a group of people with significant developmental delay manifested as arrested or incomplete achievement of the ‘normal’ milestones of human development. These milestones relate to the intellectual, emotional, spiritual, physical, and social aspects of human development’. People with a learning disability are increasingly living longer with over one third now estimated to be over the age of 50 years old (Janicki & Dalton, 2000; McConkey *et al*, 2006).

According to the Alzheimer’s Society (2023) one fifth of people with a learning disability over the age of 65 will develop dementia, with greater risk associated with Down’s Syndrome where two thirds of people over the age of 60 may develop dementia, usually Alzheimer’s type. The graph below shows the prevalence of dementia in the general population compared to that of people with Down’s Syndrome. It demonstrates that people living with Down’s Syndrome can develop dementia at the age of 30 years old, increasing throughout the age span, compared to the general population who are at less risk of developing dementia until older age.

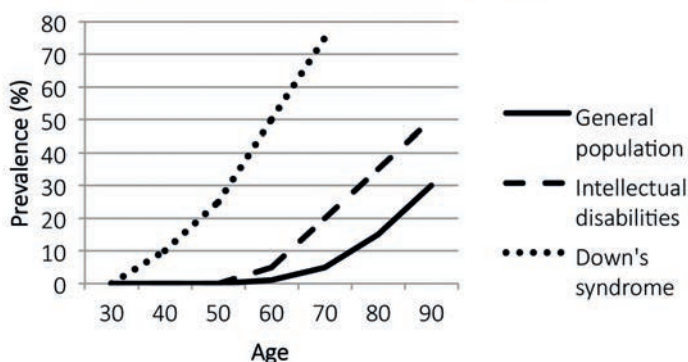
The presentation of dementia symptoms may be different in those with a profound learning disability and appear more subtly. There is greater reliance, therefore, on the expertise carers already have in understanding their loved

## Summary

The Alzheimer’s Society (2023) advises that people with learning disabilities, particularly those with Down’s syndrome, are at increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability. Many people, including family carers, are not aware of this risk and, in addition to the challenges of caring for an adult with a learning disability, are unprepared for the further complications that a diagnosis of dementia may bring. This article considers the needs of family carers and in particular, the development of a training package to provide support.

ones. Changes in mood and behaviours may become apparent, such as taking longer to perform tasks. There may also be changes in memory and language skills. Other neurological changes may take place, resulting, for example in the development of epilepsy. Where the learning disability is more profound, these changes may be masked and will rely more heavily on the skills of the carer. Co-morbid health related conditions add to the complexity of the picture. Additional health needs in this population include thyroid dysfunction and sight and hearing problems. This complex picture makes obtaining a diagnosis challenging, particularly due to the cognitive differences and difficulties already present. However, diagnosis is important to enable full support to be given to families who need to be able to access an appropriate dementia pathway. There is, however, a paucity of information and training available to support this complex dual diagnosis. The Prime Minister’s Challenge on Dementia (Department of Health 2012) strove to

Comparison of dementia prevalence rates by age



*Saff Davies is Community Learning Disability Nurse, Herefordshire & Worcestershire Health & Care NHS Trust and Teresa Atkinson is Senior Research Fellow, Association for Dementia Studies, University of Worcester*

ensure that dementia awareness, understanding and expertise was a priority in society, yet people with learning disabilities and dementia are not explicitly mentioned in any government initiatives. The Foundation for People with Learning Disabilities (2018) suggest that ‘excellence in dementia care requires everyone involved to have an in-depth understanding of dementia’s impact on the individual’ (p.8).

### **Caring for a person with a dual diagnosis of learning disability and dementia**

The diagnosis of dementia comes as an added ‘layer’ on top of the diagnosis of learning disability. This picture is further complicated by the age of family carers who themselves may be classed as older adults at risk of developing age-related conditions or potential dementia themselves. Attention must therefore be directed to the support that families require to enable them to continue in their caring role, while considering how the additional diagnosis impacts on the already established long-term caring role.

Evidence highlighting the challenges faced by carers of adults with learning disabilities comes almost entirely from small qualitative studies, which is congruent with the demographic and the often-complex role. Although evidence from these smaller localised studies is not necessarily representative of all parent carer views, there are common themes that offer useful insight and learning about outcomes for other similar family contexts. Howson & McKay (2020) suggest that the challenges facing older carers are usually socio-structural rather than related to the care recipient’s needs. Studies such as Deville *et al* (2019) highlight that despite loneliness and isolation often increasing with age, older carers feel their own needs are ignored by professionals, and sustaining relationships with them continues to be increasingly challenging with reduced health and social care resources. It is not surprising then that Cairns *et al* (2013) concluded that older carers found the role had a negative impact on both their emotional and their physical wellbeing, and that poor mental health increases their vulnerability further still, reducing quality of life. Although the latter study is unusually large for this field, with 100 participants, smaller localised studies draw out very similar themes and each of these studies highlights carers’ awareness of their own frailty, concluding they would benefit from person centred and carer specific support.

Howson and McKay (2020) reported that there is often an assumption among families who support an adult child with a dual diagnosis, that a sibling will take over when the parent who is caring dies or is not able to continue. This lack of preparation or contingency planning, and having to make decisions about somebody’s care needs quickly, is not a situation unique to parent carers of people with learning disabilities who develop dementia, but if it is accepted that socio-structures are the root cause of challenges to older carers, then it is important to address the issue of future planning and what role support services should play in this. The literature shows overwhelmingly that carers of people with dementia, particularly older carers, and those who care for people with learning disabilities, worry about future planning in some capacity

## **Key points**

- families who are ageing together and are caring for adults with learning disabilities and dementia need access to health professionals who are knowledgeable in both diagnoses
- training packages should be made available to family carers as well as paid care staff
- family carers of people with Down's syndrome need information early about risks of their loved one developing dementia
- if family carers of people with LD and dementia are informed, it can help with feel less isolated and reduce risks of carer burnout
- professionals working in LD and dementia require better training about family carers' needs and how to support them.

(Greenwood, Pound & Brearley 2019; Mahon *et al* 2019). Forrester-Jones (2021) concludes that more exploration around the views of the care recipient is needed to best support future planning needs with their carers, but in the meantime, we can look at the existing health and social care frameworks and also consider whether parent carers’ perspectives of their identity plays a role in when they feel able or ready to ‘let go’ of having a major responsibility for looking after their child.

Whilst there are positive aspects to the caring role, such as purposefulness, family connectivity and sense of belonging (Howson & McKay 2022), which must be celebrated, this positivity does not occur in the absence of distress. Beighton & Wills (2019) note that where the care recipient displays behavioural challenges or has more severe medical issues, a positive outlook is harder to sustain for parent carers with increased demands placed on their caring role.

There is also compelling evidence showing older carers, particularly parents of lifelong disabled people, experience multiple losses over their child’s lifetime and that experiences of loss only accumulate over time.

Howson & McKay (2020) mention sleep, career, identity, and friendships among other losses.

### **The need for training in dual diagnosis: learning disabilities & dementia**

The Care Act (2014) promotes a strength-based assessment process that takes account of co-support between parent and child (Department of Health and Social Care 2016). The National Institute for Health and Care Excellence’s ‘Care and Support of People Growing Older with Learning Disabilities’ (2018) guideline recommends skills training is needed for both parties but integral to longevity is specific support from a professional with clinical knowledge of both learning disabilities *and* dementia. This specialist support for parent carers is appropriate given the *complexities* of the care recipient’s needs.

Reliable access to expertise, early information about dementia, and help with future planning are some of the professional led outcomes related to this carer group. ▷

What is Dementia?	Communication and Behaviour	Health	Living Well with Dementia	End of Life Care Planning
<p>A simple definition to aid understanding</p> <p>Explanation of why people with Down Syndrome are at greater risk</p> <p>Opportunity for carer to raise any particular issues or concerns that can be addressed on the programme</p> <p>Basic outline of early, middle and late stages</p> <p>Explore with the carer at which stage their loved one may be, to enable a better understanding of the disease trajectory</p>	<p>'Life Story' work/ This is Me booklet</p> <p>Look at meaningful activities for each stage of dementia, identify some activities at each stage for their loved one, match to their likes/ dislikes</p> <p>Reasons for presenting with behaviours of concern or distress behaviours, and how to respond</p> <p>Where to seek further support if behaviour presents risk</p>	<p>Provide basic information on medication/ advise on relevant care pathway</p> <p>Ensure these discussions are within the frames of the Mental Capacity Act and involve the person with dementia</p> <p>Explain other common health issues that people with Down Syndrome may experience with ageing e.g. hearing loss, cataracts</p> <p>Explore relevant symptoms that may require further intervention e.g. new or worsening epilepsy</p>	<p>Eating, drinking and nutritional information and skills, to minimise risk of choking, malnutrition and dehydration</p> <p>Importance of keeping active, link to meaningful activities and exercise</p> <p>Signposting to assistive technology, aids and adaptations to promote and maintain independence</p>	<p>Discussion around dementia as a terminal illness</p> <p>Explanation of advanced care planning</p> <p>Information about Respect forms and how to complete</p> <p>Where to access emotional support for carer but also resources in accessible formats for person with learning disability and dementia</p>

**Table 1: Content of Training Package**

▷ However, the literature available offers recourse to additional interventions. All parent carers of adults with learning disabilities in Howson & McKay's (2020) paper report positive accounts of sharing their experiences with other carers of learning-disabled adults. While there are several national support networks for carers of people with dementia, and for carers of adults with learning disabilities several different charitable organisations relating to specific diagnoses, in practice local support networks for parent carers of people with both diagnoses are very much in their infancy and in most areas non-existent. This is concerning given the issues of isolation, negative impacts on carers' mental health and difficulty in accessing formal support.

Mahon *et al* (2019) discuss the need for professionals to have better access to training specifically about carers' needs, along with a greater understanding of mutual caring relationships, to best support these families. The evidence base does not offer sufficient indication of what might best support the positive outcomes for parent carers of adults with learning disabilities and dementia, other than continual review and consistency in personnel. McAuliffe, O'Connor and Meagher (2014) explored the experiences of parent carers of adults with schizophrenia and concluded that a family-centred approach is required to deal with the uniqueness of individual parents' circumstances, and assessment and care planning should take into account the family as a unit. This is a useful perspective, particularly if

the parent carer also develops dementia, as a whole family approach could be beneficial, drawing on other close sources of support who know both individuals well. Finally, Jacobs *et al* (2023) examined couples with learning disabilities where one partner develops dementia, and offer a relational perspective providing professionals with the information to support the wellbeing of both partners. This offers an alternative way of meeting parent carer needs of adults with learning disabilities who develop dementia, keeping both parties' wellbeing as the main focus, with attention given to the *parenting* aspect of this relationship whilst adapting to another feature of their carer identity.

While training packages are available to support carers of people with dementia, evidence suggests that those caring for people with a dual diagnosis of dementia and a learning disability require specific information to understand the changes they are more likely to see and generally have little support or guidance. Bressan, Visintini and Palese (2020) emphasise the need for families to be trained and educated to support the changes encountered with dementia. Dennehy *et al* (2022) found that carers of people with learning disabilities and dementia may not have access to specific education or training in the provision of appropriate care for individuals with both diagnoses. Without awareness of the issues that could affect their loved ones, carers cannot effectively manage the changes and advocate appropriately when they require professional help. It is important that families caring for people with



learning disabilities and dementia are as prepared and confident as they can be, so that they themselves can be prepared and in turn help their loved one to understand what is happening to them and feel safe.

### The training package

The training package was developed as part of the Postgraduate Certificate in Person-centred Dementia Studies (Atkinson, 2023) and could be transferable across a range of family contexts to support carers in the complex dual diagnosis situation. It has already been trialled and successfully delivered in several formal care settings where family members have been invited to also attend, with excellent feedback. It aims to prepare and equip family carers of people with learning disabilities and dementia to understand and manage the changes their loved ones will experience. It provides informative and experiential training, delivered in a chosen setting, by a trusted and trained health care professional, aiming to achieve sustained and improved caring roles and relationships; empower carers and promote partnership working to support effective care planning; increase understanding of dementia; reduce risk of carer burnout; and reduce health inequalities for people with learning disabilities. The training aims to maintain and improve the quality of life and promote the wellbeing of both the family carer, and the person with dementia and learning disabilities. The content of the training package can be tailored to the needs of the individuals it serves to inform, with suggested content to be covered for each session (see Table 1 on previous page, p.....). This allows for a two-way learning process with the health care professional learning more about the carers needs to ensure each family setting is supported in the most effective way. The specific content is described in the table.

### Conclusion

We are well informed from the literature that carers learn best in an environment where they support each other. Having a training package available which can support those in potentially stressful situations caring for people with a dual diagnosis of a learning disability and dementia is crucial to avoid the burn-out that carers experience. Caring for the carers is vital to support the wellbeing of people living with dementia and a learning disability. This training package could provide that vital support, to ensure our carers are informed, prepared and supported.

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# Implementing a Digital Life Stories Project on an inpatient dementia ward: Initial findings and reflections

Paper-based life story work has well known benefits, but how can it be extended for the digital age? **Aaron Smith** and colleagues found significant improvements in wellbeing for patients from their digital life story project on a hospital dementia ward

Life story work (LSW) aims to promote wellbeing and enhance a sense of identity for patients through the opportunity to share memories with others and it can help form and maintain relationships. It has taken many different forms over the years, and it is therefore difficult to provide one single definition (Kaiser 2016). It can take the form of working directly with an individual to explore and document the story of their lives. It can also be in the form of a family member or carer sharing the individual's interests and history to inform those caring for them.

The aim of LSW is to gain an understanding of the individual and to capture their life experiences in a way that can be therapeutic and helpful to the individual and family/carers. Triggering memories that can no longer be readily accessed, LSW focuses primarily on the individual's needs and interests, capturing past experiences but also hopes for the future.

A life story book can also enrich life in the present by informing staff of the person's favourite foods or music they enjoy as well as understanding them as a person. Importantly, LSW does not need to be an accurate and chronological account of their life but can focus on whatever might be of importance to include for the person with dementia (Kaiser 2016). It could range from memories or photos of the person's wedding day to what someone is doing today and what they may hope to do tomorrow.

LSW can have a significant role in person centred approaches of the kind advocated by Kitwood (1997). Where people with dementia show signs of distress, for example, functional analysis can reveal the sources of their distress so that they can be addressed. LSW can feed into a functional analysis as a means for the staff team to be able to understand the person, their experiences, needs and hopes.

## Herefordshire and Worcestershire Life Stories

Our digital life story platform has been developed by Herefordshire and Worcestershire Health and Care NHS Trust and VerseOne Group, in collaboration with Worcester City Council (co-lead), Association for Dementia Studies, Platform housing association, Worcestershire Association of Carers, Tudor House Museum and other stakeholder community and residential groups.

For more information about the background to the project, go to [www.youtube.com/@worcesterlifestories/streams](https://www.youtube.com/@worcesterlifestories/streams).

## Summary

This is an exploratory, descriptive study that discusses how a digital life story platform is currently being trialled on an inpatient ward for people living with dementia. We look at initial staff feedback on using the platform and indicators of wellbeing shown by people engaging in creating their digital life story book.

Building on the "This is me" form, the digital platform offers additional opportunities to engage multiple senses in facilitating reminiscence. It also supports families to access the benefits that life story work provides remotely, such as communication and being able to express the person's needs and wishes.

In one meta-analysis of 30 studies investigating the impact of a range of person-centred care interventions, including LSW, found an immediate reduction in distress and improvement in cognitive function for people living with dementia (Lee *et al* 2020). In developing life story books, evidence has shown increased positive relationships for the person with their carers and family members (Subramaniam *et al* 2014). Staff attitudes towards the person have been seen to improve, while being valued and recognised can lead to self-affirmation and pride for the individual with dementia (Gridley *et al* 2016).

In this context, digitisation of LSW could add another layer on top of paper-based LSW contributing to the wellbeing of patients on an inpatient ward. It can provide an opportunity to share information as well as of seeing "updates" more easily on how far the person is experiencing wellbeing in hospital. Other benefits include multisensory engagement using pictures, audio recordings, videos and written text. In some respects, this is more like reminiscence therapy (RT) which can include discussions using memory prompts such as household items, photographs, and music (Woods *et al* 2018). ▷

*Aaron Smith is assistant psychologist and Dr Julie Achiampong is clinical psychologist, both at Herefordshire and Worcestershire Health and Care Trust; Antonia-Burke Hyman is trainee clinical psychologist at Coventry and Warwick Universities; and Dr Natasha Lord is lead clinical psychologist at Herefordshire and Worcestershire Health and Care Trust.*

▷ Implementing LSW digitally can be effective in reducing negative health outcomes in an older adult population. In a review of the literature Stargatt *et al* (2022) reported improvements in mood and affect, memory, quality of relationships, social connectedness, and other health outcomes such as self-identity following digital LSW. The review highlights how promising digital LSW is as an effective intervention for supporting wellbeing among older adults.

### Introducing the platform

We will discuss an evaluation of a digital life story platform called Herefordshire and Worcestershire Life Stories,\* which is in the early stages of its implementation on an inpatient dementia ward. It is an online life stories book that can be added to and shared at any stage and can include photos, videos, music, written word, and voice recordings. Adaptable to fit individuals' needs and preferences, the book can also be downloaded and printed or shared as a video.

The aim of our life stories project was to promote inclusion, to connect community networks through reminiscence and to produce life stories easily and accessibly via digital technology. Herefordshire and Worcestershire Life Stories set out to engage patients on the ward by building on work already done using the Alzheimer's Society "This is Me" tool.

There are numerous advantages to the digital platform, including family being able to view it and add to it outside the ward, and it can continue to be adapted and built upon. Additionally, the digital nature of it enables a multi-sensory experience, drawing on photos, music and video clips via YouTube, and voice recordings, demonstrated to increase cognitive function whilst decreasing apathy for those living with a dementia (Manav & Simsek 2019, Ferm *et al* 2021).

### Project aims

Our project aims were:

- To train ward staff to use the life stories platform with patients on the ward
- To promote and encourage the regular use and support of staff using life stories
- To evaluate the use of life stories by staff on how it may facilitate and impact engagement of patients
- To evaluate the impact of life stories on patient wellbeing.

### Methods

This service evaluation received approval from the Herefordshire and Worcestershire Health and Care NHS Trust Research and Development Team. It covers the feedback from staff training on the platform using a nine item self-report survey and observations using the Engagement of a Person with Dementia Scale (EPWDS) (Jones *et al* 2018).

#### Staff training

A block of training sessions were designed to establish a clear understanding of the project among staff and how they could navigate the platform. The training consisted of a 90-minute session detailing what the life story project

### Key points

- Life story work (LSW) is an established intervention with good outcomes across a range of needs, for example: promoting and improving wellbeing, maintaining identity, forming and maintaining relationships, a better understanding of the person to those who provide care.
- Digital life story work builds on LSW by providing multisensory engagement such as using photos and audio recordings together as well as opportunities to share information and see "updates" more easily as it is not location based.
- Digital LSW can easily be adapted and built upon.
- Initial findings have found digital LSW to be effective at reducing negative health outcomes.
- Digital LSW is an intervention that, with initial support, can be used by all care staff.
- Research indicates that digital LSW is cost effective and there are promising indicators that it is effective in triggering memories and enhancing relationships.
- Our study is consistent with the wider literature that a web-based life story can take life story work further.

involved, the evidence base, and time for staff to trial the platform. Fourteen staff members received training. They were five nurses, seven support workers, one occupational therapist and one physiotherapist.

#### Supporting and observing

To start a life story book, an account on the Herefordshire and Worcestershire Life Stories website must be created and a book added. We, as the psychology team, invited families of patients to set up accounts themselves. For those who did not wish to do so, we created a book using the ward's own registered account. Then we obtained the family's consent to create the life story on their behalf following trust processes.

Before starting LSW, we checked with the ward if the timing was appropriate for staff as well as for the patient involved. For these interactions, there were two members of the psychology team present, someone to engage the patient in conversation using the life stories platform and someone to observe.

The observer used the Engagement of Person With Dementia Scale to observe levels of engagement and wellbeing before and during the interaction. This method involves making a judgement on a 5 point Likert scale that most accurately indicates the extent to which the patient is demonstrating the given response to the activity. Indicators of wellbeing include positive and negative ratings of affective, visual, verbal, behavioural, and social engagement with the activity.

For example, for "positive affective engagement", the observer must rate how much they agree that the patient ▷

▷ demonstrates “positive affect such as pleasure, contentment or excitement (eg, smiling, laughing, delight, joy, interest and/or enthusiasm).” Research has demonstrated that the EPWDS has good content validity, internal consistency, and inter-rater reliability (Jones *et al* 2018).

The patient was observed just prior to the activity commencing, ideally for a duration of 5-10 minutes. At the end of the LSW session, the observer calculated a total score for both the “before” and “during” levels of engagement. Immediately following the interaction, the observer also noted down a qualitative summary of observations of the patient’s experience.

When initiating LSW, we only approached people who were unoccupied. The staff member leading the session introduced the purpose of the meeting and asked for consent to proceed. They then started the interaction with an open question about the person’s life, interests, or something more specific, depending on the patient, such as: “So, I’m aware that you have an interest in X, please could you tell me a little bit about that?”.

After the patient had spoken about this topic, the staff member engaging them in conversation might transition to the digital life story platform by using a sentence such as: “Thank you for sharing that with me, that is really interesting, shall we add this to your book?”

## Findings

### *Feedback from staff*

Following the staff training sessions, a self-report survey was given to all attendees. This consisted of nine questions, eight of which were a 5 point Likert scale with the remaining one question being open ended. Among all 14 attendees, 79% of staff rated the value of the life stories platform as “extremely valuable” and 21% rated it as “valuable”.

On a scale assessing how confident staff feel to do digital LSW with patients on the ward, 14% reported feeling “very confident”, 71% “fairly confident” and 14% said “neutral”. No respondents rated negatively on these scales and staff also provided qualitative feedback (see below).

### *Platform utility*

Staff provided the following feedback: “absolutely fantastic”, “a game changer”, “really cool”, “can see the value”, “seems quite self-explanatory to use”, “can definitely see the value and positive impact on wellbeing, agitation and distress”, “multi-sensory has huge value”.

There were comments about its utility as a tool: “Very helpful in care and helps to explain to families patients’ current experiences and positive experiences”, “looking forward to using this”, “very inspiring - the value of the platform has been clearly demonstrated.”

One staff member also remarked on the value for “relatives to understand that we are seeing the real person, which will help with our communication with family as well as patients.”

### *Areas for consideration*

One staff member suggested a difficulty could be “overcoming barriers for people living with dementia that experience dysphasia” in terms of retrieving enough

information about them to input into the book. A support worker expressed the need for time to build trust and build relationships with patients, suggesting waiting at least a week before starting LSW.

A few staff members expressed the need for more practice using the platform and navigating it first before using with family. One more senior staff member felt that most staff will find it easy to use but felt that it would take a while for staff to use it more automatically.

### *Improved wellbeing*

Our findings are from eight participants and 12 session observations, using the EPWDS to observe engagement with digital life story work. We recorded a mean increase of 55% in total scores (figure 1, page 40) and 59% in the affect subscales, indicated through an increase in positive affect scores and a decrease in negative affect scores (figure 2, page 40).

## Discussion

Digital LSW and RT share the potential for past experiences to be triggered through a multi-sensory experience and there are well researched benefits of both, such as the enhancement of care through a person-centred approach (Gridley *et al* 2016), treatment for depression in those living with dementia (Yen & Lin 2018) and systemic cost benefit (Park *et al* 2019). Kaiser (2016) highlights the growing body of research around digital LSW and the promising indicators that it can build on paper-based LSW and might be more useful for triggering memories and enhancing relationships.

Feedback from staff taking part in the training demonstrates that digital LSW can be an enjoyable activity that, with some support, staff from any discipline are able to adopt. LSW is an intervention that all members of a care team can engage with to learn more about a patient and initiate more person-centred thinking that will impact on the care and wellbeing of patients or care home residents.

Given its universal accessibility, LSW is often cost-effective (Gramaglia *et al* 2021). Our initial findings of implementing a digital life story in an inpatient setting are consistent with the wider literature that a web-based life story can take life story work further than the paper-based version.

## Future research

This was a small, exploratory, descriptive study that aimed to embed digital life stories on an inpatient ward and to evaluate the effect on patient wellbeing. Future research might compare the impact of digital LSW with other interventions, as well as review larger datasets.

Consideration could also be given to collecting longitudinal data across inpatient wards, care homes and in the community that could be used to examine the effectiveness of digital LSW compared with other interventions such as music therapy, drug prescriptions and group-based activities.

Finally, qualitative studies looking at the effect on relationships with family members and carers could support further development in health and care settings. Such studies could build on the evidence from this study that digital LSW offers the established benefits of paper-

based LSW and brings with it additional layers, such as enhancing the sensory experience of LSW and supporting communication between carers, staff and the person living with dementia.

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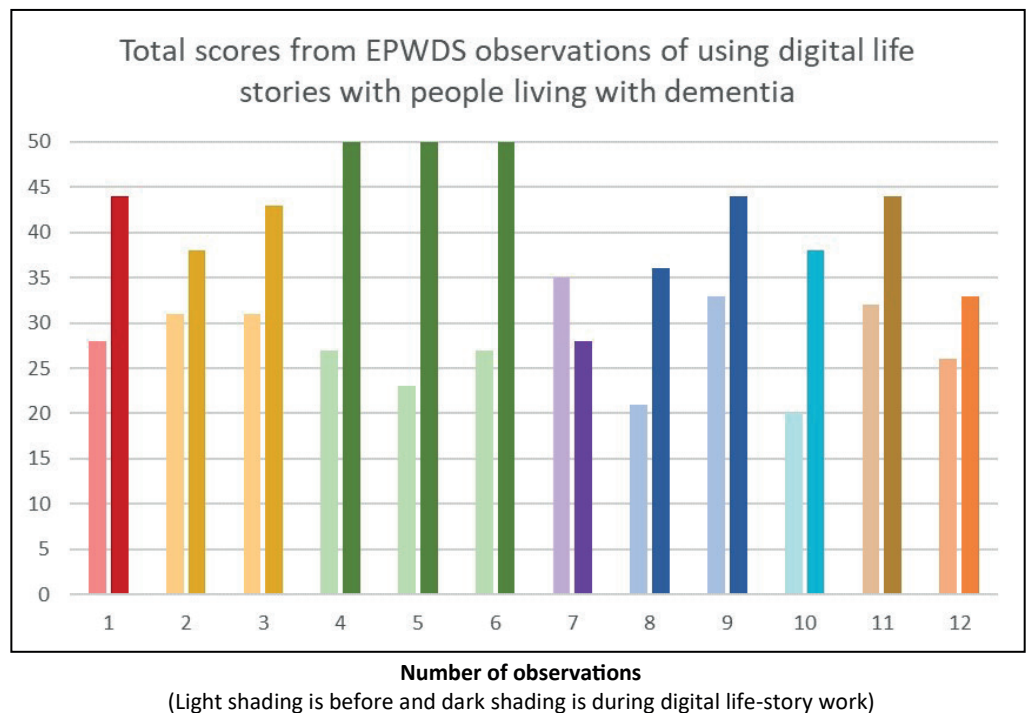
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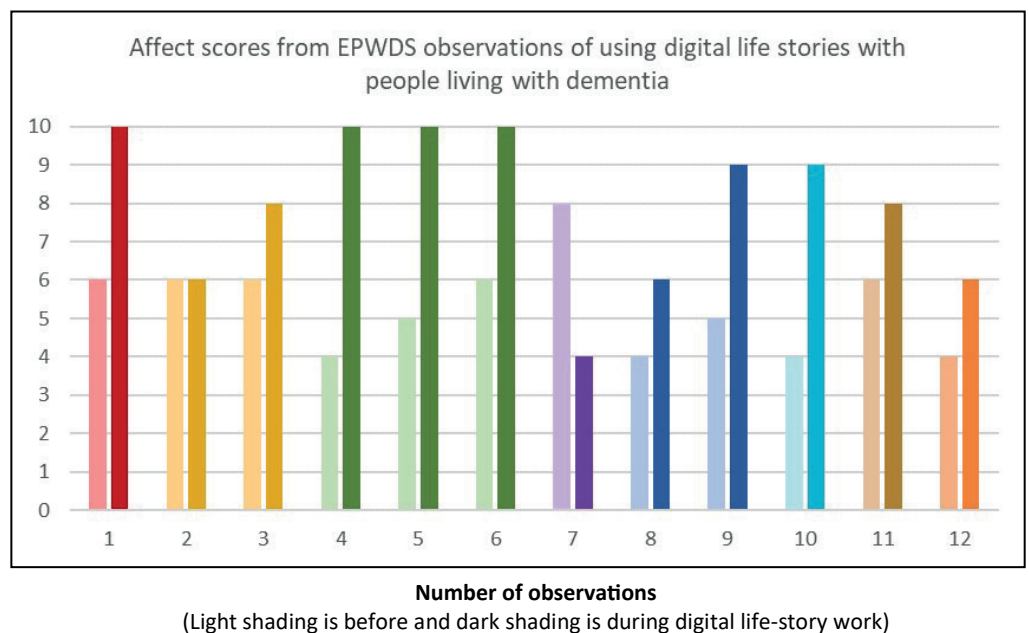
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Stargatt J, Bhar S, Bhowmik J, Al Mahmud A (2022) Digital Storytelling for Health-Related Outcomes in Older Adults: Systematic Review. *Journal of Medical Internet Research* 24(1) e28113.



**Figure 1:** This graph contains observational data from 12 pairs of observations using the EPWDS across 8 patients, 3 of which having had multiple observations. Bars in the same colour indicate separate observations of the same patients.



**Figure 2:** This graph contains observational data from 12 pairs of observations using the EPWDS across 8 patients, 3 of which having had multiple observations. Bars in the same colour indicate separate observations of the same patients. This graph represents the scores for only the negative affect and positive affect subscales.

Subramaniam P, Woods B, Whitaker C (2014) Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. *Aging & Mental Health* 18(3) 363-375.

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Yen H-Y, Lin L-J (2018) A Systematic Review of Reminiscence Therapy for Older Adults in Taiwan. *Journal of Nursing Research* 26(2) 138-150.

# Evidence for practice/Research news

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

We welcome contributions such as:

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

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

## Communicating a dementia diagnosis

Using existing literature and involving diverse stakeholders, this research sought to identify best practices in delivering a diagnosis of dementia. Best practice statements identified that clinicians should (1) show compassion and empathy (2) ask regarding diagnosis preferences (3) instil realistic hope (4) provide practical strategies (5) provide education and connections to high quality resources (6) connect caregivers to support resources and (7) provide written summaries of the diagnoses, plan and relevant resources. These statements provide a diagnosis communication framework that can be implemented across varied clinical settings. Further improving communication regarding dementia diagnoses will require health system changes, improved access to specialty dementia care and clinician training for delivering difficult diagnoses. Armstrong MJ, Bedenfield N, Rosselli M et al. Best Practices for Communicating a Diagnosis of Dementia: Results of a Multi-Stakeholder Modified Delphi Consensus Process. *Neurology Clinical Practice*. 14(1). Feb 2024. <https://doi.org/10.1212/CPJ.000000000200223>. Restricted access

## Avoiding 'Alzheimerisation' in vascular cognitive impairment

Through qualitative interviews with people living with vascular cognitive impairment and their family caregivers, this study identified five themes: (1) The assumption "no memory problem – no dementia" (2) Being respected as a person (3) Differing concerns about the future (4) The roles of the caregiver and (5) Decisiveness from professional healthcare staff. Care was affected by staff's lack of knowledge about characteristic symptoms of vascular disease; participants equated cognitive impairment or dementia to memory loss ('Alzheimerization'), although memory loss was not their biggest challenge. Decisive professionals could activate the person with vascular cognitive impairment who lacked initiative and diminish role conflict in the caregiver. The authors conclude that care could be improved by providing tailored information, promoting awareness of neuropsychiatric symptoms (particularly apathy) and by healthcare professionals providing more guidance in decision-making.

Van de Schraaf SAJ, Smit MF, Sizoo EM et al. Vascular cognitive impairment: When memory loss is not the biggest challenge. *Dementia*. Published Nov 24 2023. <https://doi.org/10.1177/14713012231214299>. Open access.

## Communication in moderate-to-severe dementia

This systematic review explored approaches for including the perspectives and preferences of people with moderate-to-severe dementia in research. Five specific communication tools were identified: Talking Mats, Augmentative and Alternative Communication Flexiboard, generic photographs in combination with a preference placement board, consultation ballot and personalised communication prescriptions. Each tool had advantages and disadvantages depending on dementia severity, verbal or physical ability, expense, researcher training requirements and ease of use. To support the use of the tools, the study identified five general approaches to optimising communication: ensuring conversations are individual and person-centred, managing external influences, engaging others, creating structure and facilitation skills.

Collins R, Martyr A, Hunt A et al. Methods and approaches to facilitate inclusion of the views, perspectives and preferences of people with moderate-to-severe dementia in research: A narrative systematic review. *International Journal of Older People Nursing*. Published Dec 11 2023. <https://doi.org/10.1111/opn.12594>. Open access.

## The impact of Alzheimer's on sexual activity

Through qualitative interviews with spouse-carers of people with Alzheimer's disease, this study explored the impact of Alzheimer's disease on spouse-carer's lives, marital relationships and sexual activity. Three themes emerged: psychological and emotional impact, social impact, and sexual impact. Some spouse-carers reported stress, poor emotional well-being, frustration, doubts about how to deal with the situation, sadness, loneliness, perception of losing connection with the partner and feelings of companionship disappearing. Others reported closer relations and greater affection for their care-recipients after the diagnosis. Changes in sexual activity were attributed to ageing and/or the effects of the illness. Participants reported conflicting perspectives towards the importance of sexual activity in the relationship and the replacement of sexual intercourse with

other modes of expressing affection. The authors believe that understanding the specificities of couples' marital relationships would be helpful for developing coping strategies for persons living with dementia and their spouses.

Moreira M, Nogueira L, Simões Neto JP et al., "Sexual activity for me is something else. It's the same as always: Sex aside and our love for each other." Changes in sexual activity in dementia from the view of spouse-carers', *Journal of Aging Studies*. Vol 67. 101193. Published Dec 2023. <https://doi.org/10.1016/j.jaging.2023.101193>. Summary text available online.

### **Gender minority experiences in residential services**

Sexual and gender minority (SGM) older adults are less likely to access long-term supports and services (LTSS), partly due to fears of discrimination. Furthermore, SGM older adults living with Alzheimer's disease and related dementias present unique challenges and opportunities for LTSS facilities. This scoping review identified three themes: (1) The experiences of discrimination among SGM residents in LTSS (2) The need for comprehensive staff training to ensure proper care of SGM populations and (3) The crucial role of inclusive facility policies.

Shippee T, Rosser BRS, Wright MM et al. Scoping Literature Review: Experiences of Sexual and Gender Minority Older Adults, with diagnoses of dementia who use Residential Long-term Services. *Journal of Applied Gerontology*. 0(0). <https://doi.org/10.1177/07334648231213532>. Restricted access

### **Virtual reality-based rehabilitation**

In order to examine the effectiveness of virtual reality (VR)-based rehabilitation training in improving cognition, motor function, and daily functioning in patients with mild cognitive impairment and dementia, a systematic review of published literature was conducted. It concluded that VR-based rehabilitation training is a beneficial non-pharmacological approach for managing mild cognitive impairment or dementia. An intervention lasting 5–8 weeks and for more than 30 min at a frequency of three times a week or more achieved the best results but training duration and schedules should be carefully considered for individuals.

Ren Y, Wang Q, Lu A et al. Effects of immersive and non-immersive virtual reality-based rehabilitation training on cognition, motor function, and daily functioning in patients with mild cognitive impairment and dementia: A systematic review and meta-analysis. *Clinical Rehabilitation*. Published Nov 20 2023. <https://doi.org/10.1177/02692155231213476>. Restricted Access.

### **Doll therapy**

This systematic review and meta-analysis explored the effectiveness of doll therapy (DT) on behaviour, psychology and cognition among older nursing home residents with dementia. It concluded that, although DT produced no significant difference in cognition, it significantly improved agitation, apathy, irritability and wandering, and psychological states (i.e., pleasure, anxiety and depression).

Peng Y, Liu Y, Guo Z et al. Doll therapy for improving behavior, psychology and cognition among older nursing home residents with dementia: A systematic review and meta-analysis. *Geriatric Nursing*. Vol 55, p 119-129, Jan-Feb 2024. <https://doi.org/10.1016/j.gerinurse.2023.10.025>. Open access.

### **Online dementia awareness course for carers**

For this research, 51 informal dementia caregivers were randomized into either an experimental (receiving the DAC course) or control group (treatment as usual). Outcomes relating to perceived burden, attitude, competence, relationship quality and positive caregiving aspects were measured at baseline and follow-up, alongside statistics relating to recruitment, retention, attendance, and adherence. The study found high retention and

attendance rates with low levels of unexplained attrition. The findings provide promising evidence for the feasibility, acceptability and impact of the DAC when delivered online to informal caregivers in the UK.

Patel R, Evans I, Stoner CR, Spector A. Investigating the Feasibility, Acceptability, and Impact of a Brief Dementia Awareness for Caregivers (DAC) Course: A Mixed Methods Study, *Clinical Interventions in Aging*, Vol 18, p 1923-1935, Published Nov 21 2023. DOI: [10.2147/CIA.S429556](https://doi.org/10.2147/CIA.S429556). Restricted access.

### **Non-Pharmacological care alternatives**

This abstract presents a range of non-pharmacological methods used in care for people with Alzheimer's disease as evidenced in published studies. It suggests that physical activities such as yoga and exercise have shown promising results in improving cognitive function. Meditation, mental imagery, music and creative expression are fun and relaxing activities and acupuncture has documented health benefits. Massage and aromatherapy are physically soothing, release tension and calm the mind. The authors highlight that, in order to increase their acceptability and successfully integrate them into clinical practice, more extensive evidence-based studies need to be conducted.

Yu-Tan E, Martinez Faller E, Tiwari P. Non-Pharmacologic Alternatives in the Management of Alzheimer's Disease. *German Journal of Pharmaceuticals and Biomaterials*. Vol 2, No 3. Published Nov 18 2023. <https://doi.org/10.5530/gjpb.2023.3.7>. Abstract.

### **Person centred care for sundown syndrome**

This study used focus group interviews to explore the experiences of nurses and nurse aides dealing with sundown syndrome in specialist person centred dementia units. The central theme was commitment; other themes included self-preparation, non-suppression, diversion, pacification, continuity of meeting and collaboration. The findings can inform care practices in long-term care settings and contribute to the development of education and training materials for staff.

Huang SF, Wang BY, Liao JY. Experiences of person-centered care for sundown syndrome among nurses and nurse aides in dementia special care units: a qualitative study. *BMC Nursing* 22, 435. Published Nov 17 2023. <https://doi.org/10.1186/s12912-023-01598-x>. Open access

### **Physical activity and Alzheimer's disease risk**

This meta-analysis sought to identify the relationship between physical activity and Alzheimer's disease (AD). It concluded that moderate to vigorous physical activity with follow-up of less than 15 years reduces the incidence of AD. The authors conditionally recommend physical activity as a modifiable lifestyle factor to prevent AD.

Zhang X, Li Q, Cong W et al. Effect of physical activity on risk of Alzheimer's disease: a systematic review and meta-analysis of twenty-nine prospective cohort studies. *Ageing Research Reviews*, Vol 92, Published Dec 2023, <https://doi.org/10.1016/j.arr.2023.102127>.

### **Dance Movement Therapy**

Dance movement therapy is an embodied psychological intervention that can address complexity and thus may be useful for people with dementia. This Cochrane Systematic Review concluded however that, although the literature in this area is growing, more research is needed in order to assess its effectiveness.

Karkou V, Aithal S, Richards M et al. Dance Movement Therapy for Dementia. *Cochrane Database of Systematic Review – Intervention*. Published: Aug 7 2023. <https://doi.org/10.1002/14651858.CD011022.pub3>

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