



Speaking from Experience Alzheimer's Disease & other Dementia

Transcript for chapter 4 of 8: What next?

Ellen: I suddenly thought, what do we have to do next and it's just like being faced with a blank sheet and you think 'where do I go? What help can I get? Who's been there before? Who can I call on?' And you feel very much that you have to get help but you don't know where to get it from.

Jan: Soon after diagnosis I think the children and I went to the Alzheimer's association and had a session there as a group and that was really helpful because we were able to decide and talk about what we'd tell people, what the future possibly held and how we'd deal with it at this stage and that was terrific.

Judy: My other sister and myself sat through six weeks of a course called 'drawing the threads' which gave us every facet of it and we would feed it to Susie and say this is what we've done – because Susie works - and we fed her all that information and then we tried to put it into practice.

Jim: We've sort of been fortunate enough as it's developed we've helped each other get over that next hurdle. And we've also had a lot of help from other people to get over the hurdles. Some people have been able to tell us where the hurdles are and give us some idea of how we're going to jump over them. Others we've hit our feet up the top hurdle and fell flat on our face and have had to try something else.

Ellen: Finding the support. Finding the groups you can go to, the support groups, finding day programs, finding out what's available – you have to take the initiative, it doesn't just fall in your lap. You have to do a lot of talking, a lot of investigating.

Judy: We had to explain to mother that people of her age were allowed to have people from the council to come and help. We worded them up and they came and gave her an assessment and were very, very good. And they gave us then some more information on what we needed to keep her at home and in place and as happy and healthy as we possibly could.

Ellen: The whole thing has been a learning exercise, from having nothing to a stage when you say 'Right, well I have nearly found my way through the maze so I have nearly found all the strategies and the things that I need to help me through. So it's very helpful too, to have professional people who can give you advice which is not... they're not emotionally involved.

Jim: You have to go and seek these things they don't always hand you the face, but I think you can belong to a local support group initially, get into the things when your partner or your person is early in the disease because they stand by you later on. You're going to suffer grief, you're going to feel you're all alone, and you can get help in those areas... but you've got to seek it.