

# Introduction

In the early stage of dementia, some people may be able to give insights into their experience. But once the condition has advanced, it would not be possible for someone with dementia to tell their story in the way Jack does. Jack wouldn't really be able to reflect on his condition or analyse it or find the words to describe what he was thinking or feeling. So with this little book, I would ask you to "suspend disbelief", and listen to the words that someone with dementia might tell you if they could.

Living with dementia is a challenge for those with the condition, and for those who care for them. I hope that Jack's words will help to show how behaviours that might seem puzzling and bizarre make sense if we appreciate what it really means to lose your memory, and lose your ability to think clearly, to reason and to communicate. If we step into Jack's shoes, we can try to understand what life might be like for someone with dementia. If we understand what it might be like, we are much more able to help.

What can be done to help? Medication can temporarily slow the progress of certain forms of dementia. Being physically active and keeping the brain engaged by doing things such as crossword puzzles may have a positive effect. There are many ways we can structure the environment to make life easier. But it is the way we relate to and behave towards the person with dementia which has by far the biggest impact on their quality of life.

We need to respect the person as an individual, ensuring that they continue to feel cared for and

valued. This will mean acknowledging a reality that may not (initially at least) make sense to us. People with dementia lose the ability to remember new information, so they may make sense of what is happening now by using the only memories they still have – those of the distant past. You may think it is silly for an elderly person to worry about his children getting to school on time, and may think it is doing him a favour to point this out to him. But in this sort of situation, pointing out that he is “mistaken” can be counterproductive: it serves to increase distress, not reduce it.

Once we accept that what is true for them is true for them, we can avoid fruitless arguments of the “Oh yes it is/Oh no it isn’t” variety, and life can become happier for the person with dementia and for their carer.

Even if we know (in our fully functioning brains) that what the person with dementia is thinking is not “accurate”, it helps to go with their flow, and play along as if we “know what they mean”. This can be a difficult thing to accept or do, but it makes all the difference to their well-being (and ours). I remember watching my husband appearing to have an animated conversation with his mother, who was in the late stages of dementia with Lewy bodies (see p. 44). If you listened to the words they spoke they made no sense, but there was a real sense of a conversation going on with nods, and nudges, and hand pats and conspiratorial smiles. My husband had entered into his Mum’s world, and they had connected: she seemed to be enjoying a really good chat.

Learning how to listen and observe, finding ways to reassure or distract, learning not to contradict or confront but to steer the conversation to topics that make the person relaxed and happy, understanding and coping with unusual behaviour

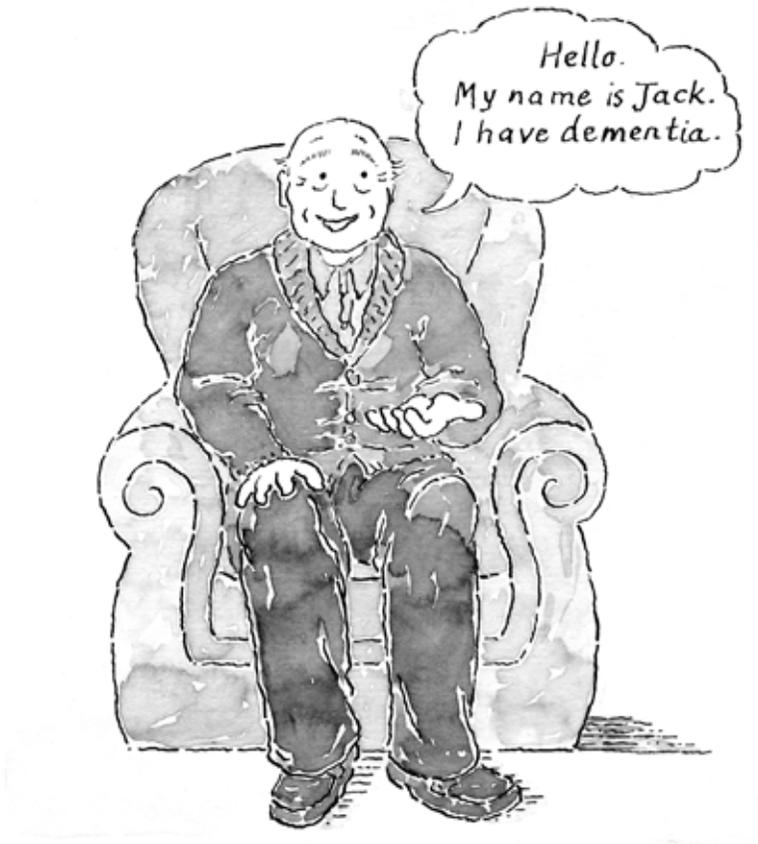
caused by problems with reasoning or memory, finding satisfying activities they can enjoy, keeping them safe and “on track” (reminding them gently what day it is if that are confused, for example)... it all needs tolerance, creativity, stamina, a sense of humour and heaps of patience! It can be emotionally and physically exhausting. But it’s not all doom and gloom: it is still possible to have fun and laughter.

If you are caring for someone with dementia, make sure you also take care of yourself, by seeking help, support and guidance, by sharing the caring, and by taking breaks. Caring for someone with dementia is not something you can do alone. Check out the organisations on pp. 46–48, and don’t be afraid to ask for help.

Everyone’s story will be unique. The way someone experiences dementia will depend on various factors, including the type of dementia they have, the type of personality they have, and the quality of support they receive. But I hope that Jack’s story will help you understand what the experience of dementia is like for someone you care for, so that you can make a positive impact on their life.

Now, over to Jack...

CAN I TELL YOU ABOUT DEMENTIA?



“Losing my memory is at the heart of it all. I can’t remember anything new, and old memories are disappearing too.”

“ I’ve had dementia for quite a few years. I’ve got Alzheimer’s disease, the most common form of dementia. There are other types of dementia,<sup>1</sup> but they all damage the brain so that it can’t work the way it used to.

It’s strange: I can sometimes still remember things that happened long, long ago – but I can’t remember what someone said or did two minutes ago. Nothing sticks. And distant memories have begun to disappear too. Now I can’t understand things I used to understand easily. I find it hard to make decisions and to carry out everyday tasks. I have problems with communicating too.

It’s not surprising that it affects my mood. The world doesn’t make sense any more. I sometimes feel frightened, confused, angry and frustrated if I can’t remember what I was going to say, or I can’t understand what’s happening or remember who people are.

I’ll tell you about the way dementia has affected me over the last few years. Some of the problems, like wandering, stopped after a while. Others, such as memory loss, have got worse.

I’ll tell you about things that have helped me feel good and have helped me connect with the ‘me’ I used to be. Things like reminiscing about football, watching old films and singing songs from the old days.

I’ve had a good, long life. I served in World War 2. I used to run my own business. I took pride in looking after my wife and family. Now I have to rely on other people to look after me. But I’m still an individual, who needs respect. I’m still Jack. ”

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<sup>1</sup> Other types of dementia are described on pp. 43–45.