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Please remember the real me when I cannot remember you

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In this interview, Julie White speaks to *Neurodegenerative Disease Management* about her experiences following her husband's diagnosis with early-onset Alzheimer's disease, the impact that this has had on their lives, and what she would like to pass on to doctors treating patients with this diagnosis and others in this situation.

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When was your husband diagnosed & what were his initial symptoms?

Initially Stephen's symptoms were difficult to detect. He lived a 'big' life at a fast pace, and he was larger than life. He had an executive assistant looking after his business life, and I also worked in the company and knew the day-to-day operations. Our family life ticked over smoothly because I ran a 'tight ship' as Stephen spent so much of his time traveling.

On reflection, the symptoms were practically indecipherable, and Stephen was very canny about concealing his illness because he had people in place to support him. Daily he misplaced his keys and wallet, about which we teased him. However, I noticed that he was uncharacteristically stressed when packing for a business trip, unclear about the details of when and where he needed to be, mislaying his travel agenda and worrying if the taxi would show up on time.

A memory of his 65th birthday haunts me. We were at our favorite restaurant in France with family and friends. A photographer strolling through the tables asked if we would like some pictures taken. I said 'yes'. The photographer then asked Stephen if he would like a photo of just the two of us. Stephen flatly refused. I tried coaxing, but he simply said no. It was such an out-of-character response from my loving husband that I was alarmed. Later, when I asked him about it, he had no memory of the incident.

In 2016, one of our senior colleagues mentioned that Stephen's recollection of what was discussed in meetings was hazy, and he repeated the same questions time and again. Stephen had undergone a kidney stone operation and major hip operation the previous year plus two further kidney stone operations. He had recovered well from the operations, but he had been subjected to two rounds of anesthetics and a great many painkillers. A neurologist later told me that significant operations could bring on Alzheimer's earlier than would have otherwise been the case – Stephen was one of those very unlucky ones.

In discussions with our GP, we decided to take Stephen off the prescribed statins as the press had linked them to memory issues. However, when there was no improvement, Stephen began to acknowledge he had a memory problem. In the autumn of 2016, he finally agreed to a full cognitive evaluation at University College Hospital (London, UK). Following 2 h of grueling testing, he told me he did not think he had done very well. Some months later, the results came in: *"These results reflect a significant degree of intellectual decline, especially on nonverbal tasks with an abstract reasoning component"*. I read the report and knew I could not share its contents with Stephen or anyone else. I filed it away and began to think of a plan to keep whatever was happening at bay.

How long did it take to receive a diagnosis & were doctors helpful in this respect?

As the years went by, Stephen's ability to recall things worsened and issues with word-finding began. An atypical lack of empathy came to the fore, and he made nonsensical decisions and said odd things. Eventually, he agreed to a brain scan. With no time to waste, we chose an eminent neurologist in W1 who conducted the test.

18 January 2018, 6 pm will be forever imprinted in my mind. Our GP joined the meeting at the neurologist's office, and the two doctors had spoken before Stephen and I arrived. The four of us sat down, and the neurologist explained the parts of the brain. The channels that were enlarged in Stephen's brain and the white areas indicated that he had early-onset Alzheimer's. I experienced a thunderous rushing in my ears, and shakily took Stephen's hand to reassure him, but he appeared unfazed. I then realized he was not able to process the enormity of what had been said.

I will never forget the moment, we stepped outside into the crisp cold air on that January evening. People were rushing to get home, and yet we stood anchored to those black railings, unsure whether I could put one foot in front of the other. Stephen, a man of many ditties, when faced with a problem, always said 'throw money at it if you can'. That is precisely what we did that evening. We walked to our favorite restaurant, had a lovely dinner and did not mention what had transpired in the doctor's office. Stephen only referred to his diagnosis twice in subsequent years. I have never recovered from the shock and it is with me always.

What was the immediate impact on your husband & yourself? Were you provided with any specific support?

The neurologist gave me a card for Admiral Nurses (the only one in London) and said Stephen could 'work strategically' at his company. He prescribed a low dosage of one of the drugs for Alzheimer's, and we made an appointment to return in 3 months. The drugs had particularly unpleasant side effects, and when we returned, the medication was changed. We also saw the neurologist at our NHS practice, where a great deal of research into dementia was being conducted. We were asked if we wanted to participate, but I decided that rather than committing our immediate future to clinical trials we should get on with life and revisit some of the places we loved while Stephen could still travel. Dementia has many versions and because of this the medical profession find it difficult to give a clear trajectory of the deterioration and the associated timelines. This makes it so terribly difficult for the family to know what to expect and when. In our case there was only 26 months from diagnosis to Stephen moving from our family home into nursing care; our timeline was breathtakingly short.

This would obviously be a difficult situation in any circumstance, but what particular challenges have been presented by your husband's age at diagnosis?

My husband was *NEVER* going to retire. Over time he had planned to take a step back from the business he founded, nurtured and loved, but he would *ALWAYS* work. Having to tell Stephen that he could no longer work, interact with and advise his clients was one of the toughest key messages I had to deliver. Another was telling my husband, a man passionate about cars, that he could no longer drive. Every day he blamed me. Stephen was in his late 60s and very physically fit at the time of diagnosis. Trying to substitute his daily work routine for activities at home was extremely challenging. While Stephen was still capable of understanding, we decided not to tell our children, my stepchildren, or in fact, anyone. Our children (20 and 22 years old) had their lives ahead of them. I wanted them to have the freedom of life for as long as possible without the burden of this crippling diagnosis. They recognized that their father was having many difficulties. However, there is a difference between suspecting something and having the cold hard facts of a medical diagnosis.

Your husband was diagnosed 2 years ago; how has the condition & your management of it, changed over time?

I do not agree with the use of the word 'condition' Alzheimer's is not a condition; it is a terminal illness.

We traveled extensively until July 2019. By September, I realized that the illness was rampant, and I employed live-out carers to help him, take him out and try to keep him active. I joined at least 20 special dementia days out: Lords, Transport for London, Song Haven concerts, the list went on and on. I took control of the business – a respite from this impossibly cruel illness which was devouring Stephen and derailing my family. Stephen continued to deteriorate at such a pace that when I planned Christmas and New Year, I knew in my heart this would be our last as a family, and it needed to be the best.

How do you think support services could be improved for people in your situation?

There are few support services for the early-onset dementias. I was fortunate to find at St George's Hospital in Tooting, a brilliant support group. The team who run it are committed and marvellous. People travel for miles to attend. But as always with these much-needed groups – it is underfunded.

How informed have you found others to be about Alzheimer's? Are there any common misconceptions you have come across?

One of the misconceptions about Alzheimer's is that it is a memory loss illness. It is not. Memory loss occurs very early on, probably at the mild cognitive impairment stage and long before any other indications there is something amiss. It is often dismissed as something that happens with age. Having stood by and witnessed my husband's demise, I would say that Alzheimer's is **brain failure**. Stephen's illness has consumed him – his personality, understanding, communication, emotions, executive functioning, behavior, mobility and yes, his recognition of those he deeply loved. Brain failure will continue until his brain is broken.

What would you like others to know about living with Alzheimer's, both operationally & emotionally?

This is not a 'journey'; this is an incurable illness, with no hope and no treatment. Early-onset dementia throws up a completely different set of challenges to late-onset. Emotionally you are in a constant state of trauma, trying to face what is happening to your loved one while trying to keep all the plates spinning at the same time.

What advice would you offer to anyone newly diagnosed & their caregivers?

Be practical. Find a good solicitor who has experience in elder legalities. Put in place power of attorney for both health and finances for both of you, not just the person with dementia. Review your wills with a solicitor and put particular emphasis on providing financial support for the partner with dementia who may be unable to make financial decisions regarding your estate in the future.

Recognize that living with a person with dementia also depletes your brain stores. From the beginning, take proper time for yourself – not just a couple of hours a week, but scheduling several days weekly to have quiet and relief from the 24/7 care.

Work through your feelings before telling family and friends. Managing their emotions becomes another burden. We did not tell our immediate family and very close friends for 6 months.

Plan, plan and plan. Research how to afford care and the agencies that can provide it. Make an appointment with the brilliant people at Age UK and apply for attendance allowance. At a later stage, if income has reduced, a carers' allowance may be available. Think about the house you live in, could it accommodate a live-in carer when needed and if so, what might you need to do now to make that work? Ask the family if they will be able to commit to some hours each week to care and draw up a rota. It is so important to ensure a routine is in place especially when being able to work stops.

Do not expect everyone to 'step up to the plate' to help and try not to be disappointed or angry when some close family and friends fall away. Not all can cope or watch from the side-lines. There are a few support groups and the fact each of you is experiencing similar problems, binds you together. Watch for your children's mental health, offer outside support and discuss your decisions with them depending on their ages.

Post script

Fast-forward 2 years exactly to 18 January 2020. Over coffee in our conservatory, I was ready to read the Saturday papers to Stephen as he had lost the ability to read. He looked at me and said "*You are very beautiful*", and I said, "*Well that is a nice thing to say for an average Saturday morning*". Stephen said, "*But I don't know who you are, who are you?*"

Disclosure

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