

Caring For Loved Ones with Dementia: Real Life Stories

Our partners at Chosen with Care present four real life stories of people experiencing dementia with their loved ones, as well as tips for how you can support yourself or your family with dementia.



What's it like to care for or live with a loved one who is diagnosed with Alzheimer's or dementia? These family members share their dementia journey and how it's changed their lives, sometimes in surprising ways.

Learning that your mum, dad, gran, brother, sister or anyone you love has a form of dementia can be truly shocking. Life-changing, even. It's something more and more of us are having to get to grips with these days, with finding out how to help and support our loved ones a top priority.

Accepting the diagnosis is a challenge for anyone, particularly the person being diagnosed. But it's the time after the diagnosis, **when you have to put support in place**, that can be really tricky. There are obstacles to overcome and lots of people and organisations to work with.

Here are some stories of people who are going through the journey of dementia with their family members. They have had to juggle the different stages of this process and learn so much along the way; not least that love really does grow stronger through caring for others.

Noticing the Dementia Symptoms

When someone you love is getting a little older, you probably begin to recognise a few 'eccentric' behaviour patterns. Maybe they just say a certain phrase more regularly or focus on one particular TV programme.

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You might spot them forgetting how to make a cup of tea or struggling to recall what word or sentence they want to say.

But it's when these signals are building up and becoming more persistent that you might suddenly see a pattern. This is quite common for many family members who are around their parents every day and pick up on these signs.

Jenny and Sylvia

Jenny, a 52-year-old nurse, started to detect behavioural shifts over time with her mum, Sylvia. Sylvia is in her seventies and a retired technical teacher. She has always been very active, getting stuck in and making sure things are done well.

Jenny lives ten minutes away from her mum, who is now alone as Jenny's dad passed away ten years ago. Over the last decade, Jenny noticed Sylvia becoming more forgetful, wandering aimlessly around the house or a shop and struggling with quite simple tasks, like making her dinner or boiling the kettle.

"Mum loves her tea. She's always making cup after cup. The teapot really was the centre of our kitchen table, growing up. So, when I realised mum just couldn't remember the steps to make a cup, I began to get really concerned."

Greg and Albert

It's a similar story for Greg. Greg's dad Albert seemed to struggle more and more with communication and finding the right words. Albert worked as a mechanic in a factory before retirement and loved to go to the pub for a pint with his mates.

When Greg tried to have more complex conversations with his dad, he noticed that Albert struggled to find the right words and often substituted these with other related terms, like 'box' for 'TV'. Albert suffers from frontotemporal dementia (FTD) which limits speech ability - a common situation for many dementia sufferers.

As Greg says, "Dad is a real people person. Always chatting away, telling tall stories and discussing football. I knew there was something wrong when he just couldn't get his words out. He just stood there, looking confused. It was really hard to see him struggle."

Getting a Dementia Diagnosis

What happens when you're pretty convinced your loved one has a condition that affects their memory? Booking an appointment with their GP or doctor is usually the next stage for many people in this situation.

It's good to hear that for most, this experience is a positive one. Jill's dad, Terry, was displaying a range of symptoms. She decided to book him in with his GP to see what could be done to help.

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For Jenny, Greg and Jill, the GP was a gateway to better care and support for their parents. There were feelings of worry, concern, and anxiety beforehand. What will happen? Am I doing the right thing? Will my parent understand what is going on?

All of these reactions are perfectly normal. Jill talks through what the meeting with the GP was like and what tests were completed to support a diagnosis for Terry.

Jill and Terry

Jill was very nervous before the appointment. "I felt really worried that dad wouldn't understand why he was there and what the questions all meant. I shouldn't have worried really, as dad's GP was brilliant. They know each other well anyway, but the GP was really caring and sensitive and didn't push any difficult questions on dad."

A few common processes take place during this type of appointment. The GP will probably try to put your loved one at ease, chatting with them and settling them down.

It's likely that something called a mini-mental state examination (MMSE) will be performed. This is a series of questions and tests that are used to assess memory, attention, and language.

You should expect a few blood tests as well, to see what is going on physically in the body.

Greg and Albert

Greg found this meeting difficult but necessary. "The doctor asked my dad to remember a few details - Mr Brown, lives at 5 Crown Lane, works in a supermarket. He then asked dad a few other questions. In the end, he asked dad to recall the information. Dad just couldn't remember any of it. We knew then there was a problem with dad's memory."

The next step a doctor will take is to refer the patient to a memory clinic to confirm the diagnosis with more tests, or to a consultant. This is an important stage, as once the diagnosis for Alzheimer's or dementia is confirmed, then relevant care and support can potentially be accessed.

Care at Home for Dementia Sufferers

Losing skills, such as the ability to drive, make food, or get washed and dressed become more common after a dementia diagnosis. It can take months or years, but the deterioration of memory and related skills will begin to impact a person's ability to look after themselves.

Many family members try to either look after their loved ones themselves at home or get carers into the home to help.

As Jill says, getting carers in to look after her dad was the best decision she could have taken. "We got a really good local company to help out. Dad got to know the carers and, even though there are quite a few of them, he allows them to help him get dressed and prepare food. He loves to listen to them chat, too."

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Sylvia found having people she didn't know well in her home quite confusing at first and struggled to let them help her. Jenny found this hard, too. "We had a few mountains to climb in the beginning. Mum needed encouragement to let them in the house as she didn't recognise them at first."

This is often a common experience for many at the start of the process of accepting carers. Most carers will know how to manage this and it does help to talk to them about what they can do to help put your loved one at ease.

Jenny goes on to say, "Once she got into a routine, she warmed up to her carers and understood they were there to help her. She really loves having them there now as she wants the company and knows she needs help."

Moving To a Dementia Care Home

Making the decision to move someone you love into a care home is an emotive, complex choice. Sometimes, hospitals and doctors may insist on this move if a patient is deemed too vulnerable to stay at home, even with carers.

However, the majority of people get to the stage when they know they have to take this step. It's filled with conflicting feelings and emotions, but for some people suffering from dementia it can be the best place to be.

Staying at home can prove impossible for some. Greg describes what it was like when he had to find a care home place for his dad, Albert, when doctors advised him that this had to be the solution.

"I never thought I would ever put my dad into a home. It wasn't something that had crossed my mind. But dad's doctors were adamant that this was the best place for him. We **searched online** for the right place for him and drew up a shortlist, from which we selected the one that looked the best. At first, I was so nervous and worried. In fact, he soon settled in and had the security of the same carers looking after him night and day."

It's a tough choice to make and no one wants to think about having to make this decision for someone they love, yet it can be a real lifesaver and create a new lease of life for many dementia sufferers.

A sense of security and safety can be fostered: being in the same place and looked after by familiar people with others around you in a similar position.

What Are the Positives After a Dementia Diagnosis?

It's fair to say that a dementia diagnosis knocks most families for six. In truth, it will confirm what you are suspecting about your loved one, but that doesn't make it any less shocking.

Some people have managed to see the light in what can be a dark time for the family. There can be a sense of acceptance and understanding because a diagnosis has recognised what is going on with your loved one and has opened up avenues of support.

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For Jill, there has been a period of calm after the storm for her dad. "We know now what the matter is, what condition he has. We are prepared and can plan for his care, look after his shopping and make sure he has company with people he trusts."

In Jenny's case, she has felt a real sense of loss about what has happened to her mum. But, on the other hand, Sylvia is settled and happy, likes the routine of her life now, and rarely gets upset.

This means that, even though a dementia diagnosis is so hard for families, it can lead to a better understanding of the condition and a practical ability to deal with the situation. Ultimately, it can encourage feelings of safety and security for affected loved ones, with the correct support in place to look after them well.