Speaking from Experience
Alzheimer's Disease & other Dementia

Transcript for chapter 7 of 8: Life now

Jim: More recently she's losing her ability to speak, and that's becoming very difficult to handle because she needs to be guided everywhere and the memory is slipping. So those things are. But I still continue to ask her what she wants, I still… We still – we - we still try to maintain as much real contact with each other as we can.

Ellen: There seem to be plateaus and then all of a sudden, almost overnight, there is something that you find that he can't do, like suddenly can't remember how to make a cup of tea or suddenly can't remember where the cups and the plates and the knives and forks go.

Gwen: I've made up my mind, I'm going to fix the house up so that when you walk in it's beautiful and I feel I've got lovely, happy, beautiful surroundings and then I'll just accept what happens.

Ellen: Russ just likes listening to what everyone else is saying and occasionally he will put in a little humorous remark – he's always been quite… so occasionally there's just a flash of the old Russ, and that goes down very well.

Anne: He has so much trouble communicating with people, it's very hard for them to even come and visit because basically I sit down and talk to them and he wanders off.

Ellen: Occasionally you get, like a bolt out of the blue, suddenly he'll come and put his arms around you and suddenly he'll say, you know, 'I love you'. And you think 'Wow!' you know, it's just like winning a lottery when that happens.

Anne: There's the problem that because his personality has changed a lot he's very intolerant of noise and he's intolerant of mess around the house. And with children, that those two things unfortunately go together, and so it's very hard for our children to have friends around to play or to sleep over. And I think that's perhaps going to affect them in some way further down the track.

Jan: I think he thinks that because I look after him and I've become the centre of his, sort of, universe, I think there's some part of him that thinks that it's important to keep me happy.

James: She looks after me so well.

Jan: Just even eating, we now eat food that's very easy for him to manage. So, you would never give him spaghetti for instance.

James: She cooks meals, fantastic meals.

Ellen: He doesn't read, he doesn't watch television, he hasn't got any hobbies. He cannot entertain himself. He occasionally get out in the garden if it's a nice day and he'll rake up the leaves and pick at the daisies that are growing in the lawn, pick up gumnuts. I'd like him to weed the garden but he doesn't see the weeds, but he will sweep the paths. So on a nice day I can rely on about half an hour being outside and he will mow the lawns under supervision.

Anne: I'm really grateful for the football season, I didn't think I'd every say that but it gives him a focus in his life and I feel that at least there is something that he's gaining some enjoyment from because there is very little else that he seems to gain any enjoyment or pleasure from.

Ellen: I've had three lots of respite for two weeks, and that was so hard to leave him for two weeks while I have a break, but at least I've done that so if he does have to go into a low level hostel that is going to make it a bit easier for me because I've already had the respite, and you need respite. You don't realise how tired you are, how exhausted, until you come home and sleep for 11, 12 hours for the first three nights. You just realise what a strain it's been.

Jan: For me that's the hardest thing, is actually acknowledging that he's getting worse and I need help, I need breaks and so the thought of putting him into respite care at the moment, up until now has been really hard and I think that's my next step, so that he goes and stays somewhere for a week or two and I have a break.

Jim: We've chosen to retain Molly in a home environment for as long as possible, and will continue to do so. But that's an individual choice ever person has to make given the facilities you have.

Ellen: He's been assessed as being suitable to go into a low level hostel, and I think that probably, even though it's very hard for me, it might be the best if I can manage to get a place for him.

Jan: I see the future as slowly getting more help, and slowly, you know, Jamie continuing to deteriorate and me looking after Jamie as long as I can and then Jamie entering a nursing home. And I know that that's what he'd want although now I don't think he wants it though I think when he was rational and able to discuss the future that's what he saw as his future. But the closer he gets to it, the less he wants to go into a nursing home.

Susie: All our lives she cared for us, she supported us; she was the shoulder we needed to cry on. Even in our adult years if we had problems she'd always listen, she was tolerant, she was understanding – never critical – and all of a sudden that relationship plateau and then it completely changed, she was completely dependent on us. It felt different, it felt strange. I was so pleased that I was able to help her -that the three of us were - when she was in trouble in these final years. It was sad. For me it was also frightening because you knew that the tables weren't going to change again.

Gwen: I've got to learn to accept it. If I can accept it before it gets bad, well that will make it easier in the end. And when I do have to have someone to care for me and do things for me, well I will perhaps accept it without rejecting it and without worrying about it. And I'll think to myself 'Well, I'll just lie here and be comfortable and if I've got something attractive to look at, well that's all I'm going to worry about.'