Join dementia research

NHS
National Institute for
Health Research

CASE STUDY - SUE BOEX

SHORT BIOGRAPHY

Sue became a carer for her father after he was diagnosed with dementia, providing support alongside her mother and sister. The family felt unprepared as they didn't know enough about the condition, nor was there much available in terms of effective treatment and care. Her father was diagnosed quite late and soon lost his ability to speak.

Sue wonders how long he was struggling without telling anyone. This is what has motivated Sue to get involved in research. She wants to help raise awareness so that people seek diagnosis sooner and families are better able to cope. She wants to help researchers to find new drugs, "*I don't want anybody else to be in the position we were in. There's a cure out there and it is everyone's goal to find it. Everybody has to do their bit*". She also wants to support research that aims to help people manage their condition and improve the quality of their lives, "*It's all the spin offs of the disease, like people in hospital becoming confused and malnourished because they forget to eat, or living on their own. People shouldn't have to suffer. I'm really passionate about that and that's what spurs me on*".

"You need to be the voice of the patient and remind them why they are doing it"

Sue got involved in research through the Alzheimer's Society. She joined their Research Network and has been involved in reviewing research proposals and monitoring funded projects. She then joined the Dementia Clinical Studies Group for DeNDRoN and has become an adviser for a number of research studies. In these advisory roles, Sue believes she adds value by bringing the carer's perspective, "*The researchers are so enthusiastic about their research, sometimes they forget there is a patient at the heart of it – you need to be the voice of the patient and remind them why they are doing it*". For the past two years, she has also worked as an adviser and champion for the 'Join Dementia Research' project which she hopes will encourage more people to take part in research.

Most recently, Sue has become a co-researcher on a project at Warwick University jointly with Alzheimer's Society, which aims to improve care for people with dementia after they leave hospital. She has received training and will be carrying out interviews and helping to analyse the data. Again, she will be using her experience to help keep the research grounded and meaningful for patients and carers.

SUE BOEX – CHAMPION FOR JDR

Sue became a carer for her father after he was diagnosed with dementia and subsequently volunteered at the Alzheimer's Society. Through them she got involved in the 'Join Dementia Research' Project and worked with the JDR team from the beginning. She is now a JDR Champion. We talked to her about her experience of working on the project.

WHY DID YOU GET INVOLVED IN JDR?

Unfortunately if you get a dementia diagnosis there is very little hope because there's no cure. People must have hope and help to live and cope with the disease more comfortably. That's why I'm passionate about research to find a cure. We need to get more research done and get more people taking part - the JDR service is one way we can do that.

Join Dementia Research is for both the researcher and the person with a diagnosis and you can also sign up if you're a healthy volunteer. The researchers enter their projects and the patients put on their personal and health details. If they match up, then the researchers can get hold of the patients straight away. It will really help speed up the process of finding people to take part in research and help the patients find out what is going on in their area and nationally.

HOW WERE YOU INVOLVED AT THE START?

We had a lock-in for three days! There were a large group of us, including two lay people and we started from scratch. We designed the whole thing – the colours, layout and thought about what questions to ask people and what the researchers wanted, and discussed governance, policies and security. So our views were taken into consideration from the beginning. For example, it will be important for patients and carers to go back to the website and get updates, but we realised that people have memory problems and won't remember to do that, so the team have been thinking about how to send out reminders.

HOW ARE YOU INVOLVED NOW?

The project has taken about two years to get off the ground and now we're preparing for the national launch. I'm one of the Champions. We have had some media training and we've got posters and leaflets. I'll be going out and doing the ground work locally, giving talks about the service and encouraging people to sign up.

HOW WILL YOU BE HELPING AND ENCOURAGING PEOPLE TO SIGN-UP TO JDR?

By trying to raise awareness. People might not be used to the internet, so we've made sure that there are other ways to add your details. There are paper applications and if you're in trouble you can go to one of the two Alzheimer's charities and they will help you through the process

Another worry for people is putting their details onto a computer, when they might not want others to know they've got memory problems. So we've put all the safeguards in place to keep the information confidential. I know how carefully all these things have been gone into so I'll be able to reassure people that they can have confidence in the system. Their details are not going to be sold off anywhere. As a patient, you can obviously look at all the research proposals, but you have to sign in and can only look at your own account - not any other patient's. It is also an important feature that a carer can register for the people they care for.

I also want to reassure people that they won't be pressured into anything. If a match is found then the researcher will contact them. Then they have the opportunity to ask as many questions as they want before they decide whether to take part. If it's something they don't feel comfortable with, they don't have to say yes. You can do as much or as little as you want to.

WHAT DO YOU WANT TO TELL PEOPLE ABOUT JDR?

The message is "Help us to beat dementia". We all want a cure – it's a simple message and I know that people with memory problems are desperate to be on a research programme. It's up to everybody to do their bit because we can all get this awful disease. I want people to sign up and visit the website – so that people become more aware. There's a lot of research going on. There's a lot to be positive about, but also lots more work to be done. We need everybody to help.