

“I’m only an expert on my own experience. There’s no way I can speak for everybody else – everyone’s an individual.”



Chris was diagnosed with mixed dementia at 50. Along with his wife Jayne, Chris campaigns for the rights of people with dementia, sharing his experience in groups and at events all over the world. Chris is an Ambassador for the Alzheimer’s Society, and the Vice Chairperson of the European Working Group of People with Dementia.

After being diagnosed with dementia, most people would turn inwards, focusing on themselves and their families. What made you decide to campaign for the rights of other people living with dementia?

It wasn’t an instant decision. Initially we were both in shock and a deep depression. It was a fear of the unknown, and a lack of knowledge can cause so much fear. We got the family together for what we thought would be our last holiday, and when I got back, I was still me. I started to do some research on dementia. As I learnt more, I started to be less afraid, and I realised that while most people had heard of dementia, very few understood it.

How did you start speaking in public about your experiences?

We attended a Dementia Friends session run by the Alzheimer’s Society. We thoroughly enjoyed it, and found it really informative and useful. We started to run Dementia Friends sessions ourselves. As well as giving us our lives back and helping us come to terms with living with dementia, we found that it was helping other people too. People would come to us and tell us how much these sessions were changing their lives.

Later on, we got invited to a conference about dementia in Leeds, and for the first time we saw people with dementia on stage, speaking about their experience, and realised that this was something that we could do too.

Your schedule is really hectic. What keeps you going?

What inspires me to carry on every time I think about stopping is when I get messages from families and people living with dementia, who now feel that they can start to live with dementia and, most importantly, don't feel alone any more.

What is your key message to the public about living with dementia?

Throughout the media, there's a focus on the late stages of dementia. It gives the impression that you get diagnosed and you're suddenly in the late stages of dementia. There's a beginning, a middle, and an end to dementia, but it's only the late stages of dementia that seem to get talked about or seen.

Even our own perceptions and thoughts about the disease were originally wrong. When I was diagnosed it took away my confidence, my value, my focus – it took away 'me'. You have to know yourself, get to know your illness and only then can you accept your new life.

You have to look past the diagnosis, and see the person as what they were before. When I received my diagnosis, we walked in as husband and wife, and left as a dementia sufferer and carer. That upsets the whole family dynamic, and puts so much stress on everyone. We have to change this. We should have walked in as husband and wife, and walked out as husband and wife.





Do you think that the voices of people living with dementia are starting to be heard now?

When I first started speaking about dementia four or five years ago, I'd only heard of a few other people doing this. For around three years, it felt like I was the only person in Wales talking about their personal experience of dementia.

There are now more and more people living with dementia coming forward and having their stories heard – it's fantastic, and it's working. It's almost giving people permission to act and permission to carry on with their lives. People are now seeing the positive side of what is a terrible illness.

We're normalising dementia, getting rid of the myths and the stigma, and inspiring other people to have their voice heard all over the world, not just here in Wales. The more of us there are and the bigger the voice we have, the more public awareness changes, and the knock-on effect of this is that services for people with dementia will improve.

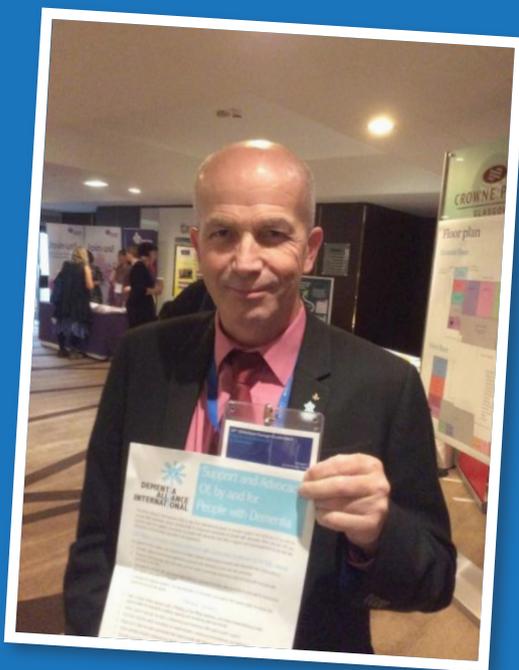
Things like Dementia Friendly Communities are having a big knock-on effect, opening people's eyes to understand that you can't make assumptions about people. It's helping to encourage people to support others in the community, not just people living with dementia, but all sorts of people living with hidden disabilities and hidden illnesses. If you get it right for people with dementia, you get it right for everyone.

You're part of a local support group for people with dementia and their carers. How did this start?

Our first thought about joining a support group was that we didn't want to hang out with a load of people with dementia. However, when we finally started our own group, we found out that everyone was thinking the same thing, and that they were just people like us. We meet in a pub. We all get a great degree of support by meeting together with like-minded people. What's important is that it's a safe place, with no judgements made about people and an unspoken understanding. You need to live, but you need to live and be social, and our group is a great way of staying connected.

What would you say to someone who was thinking about trying to make a difference?

Nothing is too small or too large. Just asking how your neighbours are or being patient when someone might be struggling in a supermarket queue makes a big difference. If you want do more, there are loads of people who will welcome, support and help you. Once you find these people, you can do anything. So many people want to help, often all you just need to do is ask.



For more information on DEEP (Dementia Empowerment and Engagement Project) groups in Wales, visit www.dementiavoices.org.uk or phone 07720 538 851.

For more information on Dementia Friendly Communities, visit www.alzheimers.org.uk.

To find a Dementia Friends session near you, visit www.dementiafriends.org.uk.