

“THE THINGS THAT HAVE HAPPENED TO ME SINCE I WAS DIAGNOSED...”

Hilary Doxford was diagnosed with early onset Alzheimer’s in 2012, and since then has volunteered for the Alzheimer’s Society and for Join Dementia Research. She first became a member of the Society’s Research Network, and later a Join Dementia Research Champion. Now as a member of the World Dementia Council, she works to promote global collaboration against dementia. She travels to meetings and conferences in many different countries, often talking about what Join Dementia Research has achieved, and encouraging other countries to set up similar initiatives

When she was first diagnosed, Hilary was surprised that her consultant was unable to tell her about any ongoing dementia research, “My first question was ‘How long have I got?’ and my second question was ‘What research is going on?’ But my consultant just shrugged his shoulders and said that he didn’t know - an expert in the field and even he couldn’t signpost me anywhere.”

She went home and looked for the information online, and came across the Alzheimer’s Society and its Research Network for people affected by dementia. Hilary had been a manager in another disease-related charity, so she knew a lot about clinical research and audits. “With that work background, they welcomed me into the Research Network and since then everything’s just sort of gone exponential!” she explained.



Hilary soon became an Ambassador for the Alzheimer’s Society and attended David Cameron’s G8 Dementia Summit in December 2013. She was then invited for afternoon tea at Number 10, along with five other dementia experts. The BBC filmed the discussion with the Prime Minister, which was a whole new experience, as Hilary described, “We were each allowed to ask him one question, so I just said to him ‘You said that dementia’s a national crisis, if it was a national crisis you’d be throwing money at it. Where’s the money?’ And he said, I remember this, ‘I don’t want to sit here adding up numbers, Hilary’. And I just sat there thinking, ‘But I DO want you to sit there adding up the numbers’. It had taken all my guts to get the first question out, and I hadn’t got the guts to say any more. So after that I made a mental note to myself that whenever you’re given an opportunity you grab it, and use it, and do it, because I had such an opportunity that day and I only did about half of what I wanted to do”.

Hilary later took part in a local research project, where she learnt from the researchers about how difficult it can be to recruit people to a study, “They were saying it was going to take two to three years to find 20 people. I couldn’t believe it! So many people with dementia and they can’t find participants! And it wasn’t even a high-risk study.

I was so frustrated by the trouble that researchers have. They've got skills they should use for finding cures, not for finding people to participate. So at that point I became a champion for Join Dementia Research."

Being a champion often involves giving talks to different groups of people. With all of her different roles, Hilary has given talks to health professionals, government staff, members of parliament, researchers, people with dementia, carers, care homes, church communities, charities, the National Institute for Health Research and even The World Health Organisation in Geneva. Looking back, Hilary concluded, "You know, it's just been incredible! The places I've been to, the things I'm involved in. I realise it has opened so many doors. If you're prepared to put yourself out there, there's so much you can do."

Hilary had no expectations of getting involved in this way, and in fact never used to like public speaking. She gained confidence from simply going out and doing it, as she explained, "I didn't want to do this sort of thing. I used to hate speaking publicly, absolutely hate it, but dementia is perfect for it,

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because when you go blank, or you forget the words, you just go, 'Hey, there's my problem!' So you don't have to worry about getting it wrong, because that's what dementia does to your brain, so it takes all that pressure off you. I actually really enjoy it now!"

Hilary has the following advice for anyone thinking about becoming a Join Dementia Research Champion:

- Recognise your strengths and your knowledge and think how you can apply those. If you're not sure about how you could use your experience, talk to one of the Join Dementia Research organisers and ask them what they think. There will always be a way you can contribute.
- There's a lot you can do without necessarily having to stand up in public. Just get involved in some simple way, even if it's just going down to your local Memory Café and making sure that everybody there has heard about Join Dementia Research. Talk to your friends and your networks. You don't have to do anything out of the ordinary. It's just a topic of conversation for one day.
- Start up conversations about dementia research with the people you know, whether you think it's good or bad, how to get people involved, and what could be done to make it better. Even if you don't want to take part in research yourself, you can still spread the word about it.
- Public speaking is not the only communication channel for Join Dementia Research. A lot can be done through local networks, like the Hand Out Hope campaign ([handouthope.today](https://www.handouthope.today)), where we are trying to get all the clinicians in memory clinics to hand out the Join Dementia Research leaflet. Giving out leaflets, which might only take a few minutes, is a very good way to get information about research out to people with dementia, and importantly will give them hope again.

For more information visit:

nhs.uk/joindementiaresearch.nihr.ac.uk