



What I didn't know about dementia

By Fiona Thompson, published on www.qwell.io

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Before my mother was diagnosed with dementia, I have to admit I didn't know much about the disease. I thought that people became incapable pretty quickly and that there was an on/off memory switch. One day, the person had their memory; the next, they didn't.

As I've come to realise, the disease is very different to how I imagined. There is no on/off memory switch. It's a progressive disease, and some elements of people's memories last for a long, long time. Others disappear swiftly.

Also, as a friend told me, "When you've met one person with dementia, you've met one person with dementia." There are so many different varieties, and the disease affects people in many different ways.

Numbers on the rise

Close to a million people currently live with dementia in the UK, and research suggests this figure will rise to over 1.3 million by 2040. More and more of us may know someone who has the disease or develop it ourselves. Given that, I'd like to share my experience of how the disease has affected my mother and some of the ways we've learned to cope.

How it started

My mother is 88 now, and her memory started slipping maybe around five years ago. Ironically, it's hard to remember exactly what it was that concerned me, my sister, and my dad. I think it was a few lapses of memory, repeating questions, and not always remembering something we'd just told her.

My dad took her to the GP, and they referred her to a memory clinic, where my mum did some standard memory tests. From what I recall, her results were okay and just showed a few memory lapses. My mum was happy to go along for the test, particularly when the report

highlighted her excellent linguistic skills. This came as no surprise to me; my mother's a very intelligent woman who had a career as a Latin teacher.

The important thing for us was that this test gave us a benchmark that would allow us to measure any progression of my mother's memory loss.

The crossword clue

I do, though, clearly remember one incident that marked a decline for me. My mum's always enjoyed doing sudoku and crosswords. About two and a half years ago, I saw she'd written "ill-gottan" instead of "ill-gotten" in answer to a crossword clue. It drew me up short. It was a real shock. My mum was always the person who would explain grammar to other people. She would never have spelt that word wrong.

A gradual decline

Since the crossword clue incident, I've noticed that my mother's memory has gradually declined. She wears a daily medication patch, which is meant to slow the deterioration of her memory. Who knows if it works or not?

Thankfully, she still recognises me, my sister, and my dad, although it's hard for her to place acquaintances. She no longer wants to read books or magazines and finds it difficult to follow TV programmes. She's happiest when she's out with my dad having coffee at her favourite café, where she recognises the owner and always recounts the same anecdote about him to us. She loves to go to the seaside and feel the sea air, to sit in the garden and look at the birds and the flowers, or go for a walk to the local churchyard, sit on a bench and watch the passers-by.

Surprising moments

My mum can still surprise us, though, with what she does remember. A friend sent her an old black-and-white photo in last year's Christmas card. My mum picked it up and immediately told us the full story. She'd been on a school trip to the Netherlands, aged 16 or 17. She told us the names of the two close schoolfriends who were with her and talked about the strict teacher who'd accompanied them on the visit. In the picture, my mother was eating a raw fish as a dare.

Around the same time, my sister was playing some Christmas carols. My mother joined in singing the alto line, drawing on her many years of singing in local choirs. This all happened last Christmas, when my mum couldn't have told you what day it was or whether she'd had breakfast, let alone who was prime minister.

Memories like a bookshelf

This ties in with the bookshelf analogy, often shared by dementia charities. According to this, our memories are stored on a virtual bookshelf, with the most recent memories on the upper shelves and older memories on the lower shelves. Dementia comes along and shakes the bookshelf, toppling the books on the upper shelves first, but leaving books on the lower shelves in place. In the same way, dementia typically peels away recent memories, but older memories stay with people for longer.

10 tips for helping someone with dementia Here are some of the things I've learned over the past few years that you might find helpful:

1. Hold their hand

You may not be able to have in-depth conversations or ask their advice like you used to, but the person you love is still there. Hold their hand and just talk to them about anything. Keep that connection going.

Wendy Mitchell, a former NHS manager who developed dementia, wrote a wonderful book about her experience, *Somebody I Used to Know*. In it, she says that she may not remember someone's name, but she will remember how they made her feel. So, even if the person with dementia forgets who you are, you can still add some joy to their day by sitting beside them, listening and holding their hand.

2. Avoid difficult questions

Don't start sentences with "Remember when..?" or "You know that place we went to...?". The person with dementia likely doesn't remember when, and they probably don't recall that place. Instead, talk to them about what's in front of them. If they pick up a magazine, start a conversation about the articles or pictures inside. If you're outside, talk about what they can see or how they feel.

3. Answer repetitive questions

Someone with dementia will probably ask you a question twice, or three times, or four times. Just keep answering the question. If you like, vary your answer, but don't huff or puff or show your irritation. For them, the question is fresh every time.

4. Learn the art of distraction

People with dementia can get a little fixated on things, such as where they've put something important. Don't let them get too caught up in this behaviour by kindly and gently distracting them when they get onto that topic again.

5. Keep visiting

Don't assume that someone with dementia won't appreciate a visit. Even if they're a bit hazy about who you are, they might still enjoy the stimulation and sense of social connection they get from a cup of tea and a chat. If you only drop in for 20 minutes, you might make such a difference to their day – and to the morale of their relatives/carers.

6. Consider the physical challenges

Dementia affects the body as well as the brain. It can make people less steady on their feet and alter their perception. For example, they might see a dark mat on the floor as a hole in the ground. Check out the Alzheimer's Society for information and ideas on how to help someone stay mobile, safely.

7. Involve them in everyday life

My mother can't cook any more, but she does still enjoy peeling vegetables, setting the table, and doing the washing up. A person with dementia may have limited abilities, but don't take everything away from them. Give them tasks to do and involve them where you can.

8. Look at old photos together

Old photo books have been a lifesaver for opening up conversations with my mother. She'll

look at photos from her childhood, teenage years, and her twenties and tell you all about the people and the places she remembers. Those memories are a place of safety and happiness for her. And, as the photo of the fish showed, a newly-discovered old photo can revive old memories.

9. Get help

If you're caring for someone with dementia, get help wherever you can. It's a lot, and you can't do it on your own. Ask for help from friends, relatives, neighbours, local groups, and volunteers. If you can, get a carer to give you some respite. Ask Citizen's Advice to help you with applying for the Carer's Allowance. Ring the Dementia Support Line or Admiral Nurse Dementia Helpline to get support from people who understand the issues you're facing.

It's vital to remember that however you're feeling is valid. You might feel frustration or even anger at your loved one, and that's both normal and understandable. While we understand that dementia is not the person's fault, it's still common to experience a lot of complicated feelings around their behaviour and their care. It's so important to have a safe space to process and be honest with yourself about the impact on you and how you feel.

10. Make the most of every moment

It can be sad and stressful watching someone you love develop dementia. Equally, though, it's important to make the most of the time you spend together. Appreciate the small ways you can enjoy each other's company. They're still there, and they're still the person you love.

For more content on dementia, read our Qwell article, "[Dementia: grieving for the living](#)". And if this article has affected you in any way, or if you just want to reach out to the team about anything at all, you can do that by [messages or live chat](#).