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

The SPIN Dementia Network+ was founded in 2024 and is funded by:







Wednesday 2nd July 2025

Marshgate, UCL East

Wednesday 2nd July 2025: Lecture Theatre

Welcome Address, 10:30-11:15

Georgina Charlesworth: I am co-lead for the SPIN-D Network, Professor of Clinical Psychology of Ageing and Dementia at UCL and Honorary Consultant Clinical Psychologist at North East London NHS Foundation Trust. I am a member of the British Psychological Society's Faculty of Psychology of Older People, the pan-European network of INTERventions in Dementia (INTERDEM) and the UCL Unit for Stigma Research (UCLUS).

Ruth Eley: I am the chair of tide and the charity is proud to be a strategic co-production partner for this research network. I will be enabling unpaid carers to get involved in the network and helping to ensure that their voices are heard and listened to in all aspects of SPIN-Dementia+'s activities.

Chris Fox: Chris Fox is an expert in mental health and dementia research. He was a full time NHS consultant 2000-2010 and during then undertook an MD on anger in elderly mentally ill patients at UCL. In 2010 he was appointed as the first Clinical Academic Psychiatrist at Norwich Medical School and he was head of department of clinical academic medicine until 2019-2021. He has been a clinical academic at the University of Exeter since 2022 and leads the NIHR health tech research centre (HRC) in sustainable technology and is national industry lead for the HRC coordinating centre in England. He runs an NHS memory clinic. He is engaged in international research in mental health and AI, Early diagnosis, treatment and prevention of dementia.

Clare Hammerton: Dr Clare Hammerton is SPIN-D's Coproduction and Involvement (PPIE) lead, based at the University of Exeter. She works with network members to involve people and carers throughout SPIN-D's activities and research. She also works with voluntary sector organisations across Suffolk to address and realise rural equalities.

Clare has previously worked with international, national, and local, statutory and voluntary sector organisations across the UK, Eastern Europe, Sub-Saharan Africa, and Centra Asia. Much of her work has been to lead programmes and evaluations on Health and Social Care provision to address the needs of people and carers with diverse and intersectional identities and experiences, including Dementia, LGBTQ+, Ethnicity and Religion, Learning – Sensory – Physical Disabilities, and Family Carers.

Clare's focused research is on the complex processes and components of mainstreaming rights, to address inequalities.

Symposium: State of the art in dementia prevention, 11:15-12:15

Prof Claudia Cooper: NIHR/ESRC APPLE-Tree dementia prevention programme,

APPLE-Tree: Active Prevention in People at risk of dementia through Lifestyle, bEhaviour change and Technology to build REsiliEnce

Dr Seb Walsh: A public health approach to dementia

Biographies:

CHAIR: Chris Fox. Chris Fox is an expert in mental health and dementia research. He was a full time NHS consultant 2000-2010 and during then undertook an MD on anger in elderly mentally ill patients at UCL. In 2010 he was appointed as the first Clinical Academic Psychiatrist at Norwich Medical School and he was head of department of clinical academic medicine until 2019-2021. He has been a clinical academic at the University of Exeter since 2022 and leads the NIHR health tech research centre (HRC) in sustainable technology and is national industry lead for the HRC coordinating centre in England. He runs an NHS memory clinic. He is engaged in international research in mental health and AI, Early diagnosis, treatment and prevention of dementia.

Claudia Cooper: I am a Professor of Psychological Medicine at Wolfson Institute of Population Health, where I am Deputy Institute Director. I am a consultant old age psychiatrist in East London NHS Foundation Trust memory services.

I led the NIHR/ESRC APPLE-Tree programme (Active Prevention in People at risk of dementia:Lifestyle,bEhaviour change/Technology to REducE cognitive decline) from 2018-24, investigating how lifestyle and behavioural change can prevent dementia in older people. I co-direct an NIHR Dementia and Neurodegenerative diseases Policy Research Unit (Queen Mary) and the new Alzheimer's Society Integrated Care Doctoral Training programme.

From 2018-24, I led the Alzheimer's Society Centre of Excellence for Independence at home, in which we developed interventions to support people living with dementia at home that we are now testing in implementation studies. I am a member of the UK Cabinet Office Evaluation Task Force Advice Panel, which advises and supports evaluations of national government programmes and policies; and an NIHR Senior Investigator. I am an honorary research fellow at University of Melbourne.

Seb Walsh: I am a public health doctor and dementia researcher, working at the interface of public health research and policy. I recently completed my NIHR Doctoral Research (PhD) Fellowship at the University of Cambridge. My research focuses on applying a population-lens to dementia, including primary and secondary prevention, and working directly with policymakers. I use quantitative and qualitative methods, incorporating perspectives from public health, epidemiology, clinical medicine, health economics, health policy, and social sciences. I am a co-author of the 2024 Lancet Commission on Dementia, leading on the 'Public Health Approaches' section. I founded and co-lead the international Population-Level Approaches to Dementia Risk Reduction (PLADRR) research group. I also founded and co-chair the Academic Special Interest Group for the Faculty of Public Health. I was awarded the Rising Star Award in the Alzheimer's Society 2024 Research and Care Excellence Awards.

Brain Health Question Time Panel: Can we reduce dementia risk?

13:15-14:15

CHAIR: Orii McDermott. Orii is a Senior Research Fellow at the Institute of Mental Health, University of Nottingham. Her research focuses on dementia psychosocial interventions, and she has a particular interest in co-production and working with diverse communities. As a NIHR/ ARC Dem-Comm Fellow, Orii works with Caribbean co-researchers to increase dementia awareness and acceptance within Caribbean communities in Nottinghamshire. Orii is a HCPC registered music therapist and continues to work as a clinician in Central and North West London NHS Foundation Trust. She is an Associate Editor for Nordic Journal of Music Therapy and serves on the Editorial Boards of the Journal of Music Therapy, Music & Science and Aging & Mental Health.

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Joan Viskant. Joan is a registered Nutritionist with the British Association for Nutrition and Lifestyle Medicine (MBANT) and Registered Nutritional Therapist with the Complementary and Natural Healthcare Council (CNHC). She obtained a BSc (Hons) in Nutritional Therapy from the University of Greenwich and a Diploma from BCNH College of Nutrition and Health. She has had a specialized interest in the Functional Medicine approach to health for the last eight years and has focused on complex cases in her private practice.

Joan's own long recovery from brain injury and experience of family members with dementia has led her to a focus on nutrition for dementia and healthy ageing. In 2024, Joan founded Jenny's Corner, an inclusive and dementia-friendly community garden and outdoor meeting space project aiming to support wellbeing for all ages.

Joan is currently giving nutrition talks for Hammersmith Council, the Creighton Centre and the Well-Being Programme at the London Mindsports Centre for 50+. Recently, Joan co-produced a meal-planner with members of the Good Life With Dementia as part of their peer-led training programme now running in Hammersmith, Hounslow and Ealing.

Symposium: Culture and Dementia, 14:15-15:15

Nick Farina & Jemini Bhatt: Dementia related stigma: where we are and where we are going?

Shuhala Abbas: Cultural Connection in Dementia

Emily Dodd: The south Asian dementia diAgnosis PaThway: an online toolkit of enhanced

interventions

CHAIR: Nick Farina (Plymouth). Nick has over 10 years experience working in the field of dementia research. His interests include understanding and improving quality of life of people with dementia.

Nick is currently is co-lead for the <u>DEM-SKY</u> project, which is implementing dementia screening in rural Kenya. In addition, he is the Primary Investigator for the <u>RadioMe</u> project which seeks to tackle agitation in dementia through the use of music and radio. In recent years he has led work packages on the <u>STRIDE</u> project, which sought to improve dementia care, treatment & support systems in middle-income countries so that people living with dementia are able to live well, whilst also ensuring that family & other carers do not shoulder excessive costs. Nick is an advocate for raising awareness about dementia internationally, and has developed a research theme surrounding better understanding attitudes towards dementia and how we can combat stigma.

Nick has previously been the project manager for the MODEM cohort study (<u>MODEM project</u>), and has been responsible for setting up and operationalising data collection for a number of large grant projects, including the Time for Dementia project and DETERMIND.

Shuhala Abbas (Alzheimer's Society). Shuhala Abbas- Local Communities and Volunteering Lead-London. Working to increase our impact and outreach in the marginalised communities. 20 yrs with the Alzheimer's Society, Working on health inequalities within health and social care sector.

Jemini Bhatt (UCL). Dr Jem Bhatt is a HCPC registered Clinical Psychologist and a Clinical Research Fellow at the UCL Unit for Stigma Research. In her research role, she is interested in understanding how stigma shapes the experience of dementia for those with a diagnosis and their family units. Jem has a special interest in intersectionality, health inequity and representation in dementia research and she actively contributes to national and international research programmes. In her NHS role she is a Macmillan Clinical Psychologist working in a Cancer and Palliative Care Service supporting those who have been affected with cancer as well as those within the last 6 months of their lives.

Jagdish Brar-Orgill (Manchester). I gave up my career to care and advocate for my dear Mum (living with Alzheimer's and vascular dementia), across all the fragmented services. Ensuring Mum remained in her own home, safe, nearly broke me. I am channelling my grief in raising awareness of the inequalities, inequities and lack of inclusivity within the dementia pathway for South Asian/marginalised communities and services afforded to them. It's imperative that our lived experience as carers/experts by experience is central to research to inform policy and services. Dementia doesn't discriminate, but services can. Culturally appropriate and inclusive representative voices matter. I want to help effect a change. Jagdish, former carer for her Mum.

Emily Dodd (UWE). I am a Senior Research Fellow in the School of Health and Social Wellbeing and a member of the Centre for Public Health and Wellbeing. I have worked at UWE Bristol since 2012, managing a number of varied projects in predominately dementia care. I have recently completed a collaborative NIHR funded project to develop an online toolkit to enhance the dementia pathway for

people living with dementia from south Asian communities raceequalityfoundation.org.uk/adapt/ (The ADAPT study).

I am working on further developments of the Living Well with Dementia (LivDem https://www.livdem.co.uk/) post-diagnostic intervention, a group intervention for people recently diagnosed with dementia. My research interests are on ageing well and population health in older adults, specifically, but not limited to dementia care and improving access to health and social care services in underserved and diverse communities. I am passionate about improving inclusivity and general public involvement in every step of the research pathway, from project conception to dissemination.

Symposium: Living Well with Dementia Risk, 15:45-16:30

Ollie Hayes, People at genetic risk of familial dementias

Madiha Sheikh, Preventing delirium

Katrina Scior, Living well with learning (intellectual) disabilities

CO-CHAIR: Louise Allan (Exeter). I am a Geriatrician with research and clinical interests in dementia and delirium. I will be working on the research evidence work stream and also the selection of research project grants.

CO-CHAIR: Christine Wise. Christine Wise is a retired academic and County Councillor. Having retired early to care for her husband, who had young onset dementia, she returned to research involvement on becoming widowed. She is currently involved in a number of projects and is an active member of the SPIN D Core Lived Experience Group.

Ollie Hayes (UCL). Ollie Hayes is a Research Fellow and PhD student at the department of Clinical, Health, and Educational Psychology. He currently programme manages the RD-TALK grant and is the trial lead for the IWARF project. His research focuses on improving mental health outcomes for people affected by various rare forms of dementia through improving access to and quality of information alongside facilitating interpersonal connection both in peer support style groups and with specialized health care professionals.

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 (CIDDR). 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.

Madiha Sheikh (UCL). I am an Associate Professor at UCL and a Consultant Clinical Psychologist in NELFT. My research focuses on psychosis, family caregiving, and cross-cultural mental health, particularly among South Asian and other ethnic minority communities. I also work on improving access to mental health services and understanding how cultural beliefs influence care pathways. I maintain active collaborations in South Asia to co-develop culturally tailored mental health interventions.

In addition, I focus on psychological care in intensive care settings, with a particular interest in recognising delirium early and promoting non-pharmacological interventions for its prevention and management. At the heart of my work is a commitment to making mental health care more inclusive, accessible, and culturally responsive.

Youth Involvement & Engagement Lab Brain Health Champions, 16:30-17:15

CO-CHAIR: Jacqueline Parkes (Northampton). Jackie's subject specialisms are dementia, mental health, public and patient involvement and engagement (PPI&E) and nursing research, with a particular focus on developing and implementing person-centred care pathways. She works extensively with local organisations to evaluate their provision of health and social care services, including community-based interventions for people living with dementia. She is the Chair of the Northamptonshire Dementia Action Forum (Formerly the Northamptonshire Dementia Action Alliance) and Chair of the Leicester, Leicestershire & Rutland Dementia Friendly Community Forum. Jackie led the development of Northamptonshire's Dementia Strategy in 2018, and is currently leading the Prevention and research work-streams in the revised 2024 version.

CO-CHAIR: Kritika Samsi (Kings College London). Kritika Samsi is a senior research fellow at King's College London, working on a range of studies that support the social care workforce for people with dementia and family carers. She is co-lead of the EDI theme in the INVOLVE work programme of the SPIN-D network.

Peter Middleton (PPIE). Peter Middleton is a passionate advocate, blogger, and volunteer living with young-onset Alzheimer's disease. Diagnosed in January 2019 at the age of 64, Peter has transformed his personal journey into a mission to raise awareness, support research, and challenge misconceptions about dementia.

Before his diagnosis, Peter served as a Police Community Support Officer (PCSO) in Northamptonshire for 12 years, following a career in IT consultancy. His experience in these roles, coupled with his diagnosis, has provided him with a unique perspective that he shares through various platforms. He authors a blog titled "Living with Dementia," where he documents his experiences, offers advice, and discusses topics ranging from daily challenges to broader societal issues related to dementia.

Peter is actively involved with several organizations, including the Alzheimer's Society and the Young Dementia Network. He participates in initiatives like Dementia Voice, contributing to the development of dementia-related projects and services. His dedication to volunteering and advocacy was recognized in 2023 when he was named a Coronation Champion by the Royal Voluntary Service, an honor awarded to individuals making significant contributions to their communities.

In addition to his advocacy work, Peter volunteers at the Burton Latimer Heritage Centre and facilitates a local dementia support group. He also engages in research through Join Dementia Research, participating in studies aimed at improving early diagnosis and understanding of dementia.

Peter's journey exemplifies resilience and the impact one individual can have in raising awareness and driving change. Through his writing, volunteering, and public speaking, he continues to inspire others and contribute meaningfully to the dementia community.