



SPIN DEMENTIA
NETWORK⁺

Sustainable Prevention,
Innovation and Involvement
for Dementia

Let's Talk Dementia: Fiction, Fact and Hope

*Festival of Science and Arts of Brain Health
& Dementia*

2nd and 3rd July

UCL East, Stratford, London

Programme and Speaker Biographies

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NIHR

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Marshgate, UCL East

Thursday 3rd July 2025: Lecture Theatre

Symposium: Staying well with dementia

Melissa Melville: Compassion-Focused Therapy for People with Dementia and Low Mood: A Feasibility Randomised Controlled Trial

Background: Anxiety and depression are common in people living with dementia and significantly impact well-being and quality of life. Despite this, few evidence-based psychological therapies are tailored to their needs. Compassion-Focused Therapy (CFT), which helps individuals manage shame and self-criticism, has shown promise in other clinical populations but has not yet been explored in dementia care.

Methods: We conducted a mixed-methods feasibility randomised controlled trial with 73 participants with mild-to-moderate dementia and symptoms of anxiety and/or depression. Participants were randomised to receive either group CFT (12 weekly sessions) plus treatment as usual (TAU), or TAU alone. Key feasibility outcomes included recruitment and retention rates, acceptability, and intervention fidelity. We also collected data on depression, anxiety, quality of life, quality of the carer–patient relationship, cognition, self-compassion and carer burden. Qualitative interviews with participants, caregivers, and clinicians provided additional insights into the intervention's acceptability and perceived value.

Preliminary Results: Findings to date suggest strong recruitment and retention, high fidelity to the CFT model, and positive participant engagement. Qualitative feedback indicates perceived improvements in emotional resilience and coping.

Conclusion: Group CFT appears to be a feasible and acceptable intervention for people with dementia. These findings support progression to a full-scale trial, pending NIHR funding decisions in July 2025.

Melisa Yilmaz: *GRACE (Goal Directed, Accessible & Evidence-based Care)*

GRACE (formerly NIDUS-Family) is a manualised intervention, helping people living with dementia and their carers achieve their personal goals with the help of a trained facilitator. It has been co-designed with and for people affected by dementia, prioritising their needs around living as well as possible at home. We found that this support helped families achieve and maintain their goals over 24 months and save the NHS approximately £9000 per person per year. We are now adapting this intervention to be implemented in primary care, secondary care and third sector services while making cultural and linguistic adaptations for our local Bengali community in East London.

Annabel Ditton: Is developing CARECOACH for people with dementia desirable?

CARECOACH is an online-hybrid intervention aimed at carers of people living with dementia which combines online resources with guidance from a human coach to promote better coping and improve quality of life. No similar intervention targets people living with dementia despite acknowledgements that dementia can negatively impact wellbeing, and that digital methods of providing support are feasible for many individuals.

Using semi-structured interviews including exploration of the CARECOACH visual prototype, thirteen people living with dementia provided data exploring whether, why, and how adapting this intervention might be desirable to be used by them. Five of these individuals were re-interviewed to refine findings to ensure people living with dementia's desires, needs, and voices were well captured.

Six themes were developed: 1). Understanding the current situation, 2). Appropriateness of adapting the CARECOACH intervention, 3). Motivation and setting priorities, 4). The impact of personal factors, 5). Incorporating into lifestyle, and 6). Supporting use. Findings also included the co-development of ten preliminary topics for the online resources.

Discussions indicated that people are often negatively impacted by a dementia diagnosis, and do not always feel the current level of support is adequate. Many wished for more support at diagnosis and felt positively about the adapting CARECOACH to meet their needs, believing access would have benefitted them and may benefit others.

Catherine Reed: Supported Holidays with Nature-based Activities by Dementia Adventure to Improve Wellbeing and Quality of Life for People Living with Dementia

Dementia Adventure is the only UK charity focused on supporting people living with dementia (PLWD) and their carers through meaningful connection with nature and the outdoors. Research consistently shows that time spent in natural environments can lead to significant improvements in sleep, appetite, and mood, while also reducing symptoms of stress and depression for those affected by dementia.

We currently offer 40 small-group supported breaks each year, delivered across 11 scenic locations throughout the UK. These breaks are carefully designed to promote wellbeing through engaging, nature-based activities. They also provide valuable opportunities for PLWD and their companions to reconnect with one another and build supportive social networks. Previous surveys show that 94% of PLWD enjoyed being outdoors, 78% increased their physical activity, and 90% engaged in more social interaction on Dementia Adventure supported breaks. Carers also reported improved understanding of dementia and greater confidence in providing care.

To build on this evidence, a wellbeing evaluation is currently being conducted. This study will assess the wellbeing of both the person with dementia and their carers at three key points: before the break, during, and after. The evaluation uses the Warwick-Edinburgh Mental Wellbeing Scales and has received ethical approval from Liverpool John Moores University.

Jurgen Grotz: Social Prescribing. In England, since the 1990s, and until the pandemic, the proportion of older adults involved as volunteers continuously increased from being the smallest to becoming the largest group of volunteers, by age. In 2016 AGE UK advised that "Later life is a time when many people wish to volunteer and make an active contribution to civic and community life..." At the same time evidence, including from the pandemic, suggests that giving up volunteering might have negative health effects, so being able to find volunteering opportunities or to continue to volunteer might be important to people living with dementia. However, volunteer involvement of and for people living with dementia is complex. Social prescribing tends to simply refer to dementia friendly activities. There is a need for balancing what is good and healthy for individual volunteers and the demands of a volunteering opportunity, as physical, personal, organisational and structural barriers affect individuals differently. This talk will briefly outline the complexity and set out strategies to inclusive volunteer involvement of people living with dementia.

Jane Cross: Developing social prescribing for people with dementia - how can this work?

The public health challenges of dementia are well documented. With UK dementia cases expected to rise to over 1.1 million by 2030, healthcare systems are poised precariously to meet the demands of a disease rooted in economic, clinical, and social complexities.

Social isolation and diminished quality of life are common experiences for people living with dementia (PLWD) and their carers. Currently, solutions to these issues are hampered by challenges in accessing post-diagnostic support and healthcare disparities. An alternative approach is required to improve social health outcomes for PLWD and enhance access to support.

Social prescribing (SP) is an emerging solution to this problem. SP connects people with complex social health needs to community non-clinical services. SP interventions are evidenced to deliver a better quality of life and re-engage participants in community life. However, its provision and efficacy for PLWD and their carers are largely unknown.

We have; Conducted interviews with SP link workers to understand the current SP provision for PLWD in the healthcare system; Run a series of PPI workshops to determine meaningful outcome measures for PLWD; Reviewed the current literature on SP interventions for PLWD and their carers in a complex intervention systematic review; Brought PLWD, carers, and staff practitioners together to capture the lived experience of using and providing SP services; and Identified areas for service improvement.

Biographies:

CHAIR: Jane Cross (UEA). My research is mixed methods focusing on older people experiencing the complexities of later life. I am particularly interested in understanding patient experiences and using these to develop and test multidisciplinary interventions. My mixed methods skills facilitate developing and testing these complex interventions in programmes of work culminating in clinical trials.

Annabel Ditton (Exeter). I am a PhD student funded by the University of Exeter where I am exploring the desirability of technology to support people living with dementia, particularly focused on its potential role for providing psychosocial support, using qualitative methods. I have interests in exploring dementia experiences, improving dementia support, empowering people living with dementia through research, and participatory action research.

Jurgen Grotz (UEA). Dr Jurgen Grotz is the Director of the Institute for Volunteering Research (IVR) at the University of East Anglia (UEA). He has over 30 years' experience of applied research across the academic, public, private and voluntary sectors. His largely interdisciplinary work about volunteer involvement has a strong focus on participative approaches and public engagement. He has co-edited the prestigious 'Palgrave Handbook of Volunteering, Civic Participation, and Nonprofit Associations' (2016), which has over 170,000 chapter downloads. More recently he co-authored the ground breaking 'Patient and Public Involvement in Health and Social Care Research' (2020) and 'Volunteer Involvement: An Introduction to Theory and Practice' (2022). Collaborating with colleagues in the field to drive advances in Volunteer Involvement research, he also co-edited 'Volunteering, research and the test of experience' (2022) and 'Mobilising Voluntary Action' (2022). His latest book 'Volunteer Involvement in UK Universities' is now available.

Melissa Melville (UCL). Melissa is a part-time PhD student and researcher specialising in cognitive ageing, dementia, and psychological wellbeing in later life. She currently works at North East London NHS Foundation Trust and University College London (UCL), where she leads a feasibility randomised controlled trial of Compassion-Focused Therapy (CFT) for people with dementia and low mood. Her PhD spans three key areas: evaluating CFT as a tailored intervention for people with dementia and low mood; conducting a World Health Organization (WHO)-commissioned systematic review on hormone replacement therapy (HRT) and its potential impact on dementia in postmenopausal women; and mapping post-diagnostic support across UK memory clinics to improve care pathways. Melissa is supervised by Professor Aimee Spector, Director of the UCL International CST Centre and the UCL Menopause Mind Lab.

Catherine Reed (Dementia Adventure). I trained as a Nurse and worked in various different specialities within the NHS including as a clinical research chemotherapy nurse. I left the NHS and joined the charity sector and have been with Dementia Adventure for 8 years now with 6 of those being Head of Adventures - by far my best job title! We are currently involved in research around the benefits of nature for people living with dementia. I am also co-authoring a chapter for a book around the benefits of adventure for people living with dementia.

Melisa Yilmaz (Queen Mary, University of London). Melisa is currently working on the INSTILLED Implementation study as a Research Assistant. Melisa has a BSc in Psychology from Durham University and an MSc in Clinical Mental Health Sciences from University College London. She has previously worked in the NHS as an Assistant Psychologist within Community and Inpatient Drug and Alcohol Services looking at the effects of substances on cognitive function. She is interested in cultural adaptations of non-pharmaceutical interventions for people with dementia and support for family carers.

Symposium: Memory Services

- **Louise Ritchie: Work Related Stress or Dementia?**
- **Aimee Spector: Menopause 'brain fog' or dementia?**
- **Charles Marshall: Timely, accurate and equitable dementia diagnosis**
- **Katrina Scior: Dementia and people with learning disabilities: Ensuring good lives through early detection and management**
- **Tom Denning: Hearing loss and dementia: prevention and beyond**

Biographies:

CHAIR: Tom Denning (Nottingham): Tom Denning is Professor of Dementia Research, University of Nottingham; and Honorary Consultant in Old Age Psychiatry, Nottinghamshire Healthcare NHS Foundation Trust.

Tom was appointed to his current post in 2012. His interests include a wide range of clinical topics and psychosocial aspects of dementia, and his main current research collaboration is around dementia and hearing conditions. He is one of the editors of the Oxford Textbook of Old Age Psychiatry, the leading international work in this field, 4th edition due in 2025. He is chair of the trustees of Trent Dementia Welcome - Trent Dementia - Helping people live well with dementia.

Charles Marshall (Barts Health NHS Trust): Charles is a Professor of Clinical Neurology at Queen Mary University of London where he leads a programme of research on timely and equitable dementia diagnosis. He runs a neurology cognitive disorders clinic at Royal London Hospital, and a multidisciplinary service with psychiatry in a community memory clinic at Mile End Hospital. He is the Clinical Director for Dementia for London.

Louise Ritchie (University of West of Scotland): Professor Louise Ritchie is the Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland. She is a psychologist, who's research focuses on understanding the experiences of people living with dementia with a focus on improving the lives of those living with dementia, their families, and their caregivers. Her current work focuses on employment and dementia, and she leads the ESRC, NIHR, and Alzheimer's Society-funded Working with Dementia Network Plus.

Katrina Scior (UCL): Katrina is Professor of Clinical Psychology and Stigma Studies at University College London, Director of the UCL Unit for Stigma Research and Co-Director of UCL's Centre for Research in Intellectual & Developmental Disabilities (CIDD). Katrina brings her expertise on stigma and on disabilities to ensure the network are mindful of the impact of societal and community attitudes towards dementia on the experience of people living with dementia and their families.

She has published widely on stigma and inclusion, focused on intellectual and developmental disabilities, mental health, dementia and stigmatised physical health conditions. Her past clinical work in the NHS was mainly with young people and adults with intellectual disabilities and autism.

Aimee Spector (UCL): Aimee Spector is Professor of Clinical Psychology of Ageing at University College London (UCL). Her research primarily focuses on the development and evaluation of psychosocial interventions for ageing, with a particular interest in global health, cultural inclusivity and implementation research in low-and-middle-income countries. She directs the International Cognitive Stimulation Therapy (CST) centre at UCL and the 'UCL Dementia Training Academy'. She also directs the UCL 'Menopause Mind Lab'; a research hub focusing on the impact of menopause

transition on both cognition and mental health. Current menopause research includes exploration of cultural differences in symptoms and help-seeking, and the development and evaluation of interventions to improve cognition. She has published over 180 peer-reviewed papers, 9 book chapters and 14 books; and is international lead for University College London's Clinical Psychology doctorate course. Websites:

- International Cognitive Stimulation Therapy Centre www.ucl.ac.uk/international-cognitive-stimulation-therapy
- Menopause Mind Lab www.ucl.ac.uk/pals/menopause-mind-lab
- UCL Dementia Training Academy www.ucl-dementiatrainingacademy.org