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This patient story described the experiences of John Larkin who was diagnosed with Alzheimer's disease 11 months ago. Throughout the story John describes the impact of the diagnosis and the help and information that has been available to him, from both family and outside organisations.

In 2016 John's daughter and close friend felt that his memory was becoming worse and suggested that he visit his GP surgery. However, at the time John felt that he had always had a bad memory and forgetful about things.

John eventually visited his GP surgery who referred him for an MRI scan and to the Memory Clinic in Barry Hospital. The scan was 2-3 weeks after his GP appointment and the in a further 2-3 weeks John's and his daughter attended the Memory Clinic, where he undertook a number of tests. At the end of this appointment it was confirmed that John had Alzheimer's disease. John explained at the point he was diagnosed he had already had a feeling that this would be the diagnosis.

"I'm not sure at the time it registers; it takes a bit of time to sink in. I just said thank you very much and went away and went on line and talked to people and did all the things that people normally do."

John did not recall receiving any information at the point of being diagnosed but went online and recalls receiving information subsequently. John felt that, as the diagnosis comes as a bit of a shock, it would not have been helpful to him to have lots of information on the condition at the point of diagnosis.

"It comes as a bit of a shock and you don't really take it in and you don't really listen to everything everyone has said. I think you need to digest it but before you are given information."

"It's a process of accumulating the information and getting used to the idea of what has happened."

"Initially I'm sure if you told people exactly what it entailed, although obviously you can't, they wouldn't remember it, and they probably wouldn't listen to you at first anyway."

After his diagnosis John used the Google search engine to find out information on Alzheimer's disease.

"I just went on line and googled Alzheimer's disease and trolled through all the stuff that was spurious until I got to the things I was interested in. Then you slowly work it out, there are things you need to know, what my life expectancy is, how long am I going to live, although it's impossible because it depends on how old you are how bad you are. So it's really a question of working it out in my mind, what was a reasonable expectation."

After his diagnosis John was contacted by the Alzheimer's Society who invited him to a support group that they were running. It was at this group that John received an information booklet, which he found very useful, but a little vague.

"The booklet from the Alzheimer's Society I thought was very good, and then all the other sources going on line.

"When you ask the questions that everybody does, how much longer have I got to live? Well I've got a minimum of two years and a maximum of ten years, which I had worked out for myself by looking online.

"They don't put it forward in a straight forward way, you get phrases like 'well that's a very difficult question to answer' I thought yes, well that's why I'm asking it. I appreciate there is enormous variation."

After attending a few groups John felt that they were not for him

"It was tea and sympathy, which is fine.

"A lot of the people in the group though it was absolutely great, people want to talk to others in the same situation; I'm not a particularly sociable person and I didn't feel that need."

John expressed that the Memory Team has been marvellous, in the support they have given, John had been puzzled recently that after almost a year since his diagnosis he felt he had not deteriorated.

"I have done little things like tested myself, what did I do last night? What did I have for tea? Did I watch television or not, and so on"

"If I watched television can I remember what programmes, can I remember the names of the characters in the programme and it seemed to me that I could. My short term memory recall didn't seem to be impaired that much and I thought it would be, which is the thing that puzzled me."

They gave John more detailed questionnaires at this point, one for memory and one for driving. Rosalind who is the principal psychologist took her time with John which he really appreciated. John highlighted that the review sessions used to take place

every six months, but now you have to request a review. However, John did not feel that a review was needed that frequently and for him things hadn't turned out the way he had anticipated anyway.

"I'm still here, I still remember what day of the week it is, I can still look after myself"

John explained that his daughter had been amazing throughout the last year and visited him every day. John has three other children who all live away, but they often all get together as a family.

"My life would be totally different without her because she is enormously supportive"

John commented that his daughter had not needed to access any outside support for herself, or at least had not told him that she had needed to.

After being diagnosed with Alzheimer's Disease John felt that the biggest impact was the loss of his independence, which was mainly due to the fact that his driving license was taken away.

"That's big one, particularly if you live on your own, being able to just get in the car and go where you want to gives you a great sense of independence"

"Losing your independence is a big one, when you have to try and work ways around that. I've got a disability scooter because I've got a back problem and that is very useful but it's not the same as having a car."

"Life isn't as spontaneous, you have to plan ahead, but you just have to work out different strategies of doing things. Tesco's deliver, but I have to remember to order to a Tesco delivery a couple of days in advance, so I have to plan the food every week and there are some foods that don't last. It just takes a lot more organising."

"It's all do-able you just have to plan ahead."

John said that he hadn't accessed any other support groups after the Alzheimer's Society and he puts that down to having his daughter as his support. He stated that had she not been there he may have accessed other forms of help.

John expressed that after diagnosis he had expected that his condition would become worse fairly quickly and the fact that didn't had confused him, hence his request for a review with the Memory Team. John stated that no one had told him this would be the case, it was just a general expectation many people had about the disease.

"It's a general expectation, people I know in the social groups I belong to always say 'Oh you're still here, you're alright' It's a common feeling that Alzheimer's is a disease which means you'll lose your memory in three months and pop your clogs in four. That seems to be the general expectation and I suppose that was mine as well, there wasn't any specific information I was given to make me think that."

John emphasized that once diagnosed information is a very important aspect of coming to terms with the illness.

“Read what’s available, life’s a terminal condition anyway, my life is just somewhat shorter that it would have been.”

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