

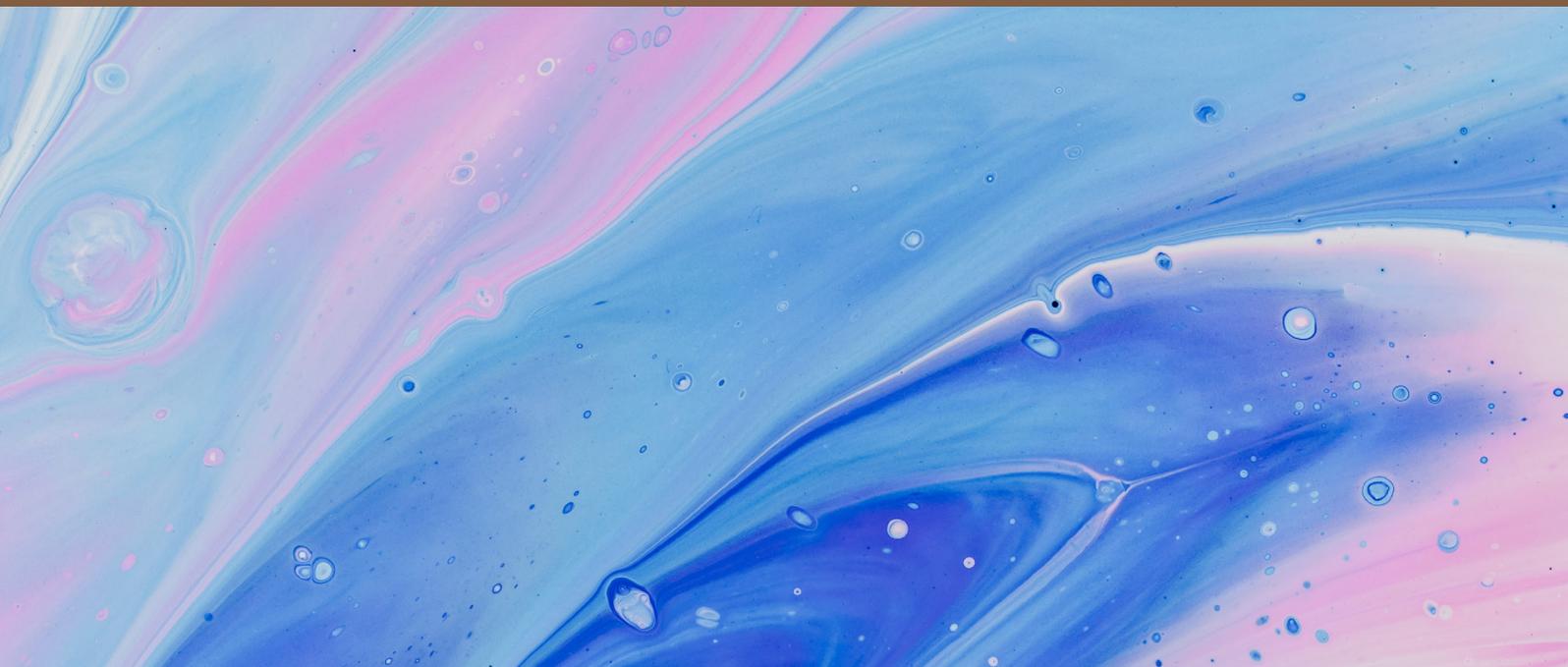


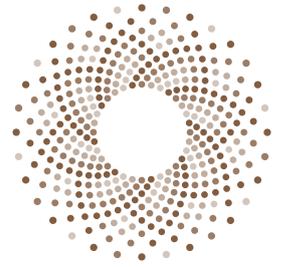
**World Dementia
Council** Leading the Global Action
Against Dementia

Global dialogue on lived experiences of dementia: Briefing

The dementia landscape project

1 November 2021





Global dialogue on lived experiences of dementia

Thank you for agreeing to take part in the dialogue on People Living with Dementia Dialogue on the 1 November 2021. You should already have received a diary invitation that includes a zoom link to the meeting. If you have not, please contact Melanie Saunderson (melanie.saunderson@worlddementiacouncil.com) who can resend the invitation.

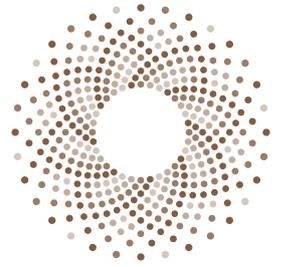
The World Dementia Council was set up by the UK government following the G8 dementia summit held in London in 2013. The Council was established to support and challenge the international community to deliver on the commitments made at the summit. There are 24 global experts who sit on the Council including two people living with the condition: Hilary Doxford and Maryana Lehmann who will co-chair the forthcoming meeting.

You do not need to do any preparation for the meeting. The Council would like to hear your perspective and experience on living with dementia.

The Dementia Landscape Project

Throughout this year the Council has been running the Dementia Landscape Project. The project is a global initiative to review international progress towards the 2025 dementia goals. At the dementia summit in 2013, G7 governments pledged to work together to make substantial advances in research, care, awareness-raising and prevention by 2025. It will assess the advances and identify how governments, international organizations and the dementia community can help accelerate progress.

Co-chairs



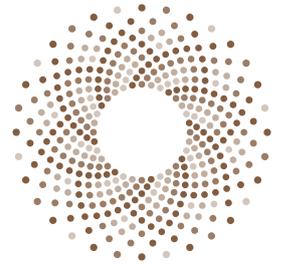
Hilary Doxford

Hilary Doxford is a former Vice Chair European Working Group of People with Dementia, Ambassador Alzheimer's Society speaking nationally and internationally as a person with dementia. She was diagnosed with early onset Alzheimer's disease at the age of 53. Hilary Doxford also volunteers for the Alzheimer's Society in England as part of their research network and user involvement programme; is a champion for "Join Dementia Research;" and is a member of Dementia Alliance International. She is a founder member of the UK Three Nations Dementia Working Group, established in 2017 to advocate for people with dementia and to collaborate with professionals working in the field.



Maryna Lehmann

Maryna Lehmann was diagnosed with dementia in February 2018 at the age of 58, and lives in George, South Africa. She was born in Johannesburg, South Africa, in 1960. She is the eldest of 5 siblings and matriculated in 1977. She enrolled for a BSc (Agric.) at Pretoria University and completed the Honours Degree in 1981. She married the same year. Her husband, André, retired in February 2019 to take care of her. In January 1982 she was employed as a farm manager of 300 sow piggery, 400 extensive cattle, 3000 head in feedlot. In the next 18 years she reared 4 sons and taught in numerous agriculture schools. On 1 January 2000 she joined Nelson Mandela University, as the Animal Science lecturer and completed a Masters Degree in Animal Science. She received numerous accolades such as upcoming researcher and upcoming teacher in 2006 and also received the "overall" teacher of the year award in 2007.



Logistics and agenda

Monday 1 November 2021

08:00 CDT Chicago
09:00 EDT New York / Toronto
14:00 BST London / Dublin
15:00 CEST Central Europe
16:00 SAST Cape Town

Duration: 60 minutes

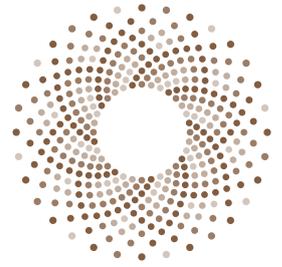
Location: Virtual (Zoom)

This meeting is to hear the perspective of people living with dementia. You don't need to do any preparation. It is to hear your experience – the good and the bad – on living with the condition.



Section	Speaker(s)
Welcome	Lenny Shallcross
Opening remarks	Hilary Doxford
Introductions	Hilary Doxford will ask everyone on the call to introduce themselves and say where they are from
Question 1	Based on your experience do you think things have improved for people with dementia?
Question 2	Based on your experience what are the biggest challenges living with dementia?
Quick fire round	What one thing would you ask your government to prioritize?
Closing thanks	Maryna Lehmann Lenny Shallcross

Participants



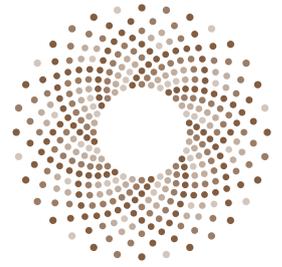
**Karen
Brochowitz**

Karen's background is in the corporate world. At age 62 her mother Joyce was diagnosed with Alzheimer's disease. This dislocated Karen and her family's life. Karen supported her father, Peter with caring. He passed away in 2002 and Joyce in 2011, 21 years after her diagnosis. Karen has presented globally, in the Medi-Help "Living with ..." She is a regular guest on national radio, TV and magazines. DementiaSA is the go-to organisation for support, information and training. They are successfully advocating for people living with dementia and local research is a key aspect of their focus. The wounds of this insidious disease have become her gift ensuring there is a social conscience around dementia in SA. She loves sewing, cooking and spending time with her two young adult children



**Arthena
Caston**

Arthena Caston was diagnosed with MCI in 2016. Prior to her diagnosis, Arthena was working in customer support for a large insurance company when she began noticing lapses in her memory. At home, Arthena found favorite pursuits, including reading, cooking, and routine trips to the craft store were becoming more challenging. Prompted by her worsening memory lapses, Arthena and her husband, Virous, shared their concerns with her primary care physician. After two years of visits to various specialists, Arthena received her diagnosis of MCI at the age of 51. After a period of reckoning with the news and "feeling numb," Arthena has regained a sense of purpose and passion for sharing what life is like living with MCI through volunteering and sharing her story. Arthena wants to encourage disease education and the importance of having conversations early when cognitive changes first appear. She also hopes to encourage others to live well with the disease. Arthena was appointed to the board of her local Georgia Alzheimer's Association chapter and was selected to serve as a member of the Association's National Early-Stage Advisory Group during the 2019-2021 term. Arthena



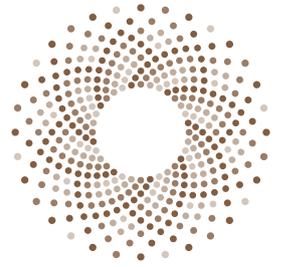
is currently a member of the Alzheimer's Association's national governing board. Arthena and her husband, Virous, live in Macon, Georgia with their two dogs. They have two adult daughters serving in the U.S. Air Force, and three grandchildren.



**Howard
Gordon**

Howard worked in healthcare for nearly 20 years before his diagnosis of Alzheimer's in March 2017. Howard is currently part of:

- World Health Organisation - Global Dementia Observatory
- United Nations Association
- Board Member, Producer and Presenter at Deepness Dementia Radio
- Disability Rights UK
- Consultant at Biohringer-Ingelheim
- Chronic Illness Inclusion Project
- Global Disability Summit - Partnership Forum
- Healthwatch Sheffield
- Dementia Enquiries
- Dementia Diaries
- DEEP group SHINDIG
- Sheffield Access Liaison Group
- Disability Sheffield
- Sheffield Dementia Action Alliance
- Sheffield Transport4All
- Northeast Sheffield Community Group
- South Yorkshire Dementia Research Advisory Group
- Alzheimer's Society Research Network
- Young Dementia UK Network
- Sheffield Home Care Service - Advisor
- Connecting Sheffield
- Lectures at Sheffield Universities
- Sheffield CCG
- Sheffield Health and Wellbeing Board
- Working with Dementia UK to bring Admiral Nurses to Sheffield
- Labour Party Yorkshire and Humber Disability Advisory Group
- Local MP and Councillors
- Facilitated 278 Online Memory Cafes since March 2020



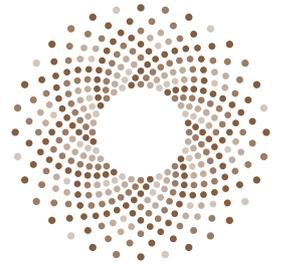
Julie Hayden is a Board Member Dementia Alliance International (DAI), a Founder of Young Onset Dementia & Alzheimer's (YODA), a Steering Group member of the 3Nations Dementia Working Group (3NDWG), Prime Minister's Champion's Group on Dementia and a Board Member Deepness Radio & Recovery College.

**Julie
Hayden**



In July 2016 I was diagnosed with Vascular Dementia when I was 60 years old, this was following a couple of minor strokes. I was diagnosed with Parkinson's disease in 2018 and with Lewy body dementia in 2020. I am an ambassador for Alzheimer's Society, Lewy Body society and National Activity Providers Association (NAPA). I am a steering group member of 3 Nations Dementia Working Group (3NDWG). I have spoken at national and international conferences as a person living with dementia. I am actively involved with Alzheimer's Society, speaking at various national conferences, such as the National Children and Adult Social Care and the UK Dementia Congress (2018). I have chaired the National Dementia Action Alliance, spoken at an International conference for Palliative Care and Dementia in Belfast in May 2019 and spoken at the dementia conference in The Hague (2019). This month I am speaking at a Lewy Body Masterclass in Belfast hosted by the Neurology Academy. I would describe myself as a dementia activist giving talks and lectures to a variety of audiences to raise awareness of dementia. I enjoy walking, gardening, taking walks by the sea and the woods observing nature.

**Christine
Maddocks**



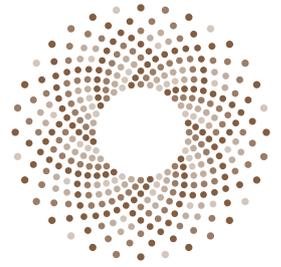
**Jim
Mann**

Since my diagnosis of Alzheimer's in 2007, I have been active in the community to reduce the stigma of Alzheimer's and other forms of dementia through volunteering in the community, collaborating with researchers on research projects and through my writing as a published author. Promoting the possibility of living well with dementia in the community, I worked with the City of Vancouver, Canada for their Dementia-Friendly City initiative to create Jim's Story. Current research projects include a focus on technology and robots in long-term care, the reduction of stigma and the promotion of social inclusion of people with dementia, and investigating consent and engagement in research with people with dementia, ethically and legally. In recognition of my advocacy toward the rights of people with lived experience of dementia, I was awarded in 2020 an honorary Doctor of Laws degree from the University of British Columbia.



**James
McKillop**

James was diagnosed with multi Infarct dementia last century, 1999. After a period of wallowing at home in self pity, he met a dedicated lady Brenda, who coaxed him back out, into a new world. He went with trepidation, and fearful of what he would find. He was not disappointed. A world where he thought, everyone would stare at him, and whisper behind his back. A world; where he had lost his citizenship, where everyone would doubt his judgement, where no one would seek his advice, where most would not ask him anything at all, not even the time on his watch, where some people who knew him and of his diagnosis, would cross the street, rather than engage in conversation, where invites to dinner parties and to social functions like baptisms, weddings and birthday celebrations etc dried up, where his employer decided not to take chances and dispensed with his services, where he could no longer babysit his grandchild by himself, where his driving licence was removed, where no one would partner him at the golf club/bowling club, where the phone would stop ringing, where the emails would get "lost" on their way to him, where notices of meetings did not arrive et cetera. However he made a new life – a good life – for himself, but that is another story.



**Emily
Ong**

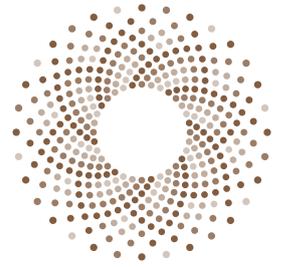
Emily Ong is the current Board Member of Dementia Alliance International (DAI) and has been living with young-onset dementia since 2017. A wife, a mother, a Special Educational Needs (SEN) advisor and a dementia advocate.

- Alzheimer's Disease International Accreditation Global Review Panel, member
- ADI Scientific Program Committee for ADI 2022 Conference, member
- World Health Organization (WHO) Global Dementia Observatory (GDO), Focus Group member
- Dementia Singapore Voices for Hope program, co-designer & co-facilitator



**Chris
Roberts**

I am married to Jayne Goodrick, we have 5 children and three grandchildren. I have vast experience in an array of jobs from Coal Mining, Farming, Sales and retail to owning a Custom Motorcycle Shop to mention just a few. We have a Property Rental business which is family run. I am living with emphysema and with mixed dementia, Vascular and Alzheimers. He spends a lot of my time raising awareness of dementia, its symptoms, services and support to dispel the stigma that is associated. I have spoken Nationally, Internationally wherever and whenever I can supported by my wife Jayne. Our lives were portrayed in a BBC Panorama Documentary titled 'Living With Dementia, Chris's Story' and in a BBC Wales, Week In Week Out program, titled 'Who Will Look After Mum, Dad or Me'. I'm very proud to part of Alzheimer Europe as a Member of the European Working Group of People With Dementia. An Ambassador for Alzheimer's Society UK/Cymru. Co-Founder & Member of the 3Nations Dementia Working Group (England, N.Ireland and Wales). Honorary Fellow & Lecturer in MSc Dementia Studies, School of Healthcare Sciences, Bangor University. Salzburg Global Fellow (International Seminar 587.). A Media Ambassador for Alzheimer's Research Uk. Ambassador for National Association of Care Caterers. Member of Dementia Alliance International (DAI) &

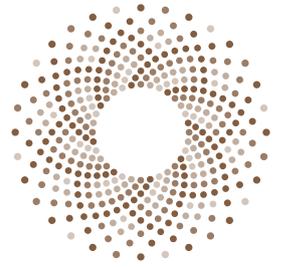


former Board Member. BSI Committee Member (British Standards Institution CH/315). I was a Member of the Expert Working Group for the Wales Dementia Strategy and part of the NICE Clinical Guidance Dementia Review Committee. An Ex Member of Young Dementia Network UK Steering Group. A National Dementia Action Alliance Affiliate Member. A Champion and Co Founder of Join Dementia Research. Outstanding Contribution Award Finalist 2015 and a recipient in 2016 as part of the People Awards. Uk Dementia Care Awards. Wales St.David Award finalist 2018. National and International Speaker on Dementia"



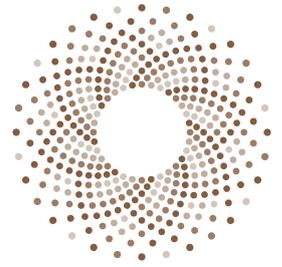
**Helen
Rochford-
Brennan**

Helen Rochford-Brennan is a Global Dementia Ambassador ,she is former Chair of the Irish Dementia Working Group and the current Chairperson of the European Working Group of People with Dementia and is the group's nominee to the Board of Alzheimer Europe; Helen is on the Monitoring Committee of Ireland's first National Dementia Strategy and WHO Focus Group Throughout Helen's time with these organisations she has campaigned to raise awareness of dementia through a Rights based approach, to the media, speaking at international conference's, engaging with pharma, scientists, clinicians, educators, students and many research projects from developing evidence –based diagnosis to palliative care to rural isolation. Helen is a former business person working at Senior Executive level in the USA and UK before returning to open her own business in Ireland; she has been very involved in community development wherever she has lived.



**Helga
Rohra**

Helga Rohra, in Germany, was diagnosed with Lewy body dementia nine years ago, in her mid-50s. A former translator, she initially wrote about her experiences under a pseudonym but abandoned this so that she could challenge perceptions of people living with dementia in a more public way. Helga Rohra worked as a freelance translator specialising in medical and scientific translations. Even before her diagnosis of Lewy Body dementia, she advocated for people with disabilities and dementia. She is Chair of the EWGPWD (European Working Group of People with Dementia) under the umbrella of Alzheimer Europe, Vice Chair of DAI (Dementia Alliance International), sits on the board of Alzheimer Europe, and is also the Chair of Trotzdemenz e.V. (a German organisation run by people with and without dementia to raise awareness of the condition). Helga lives with her son in Munich, Germany.



Previous global dialogues

Over the course of the year the Council has hosted ten global dialogues on research, care and ageing. All of the dialogues have been invite only meetings for global leaders in different fields. The dialogues have been on:

Biomarkers and treatments

Co-chaired by Dr Maria Carrillo, chief science officer, Alzheimer's Association, and Professor Philip Scheltens, professor of cognitive neurology and director, Alzheimer Center, Amsterdam University Medical Centers and chair, World Dementia Council.

Care

Co-chaired by Professor Brian Lawlor Deputy Director of the Global Brain Health Institute (GBHI) and Paul Hogan Chairman of Home Instead.

Prevention

Co-chaired by Professor Kaarin Anstey Senior Principle Research Scientist and Fellow of the Academy of Social Science in Australia and Professor Philippe Amouyel chair of the Joint Programme Neurodegenerative Disease (JPND).

Technology

Co-chaired by Jeremy Hughes former chief executive Alzheimer's Society and Vaibhav Narayan vice president Digital Health Innovation Janssen.

Clinical Trials

Co-chaired by Dr Maria Carrillo, chief science officer, Alzheimer's Association, and Professor Philip Scheltens, professor of cognitive neurology and director, Alzheimer Center, Amsterdam University Medical Centers and chair, World Dementia Council.

Dementia in low- and middle-income countries (LMICs)

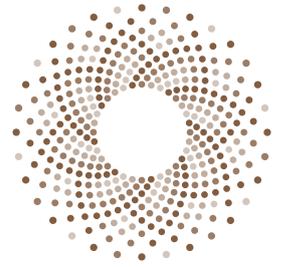
Co-chaired by Paola Barbarino CEO Alzheimer's Disease International (ADI) and Meera Pattabiraman chairperson Alzheimer's and Related Disorders Society of India (ARDSI).

Data sharing for dementia research

Co-chaired by Dr Lara Mangravite President of Sage Bionetworks and Dr Tetsu Maruyama executive director Alzheimers Disease Data Initiative (ADDI)

Dementia and an ageing society

Co-chaired by Professor Shekhar Saxena, Professor of the Practice of Global Mental Health at Harvard and member of the World Dementia Council



Health systems readiness and dementia

Co-chaired by Dr Margaret Hamburg, former Commissioner of the US Food and Drug Administration and member of the World Dementia Council, and Professor Howard Bergman, Professor of Family Medicine, Medicine (Geriatrics), and Oncology at McGill University.

Non-amyloid targets for disease modification

Co-chaired by Dr Maria Carrillo, chief science officer, Alzheimer's Association, and Professor Philip Scheltens, professor of cognitive neurology and director, Alzheimer Center, Amsterdam University Medical Centers and chair, World Dementia Council.

Over the remainder of the year there will be further dialogues on psychosocial research and the experience of early career researchers. Drawing on these expert insights, the dialogues are helping us prepare a report that will be published later this year at the Summit 2021 taking place in London in December.

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

worlddementiacouncil.org

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