

HANDING OUT HOPE

While there is no cure for dementia, taking part in research often gives people affected by dementia hope again. When Chris Roberts was first diagnosed, research gave him and his wife Jayne, a new purpose in their lives. They now do all they can to 'hand out hope' to others, promoting dementia research and encouraging others to get involved.

Chris was given a diagnosis of vascular dementia and Alzheimer's in late 2012, aged 51. As Jayne described, "After the diagnosis, we left the doctor's consultation room feeling hopeless, but then when we became involved in a local research project - a project about peer support, upskilling people with a new diagnosis of dementia, and giving them information about things they could do on their own, to take back some of the responsibility for managing their condition. Whilst it was a non-clinical research, it did actually make us feel better! That gave us our hope back."

Chris and Jayne found out about the research via their Memory Clinic, which Jayne says felt like a stroke of luck, "We just happened to be in the right place at the right time, got involved in one project, and from there the rest is history." Soon after, the couple became members of the Alzheimer's Society and Alzheimer's Research UK, and volunteered to be Ambassadors. They got involved in the Join Dementia Research initiative, and have since become two of its most enthusiastic champions!

Wanting to help other people to find out about dementia research as early as possible, Chris started a campaign to encourage all GPs to tell their patients with dementia about research, "Myself and three others, we started our own campaign on social



media. We used the hashtag **#Hand Out Hope**. We wrote a generic letter and emailed it to every GP surgery we could find, introducing ourselves as people with dementia, and introducing them to Join Dementia Research. We told them about the importance of giving out this information and directed them to a toolkit online that they could use for free. It's already started to make a difference. So when the doctors are handing out information, they're now also handing out hope."

Jayne believes the campaign has helped to overcome some of the concerns about research and importantly enables patients to make a decision about research themselves, "Some professionals can be very reticent about mentioning research in case it upsets somebody, but if they don't offer it to us, how can we say yes or no? And as an ordinary member of the public, if we want to give something back, how are we going to do it, if we don't know where to go?"

In other promotional work, Chris and Jayne give talks about their dementia experience to groups of professionals as well as members of the public. Because of this they have become well-known locally, they are often invited to give talks, but sometimes they arrange the talks themselves. For example, if Chris sees an advert for a dementia-related event or conference, he will contact the organisers to ask if anyone will be speaking about the experiences

of people affected by dementia. If this hasn't been arranged, he will offer his services or suggest one of his peers. While they mostly talk about their experiences, Chris and Jayne use every opportunity to mention Join Dementia Research and explain how it works.

They are keen to talk to non-dementia groups as well as people affected by dementia, because dementia research often needs healthy participants as controls. As Chris explained, "We try to speak to people who are not necessarily in Dementia-ville! They may know someone with dementia or could be interested in research. Local groups, like the Rotary Club, the WI and community groups are good, because they meet regularly and are always looking for guest speakers."

Jayne also recommends targeting junior health professionals, "We just spoke to this year's cohort of students - about 500 nurses, allied health professionals, radiographers - at Bangor University. These are brilliant people to speak to, because they're new. They haven't become jaded by years on the job. So hopefully they will go into their new professional lives without all the myths, stigma and misconceptions about dementia."

Giving awareness-raising talks has benefited Chris and Jayne personally, as well as the people they talk to. Chris has found new purpose in his life as he explains, "That's something that everybody needs, especially when you're given a life-changing diagnosis. You lose confidence and you lose self-worth, but this is how I found my value again." Jayne says that the experience has "...made us a team again. We're going out and doing something together, and we're doing something about this condition, so we're winning." She believes it even has health benefits. "By doing all this Chris is having to use his brain. At home, you have a very limited vocabulary - what would you like for tea? What's on TV? Whereas when we're out and about, Chris is having to find the words, because he's having different conversations. I don't know how they would evidence base that, but it's definitely good for him!"

Chris and Jayne have the following advice for people thinking about becoming a Champion for Join Dementia Research:

- If you'd like to become a Champion, you're already half way there.
- Don't give yourself a big work load. Just do what you can, when you can. You don't have to go every Tuesday morning or whatever - it's as much or as little as you're able and want to do.
- It can be as simple as dropping some leaflets off when you next go to the GP or the chemist. Or just put on a Join Dementia Research T-shirt and give out leaflets at whatever is going on - garden fetes, car boot sales and open gardens. Just invite yourself along - it can take as little time as half an hour.
- Use Facebook, Twitter or your own networks. You can post links to information about dementia, talks and events and the Join Dementia Research Facebook and Twitter pages. In just a few minutes you can get that information out to an awful lot of people. And it's something you can do from your armchair!
- If you want to get more involved, you can become a Join Dementia Research Champion. We have regular meetings and they provide you with leaflets and information online. Find out more by emailing comms.jdr@nih.ac.uk - let them know your name, contact details and a brief description of how you would like to get involved.
- If you're a person with dementia, and you're able, then getting involved beats staying at home living with dementia. You could be out helping others and yourself instead. Being active and social really helps.

For more information visit:

nhs.uk/joindementiaresearch.nih.ac.uk