



Speaking from Experience Alzheimer's Disease & other Dementia

Transcript for chapter 3 of 8: Telling people

Ellen (cares for her husband, Russ): I found it's easier to be honest with people, and the first time you can say, "My husband has Alzheimer's", is a breakthrough. After that, it's easy. Before that, you tend to say, "oh, he has a few memory problems" or "Russ isn't coping as well as he used to".

Judy and Susie (cared for their mother): My children knew, and my husband, but close friends and outsiders from the family, I didn't tell for some time. Until I got to handle the disease myself. I knew about it, knew it wasn't a frightening thing. Dementia, Alzheimer's, people didn't know what it was. I think the connotations I had were so frightening, that I think I had to come to terms with it before I could really let other people know.

Gwen (has Alzheimer's Disease): I'm coping quite well and I think it's not necessary for me to tell all my relatives, because if I do, I know they'll all be thinking the worst. And, before I know where I am, I'll be in the grave [laughs].

Anne (cares for her husband, Peter): When he had to stop work and I had to tell them that daddy wasn't going to work anymore. As I was saying that, my youngest daughter said, "Oh, because daddy's so sleepy all the time?" And I just left it at that, because she was 4 at the time, and I thought, well if she's happy to accept that as the reason that he's not going to work, then I will just leave it at that and I will tell her more when she needs to know more.

Judy and Susie: We purposely chose not to tell her that she actually had Alzheimer's. It was a conscious decision that the three of us made. We felt that it wasn't going to do her any good, for the short term that she might understand - that it would upset her more.

Jan: The best thing we ever did was tell our friends and everyone we came across. It was really hard, but it was the best thing, because people knew how to respond to us. I think it gives people a way of relating to you.

Ellen: It's interesting the reactions - some people are very supportive and some people want to do as much as they can, and others, sort of, well that's it they don't want to know you anymore.

Jim: Well, we told our friends. There's no use trying to hide it. And we said, "look, Molly's got Alzheimer's Disease, we won't be able to..." but she still continued to - we've done yoga for most of our lives, actually - and she was still able to continue to do yoga for two years after she had been diagnosed with having Alzheimer's Disease. We told the people in the yoga group.

Judy and Susie: Telling people in the service industry - the shops and the banks, and things like that - is very important because most of them were pretty good with her. The newsagency girl was always gorgeous. And the hairdresser was delightful. They'd look after for us. Once they understood - whether they understood entirely, the entire pathway of her disease or not, we will never know - but they were always very supportive of all of us. And



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we would ring them, purposefully before we took her anywhere, to make sure that the people understood that she wasn't her normal self and they were normally fantastic about it.