



Sign up to our Monthly Newsletter

Welcome to our September 2026 newsletter from Deepness Dementia. As an Autumn chill begins to settle, I hope everyone's been wrapping up warm and enjoying the last weeks of sunshine!

My name is Sophie Smith, and I am the new Deepness Newsletter Editor. I officially graduated this year with a BA in Journalism, and have worked for Deepness since May 2025 as a Personal Assistant, first to Ron Coleman and now to Howard Gordon and Audrey Ross!

In this month's shorter newsletter, you will find a short note from Karen Taylor about the upcoming Gatherings and an article from Howard Gordon on why World Alzheimer's Month should be called World Dementia Month.

Please share this newsletter with your friends, family and colleagues.



If you want to contribute to the newsletter, please get in touch with - sophie@deepnessdementiaradio.com



**Check out below a list of what is coming up in this newsletter.
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A Note about The Gatherings

by Karen Taylor

Just a short note to let people know we hope to do 2 Deepness gatherings this year. The first will be in Dundee at the Malmaison Hotel on 2nd November.

The next day we will be running a gathering in Glasgow, venue to be confirmed.

What is a gathering?

Ron Coleman came up with the idea to gather people with dementia and cognitive impairment together for a day to discuss a topic relevant to the journey they are on.



Karen Taylor

This year, we will look at 2 topics: first, feedback on two workbooks that people with dementia working with Deepness have been creating on pre-diagnosis and post-diagnosis of dementia. We want people at the gathering to review the booklets and comment, suggest training, or suggest additions.

The second topic is on co-production and whether people with dementia have actively been involved in research, designing a product, services like a new meeting centre, and involved in feedback.

This is part of a research project Deepness has been involved in, funded through The Alliance.

Lunch will be provided.

Please email karen@deepnessdementiaradio.com if you are interested in coming

Could You Help Shape the Future of Deepness?

As Deepness continues to grow and develop, we are looking to welcome new members onto our Board of Directors.

Whether you are living with dementia or simply share our values and believes in what Deepness stands for, we'd love to hear from you.



You don't need previous board experience - just an interest in helping create a world where people living with dementia have a voice, opportunities to thrive, and are at the heart of everything we do.

We are looking for people who share the Deepness ethos, creativity, inclusion, hope and possibility, and who would enjoy helping guide the organisation into it's next exciting chapter.

It you think you could bring your experience, enthusiasm or a fresh perspective to Deepness, we'd be delighted to hear from you.

In the first instance contact Deepness Co-ordinator, Karen Taylor:

karen@deepnessdementiaradio.com

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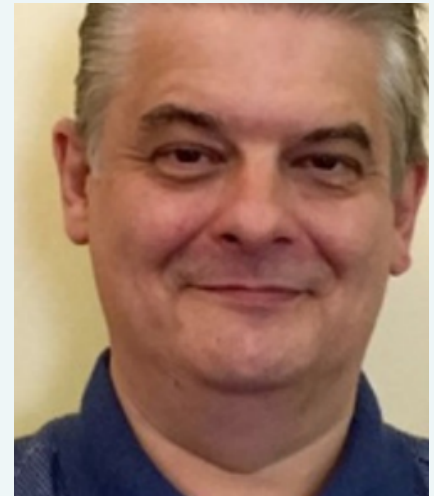
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Why World Alzheimer's Month Should Be Called World Dementia Month

Every September, communities around the world observe World Alzheimer's Month. The campaign aims to raise awareness of Alzheimer's disease, challenge stigma and encourage people to seek information, support and diagnosis. These are important goals.

However, the name of the campaign raises a broader question: should it be called World Dementia Month instead?



Howard Gordon

The main reason is simple:

Dementia is an umbrella term like Cancer; there are over 100 types of Dementia.

Alzheimer's disease is only one type of Dementia.

Alzheimer's disease is currently the most common cause, although if everyone with Alzheimer's disease who hadn't had a SPECT or PET scan was given one, the prevalence of Alzheimer's could be much lower. There have been many cases where someone has been diagnosed with Alzheimer's disease only using a Mini-Mental test, who several years later end up in Hospital unwell and are finally scanned and commonly found to have Lewy Body dementia and the Alzheimer's medication was what was making the Lewy Bodies worse.

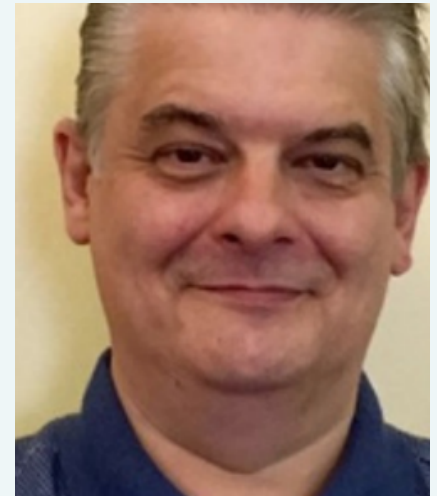
Dementia is an umbrella term covering a range of conditions that affect memory, thinking, communication, reactions to unmet needs and the ability to carry out everyday activities. Vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia are just some of the other forms that affect millions of people worldwide.

Howard Gordon

Why World Alzheimer's Month Should Be Called World Dementia Month



By focusing on Alzheimer's alone, we risk creating the impression that all dementia is Alzheimer's disease. This can lead to misunderstanding among the public, families and even some parts of the media. People living with other types of dementia may feel overlooked, while their families may struggle to find information and support that reflects their particular experiences.



Howard Gordon

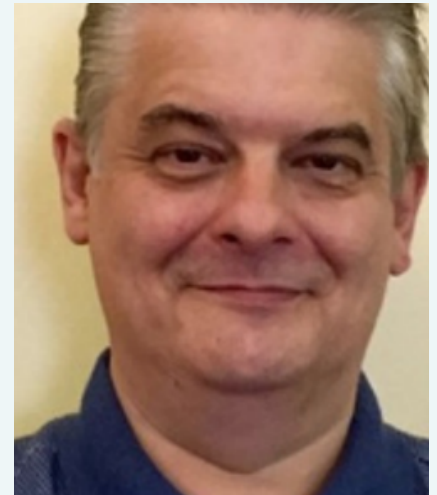
Calling it World Dementia Month would provide a more inclusive and accurate description of the issues being discussed. It would recognise everyone affected by cognitive decline, regardless of diagnosis. It would also highlight the fact that different types of dementia can have different symptoms, causes, rates of progression and care needs.

A broader name could improve public understanding. Many people still believe dementia is simply a normal part of ageing, or that it only involves memory loss. In reality, dementia can affect younger people as well as older adults, and symptoms may include changes in language, personality, judgement, movement and visual perception. Using the term "dementia" would create an opportunity to explain this diversity more clearly.

The change could also encourage a more comprehensive approach to research and healthcare. Alzheimer's research is vital, but people living with other forms of dementia need equal attention. Funding, clinical trials and specialist services should reflect the full range of conditions. A campaign called World Dementia Month could help reinforce the message that no form of dementia should be treated as less important.

Why World Alzheimer's Month Should Be Called World Dementia Month

There is also a powerful argument based on identity and inclusion. A diagnosis is not the only thing that defines a person, but it can influence the support they receive. Families affected by vascular dementia, Lewy body dementia or frontotemporal dementia may already find that their conditions are poorly understood. A campaign that explicitly includes them could reduce isolation and demonstrate that their experiences matter.



Howard Gordon

However, changing the name would not mean diminishing the importance of Alzheimer's disease. Alzheimer's would remain a major focus because of its prevalence and its enormous impact on individuals, families and health systems. Instead, Alzheimer's should be understood as part of the wider dementia community. A campaign can give Alzheimer's appropriate attention while also recognising the many other conditions that cause dementia.

The wording could also help shift the conversation from a single disease to a shared social challenge. Dementia affects not only individuals but also carers, families, workplaces, communities and public services. World Dementia Month would draw attention to the need for compassionate care, accessible diagnosis, carer support, dementia-friendly communities and better protection of human rights.

Howard Gordon

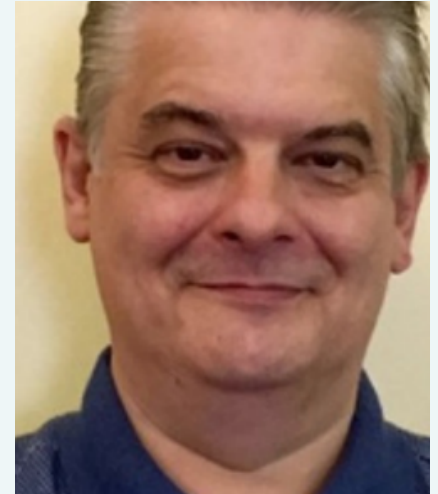
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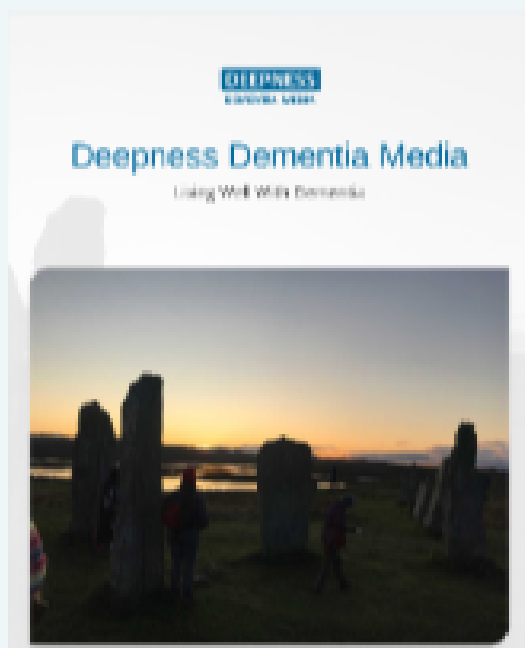
Language matters

The names used in public campaigns shape what people notice, discuss and understand. “World Alzheimer’s Month” has helped bring valuable attention to one of the world’s most significant health conditions.

But “World Dementia Month” would better reflect the full reality of cognitive disorders and the millions of people affected by them.



Howard Gordon



Dementia Media is a platform that gives people tools for living well with dementia designed collaboratively with those with dementia leading the process. By coming together in a supportive, energetic common space makes up a huge difference to the well-being of those going through dementia. As opposed to providing a cure, our goal is to help people become autonomous and get the most out of life. We bring a series of innovative projects - such as our radio station, online education courses, and much more - that use technology and music in a way that keeps people connected and stimulated.

“I didn’t want to die without leaving something for my family to enjoy and remember my strengths,” he says of the thinking behind the EP. “The whole concept was to create something that was a legacy for the person, and as soon as I thought about wanting to do that for myself I knew it was something other people would want to do, to leave our mark on society. It’s almost like leaving our families a gift.”

The Demented Poets EP is on sale now via Bandcamp iTunes and other outlets:

Bandcamp - <https://thedementedpoets.bandcamp.com>

Spotify - <https://open.spotify.com/album/6pngYVybZ3qUf6XMhOOFuK>

Deezer - <https://www.deezer.com/en/album/258048592>

iTunes / Apple Music - <https://music.apple.com/us/album/the-demented-poets-ep/1585080810>

Amazon - <https://www.amazon.com/dp/B09FRVYQ1F>

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