

Shelley Sheppard - April 2018

A mother of five was diagnosed with Alzheimer's at the age of only 44 after she missed her daughter's parents' evening. Shelley Sheppard now relies on notes to remember to do simple tasks such as turning off the oven, putting on a wash or recalling certain words. Her husband Paul, 49, even has to write the date and the year on a board every day before he goes to work so she does not forget. Mrs Sheppard, from Newark, Nottinghamshire, said: 'To hear those words, that I had early-onset Alzheimer's - it was absolutely devastating. There has been a lot of tears. It's having a huge impact on my life and it's only going to get worse over time.' Mrs Sheppard is mother to 5 and she has two grandchildren and another on the way but is terrified of forgetting them. 'I know I will forget them - it is an inevitable part of the disease,' she said. 'I can't imagine me sitting there in complete ignorance while my family's hearts are breaking because I don't know who they are. It hurts too much to think about it. 'My long-term memories are better and our two grandsons have both just turned four so I know them. What if I forget my new granddaughter? It is terrifying. We all try to stay positive and we try to joke about it as much as possible. 'When I tell people about sharing my story I ask if they want my autograph now before I forget my own name. You have to joke because if you didn't you would just sit and cry all the time.'



Mrs Sheppard was a carer for her mother until her death aged 72 in 2015. It was during this time that her memories started to become muddled. Her family put it down to the stress of caring for her mother, but last tests revealed she had the disease, which typically affects much older people. 'I'd never had any concerns about my memory but I went to the GP with dizziness last year,' she said. She was referred to hospital and sent for an MRI scan which showed she had had a 'silent' stroke. 'Many people will have them and never realise,' she said. 'It affected my brain function. 'My husband mentioned about my memory then because he'd noticed things were getting quite bad. My mum had lung cancer and I had been her carer so we thought it was just the stress of looking after her. I was referred for cognitive testing [and] after a PET scan they discovered Alzheimer's. 'I had further tests then went to see a clinical psychologist and that's when I was given the diagnosis.'

Mrs Sheppard had started to miss important events and meetings after her mother's death. She realised something was seriously wrong when she missed her youngest daughter's parents' evening. 'Last March Paul said to me, "Why didn't you go to your daughter's parents' evening? I've been telling you for weeks". I'd forgotten. It was as if he'd never told me,' she said. 'The school send texts to keep parents up to date and my daughter had given me a letter about it but I'd forgotten. It's heartbreaking.' She even started to believe her family was against her. 'The kids would speak to Paul about going out with friends and I would have no idea what they were talking about. They would say they had told me but I was adamant they hadn't, it was so confusing. 'Paul and I have never argued, but we started to have these little spats. The more and more the kids and Paul would tell me about things that I couldn't remember, the more I felt like they were all doing it to gang up on me. It made me so angry. I felt they were trying to make me look stupid. 'When I forget it doesn't feel like I cannot remember, it feels like things never happened. It felt like everybody I loved

was lying to me.' Mrs Sheppard has found it difficult to come to terms with Alzheimer's and feels there is not enough support for younger sufferers.

Only 4 per cent of those with the disease are under 65. Early-onset Alzheimer's tends to affect those in their 40s, 50s and 60s. Women are twice as likely to get Alzheimer's as men, partly because they live longer. Around 520,000 people have Alzheimer's in the UK, 40,000 of them under 65. There are support groups for older patients, but Mrs Sheppard fears attending one would give her an unwelcome glimpse of her future. She is on Donepezil, which is designed to improve understanding and behaviour in Alzheimer's patients, but the tablets make her sensitive to sound, which can be hard in a noisy family home. Doctors cannot say how her Alzheimer's will progress. Mr Sheppard, a store assistant who has been married to his wife for 16 years, said: 'The worst part is that we don't know how long it's going to be until the person we love isn't going to know who we are. 'Shelley sat me down and told me she wasn't going to put me through having to look after her and explained that she could take her own life. I was devastated to hear her talk like that. The worst thing is I couldn't tell her it would get better, I felt helpless. All I can do is explain to her that no matter what, she will never be a burden. 'Shelley has always looked after us and she's always been able to keep on top of five things at once. This illness has taken that away from her; now she needs our help.'