



Speaking from Experience

Alzheimer's Disease & other Dementia

Transcript for chapter 2 of 8: Diagnosis

Gwen: I did a CAT scan and the psychiatrist told me that I was getting Alzheimer's but it was in the very early stages and it would take about eight or nine years before it developed fully.

Judy: She presented very well at the doctors. They would ask her 'how are you going' and she would say fine. Are you eating well? Yes. Are you sleeping well? Yes. Going for walks? Yes. And we were sitting beside her going 'No, no, no' trying to tell the doctor that there was something else that was wrong and he didn't really want to hear us.

Anne: We were referred to a neurologist, then I started getting very concerned because they weren't coming up with anything that was easily explained, they weren't coming up and saying that he's got a brain tumour that we can operate and remove, he hasn't had a couple of small strokes that causing the problem. By this stage his speech had also started to be effected, he couldn't both come up with the right words to say and pronounce them properly when he could think of the right word to say. So we knew that we were looking at something that was gradually getting worse and for a period of time all the medical people were shaking their heads and saying 'We don't know what the problem is. We accept that there is something wrong but we don't know what it is'.

Susie: We finally said we were concerned about mum, they did the tests and they said that there's nothing wrong. I wasn't happy with that and went back the next day and said look we really are concerned that there's nothing wrong and he said 'Oh, she's got Alzheimer's'.

James: Jan took me to a doctor.

Jan: It was early February and we were given the diagnosis then, and John was very good, he just said it was Alzheimer's and I just remember it was just being shocked and you just don't know what to think. It just seems so unlikely and extraordinary.

Anne: I guess I panicked; I didn't handle it at all well until I had time to get used to the idea. We have two children, one six and one eight and a half, it was something that I knew what going to affect their lives dramatically. So I knew it was something that was just going to alter all of our lives for a long period to come.

Jim: I think she's pretty devastated at first but we discussed it and we talked it through, and you know, when we got married we said for better or worse, we both believe that, we've stuck to that.

Ellen: It was in one sense a relief because at last there was the label that I'd been searching round for, even though I didn't like the label, but once you know about something then I think you can adapt to it better. You can learn to live with it, you can find out as much as you can, you know what you have to deal with.



Jan: I was devastated but I just didn't know what to do because I couldn't just sit in devastation because he was so distressed himself. I mean, he'd lost so much and I think I felt I had to be strong and support him. And also the children because they were all devastated.

Judy: It was shattering absolutely shattering to hear it, and once again, like Suzie, I didn't know much about it. I thought that dementia was one of those things that you hid and didn't come out in the open with, and I was absolutely scared that I would lose the mother that I'd had – and I'd had her for fifty years and she was a mate.

Jan: The worst of it I think is just that you don't have time to plan, that all of a sudden everything starts to change and one minute you've got a future and the next minute the future's different and the future you'd planned no longer exists. You just feel shell shocked for a while.

Gwen: Well it was a shock; I think I was a bit devastated when I got home. I was very shocked, that's all I can say really. I thought about it for a little while, a couple of days I was a little concerned and didn't quite know what to do. I thought, well, it's in the early stages, I'm not young now and by the time I get to eight or nine years I might not even be here. And I thought, well I'm not going to let it get the better of me; I'm going to do something about it.