

It's vitally important to get the diagnosis early because at least then you can try to sort out your future. I went from a confident person earning my own living to a person with dementia who could no longer function at work.

- My supporter, Brenda, brought me back into the community and I am now contributing to society. If it was not for her, I would be a big burden to the state ... I am not getting any support from the services now, but I do get a great deal of support from the members of the group

I think spiritual needs do not go away. When I have fatigue I can put on my spiritual music and that inspires me and I can go into that spot through meditation or visualization. I have kept my spiritual life going, but I do like my religious family too, which I have lost.

I try to keep myself in a positive frame of mind, although at the time of diagnosis I felt as if I lost my sense of self and purpose.

Keep busy, doesn't matter what it is, at the start of the day I look forward to what I am doing next, and I am working doing everything I can possibly do.

People get to hear the word dementia and it is all lumped together and they think you are finished. You are not finished at all.

I have the life of Riley; it really is good. I know I have a deteriorating illness and it won't last but I could have died ten years ago if I had been given a diagnosis of terminal cancer, I wouldn't be here and look at all the happiness I've had.

You need to focus on the ability and the contribution that we can make rather than what we can no longer do.



Being encouraged to do as much as possible keeps me going. It stops me feel unwanted and builds my confidence

I operate in a different way to you, and need a different type of interaction, which is slower and more meaningful. People want to be busy, to talk fast, to ask for responses, but I can't cope with that

Don't just tell me what to do. Help me to make  
choices

*It is society which disables people. It is attitudes, actions, assumptions - social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options. Disability is not inherent.*

*I felt disempowered because the people that spoke to me about dementia always spoke about my loss – all the negative things. Nobody ever said “there are things that you’ve lost but there are also things you could gain.” They never really took me from the loss of power into the action.*

*The doctor said to my daughter “Have you heard of dementia. That’s what he’s got” and he pointed to me with his thumb*

*Some friends take your confidence away. They treat you like a child. Someone said to me “Come along in the car and I’ll take you out and I’ll bring you a sandwich.” I thought “What’s happened to me?” People said they would sit me out in the garden as if I was a toy. The attitude of people towards us takes away our confidence*

*I was told when the results came back that I would have 10 years to live. Then the doctor said 'how long do you think you've had Alzheimer's?' I said, 'I don't know. I think it could be two years'. 'Oh well' he said 'that's down to 8 years.'*



*We've got to be forceful because professionals can be very patronising. They do their training and they think they have the answers to the world, but they need our side of the story*

*I felt confident in what I was feeling and saying. But then people would say to me “Are you sure that’s what you’re feeling or is that your dementia?” I never quite knew. I’m sure inside but other people make me unsure. I have to sit quietly to find out who I am*