

## *Chapter Two*

# HOW DEMENTIA AFFECTS FAMILIES

### **2.1 The person will change**

**E**veryone is unique and everyone's dementia story is as unique as they are. It is thought that by the time the person has symptoms of their dementia, their brain will have been suffering damage, probably for years. The changes won't be very noticeable initially, but will progress. Some aspects of their abilities or personality will disappear and other aspects might be amplified.

### **2.2 Some things will be the same**

Whilst many things will change, some aspects of the person won't change. There are many things that the person and their family will be able to hold onto, as still being "them".

My mum always liked tea made from loose tea, and not tea bags, and she kept it in a particular tea tin in her kitchen. As she got worse, the carers would buy her tea

bag tea, as it was easier to use, but she always enjoyed any opportunity in a café or at home to have tea served to her made from loose leaf tea.

## **2.3 What the person thinks**

People usually dread the diagnosis of dementia; most people know someone who is living with or has lived with it and people hate the idea of loss of control and how the disease might progress. When the first symptoms show, there are lots of emotions that will be felt, including fear, anger, disbelief, denial and shame, as well as many more. The diagnosis of the of the condition can bring a sense of relief, however it also brings an element of certainty that it is a dreaded condition and not some other answer that they might find easier.

As the condition progresses, there are lots of emotions that can emerge, often starting with shock, denial, disbelief and avoidance. There may be a grieving process, as the person struggles to accept the loss and change. The grieving process has many stages, including shock, denial, anger, bargaining, depression and acceptance. The first stage before denial is shock, which is paralysing and creates inertia and passivity, and prevents the person from being able to take any active steps to deal with the situation.\*

In addition to grief, people are often ashamed, especially when and if it affects their continence.

People often lack insight into how bad their symptoms are, so they don't realise that things are as bad as they are. This is not because of denial, but not remembering. When I went to a café with my mum, once we had sat down and given our order to the staff, she would often ask if we had ordered four or five times, because she could not remember if we had or not. This can be really frustrating for the family member being asked the same question again and again.

If the damage to the brain affects the individual's personality, then they might not notice all the changes and think that some of the things they do are normal. When people display inappropriate behaviour or behaviour that challenges others, they do so because they don't understand that they shouldn't. It is not possible to have a rational conversation and explain to them that they need to change, because what they are doing is beyond their conscious control. The issue is about managing the situation. I had a client, Donna, who had six children and one of them had died, so she was perpetually worried about the rest. She was always dressed smartly and had a brilliant relationship with one of her grandsons, who lived three doors away and was always dropping in to check on her. Donna would become very anxious and shout at me as I was preparing to leave. With a different person I would have been able to have a conversation about abusive behaviour towards a professional trying to help, but Donna couldn't be rational and realise that her response wasn't appropriate.

People with dementia have statistically said that they are lonely\*. This is more prevalent with people who live on their own with dementia, but even those that live with others at home or in a care home still report that they feel lonely. Loneliness is known to lead to a shortened life expectancy.

During the time of coronavirus, people have reported becoming lonelier and more isolated, which has had a negative impact on their wellbeing and cognitive functioning.

The sense of dread and fear is also relevant to the issue of death and dying that is associated with any terminal disease. When I have spoken to hospice staff, I have been told that people with a terminal diagnosis almost universally want to know three things – what will happen, will it hurt and how long have I got. The answer in respect to dementia is that there is a deterioration over time, which can be slow or rapid depending on which particular form of dementia. The symptoms of dementia generally do not hurt, however there can be a lack of ability to assess risk, and accidents, such as falling over, can hurt. Although one of the reasons for diagnosing what particular type of dementia the person has, is to assist in understanding how long they have got to live with the disease, the time frame varies significantly. Until someone is in the dying stage of the disease, accurately predicting how long someone has is very difficult. Dying

can take as little as a few hours or as much as a couple of weeks in the very final stage.

Most of the people with dementia that I interviewed for this book were relieved at the diagnosis, as it explained why something had changed. They were also really resilient about the future and generally felt that as they didn't have control over the future deterioration that they would accept what would be. They were participating in groups and activities that would support them, so this may have been part of the reason for their generally positive attitude.

## **2.4 What their spouse thinks**

While spouses usually want to help and support their loved one, they also go through the stages of grief. Their concern is both for themselves and how they will cope as a carer as well as how their beloved spouse will change.

The spouse, having had years of caring for that person will want to continue to do so and will try to find strategies that will help them and help their beloved partner. They will hopefully seek medical advice and find out what medical support is available for their loved one, if any. Their doctor can also consider the medical needs of the spouse and the stress that this situation might be causing and provide medical support for that stress, if it is appropriate. The spouse can find local support groups that can provide both respite care, even if it is only for a

couple of hours, and a sense of camaraderie with other carers. Often, other carers in the local area are a great support and way of sharing knowledge that is locally available, so these connections can be very useful.

Spouses are often over-protective and can exclude others from their social circle, if they feel that maintaining the connection will not help. They can also feel shame and then guilt for feeling shame. The shame is both for them as a carer, in that they feel that they are never good enough, and separately on behalf of their partner, because of the changes happening, which are negatively perceived.

Spouses often overcompensate for their loved one, to hide the situation from the wider family and the rest of their social group. It is very common within relationships to have a division of labour, and the able spouse now has to do the work of both, and taking on these unfamiliar tasks can be challenging and stressful.

Spouses and other carers, can often look back at a situation and with the benefit of hindsight realise that they would have made a different choice and have feelings of self-recrimination. Even without looking back, they can feel that no matter what they do, it is not enough. Part of this is around the impossible task of holding back the progress of the condition; deterioration is bound to happen and they struggle to accept the slow loss of their loved one.

There is a slow living bereavement in losing a loved one that a spouse has cared for and cared about for so long, whilst they are still alive. The emotional toll that caring takes on a spouse is significant, and can often impact their own health and wellbeing.

Very occasionally, the change in behaviour or the diagnosis can be the trigger for separation and/or divorce, although this is not a common response. The legal issues around divorcing a person with a dementia are complicated and if this affects you, then seek legal advice.

The spouses that I interviewed were accepting and resigned to the situation. They loved and wanted to support their spouse and make them as happy and safe as they could. They would tease each other as long-standing spouses are often prone to do. They were also quite protective of their spouse. It was truly beautiful to witness.

## **2.5 What their children think**

The children of someone with a dementia have similar kinds of thoughts about their parents as their spouse does, however they also have the concern about whether the disease is genetic. There are some genetic elements to dementia, but the risks of old age dementia are currently not thought to be genetically linked, it is a risk of old age. There is research being done on the genetic

links with younger onset dementia - anything under the age of 65 is considered younger onset. The links are not well understood, but there may be a genetic element.

Children of people with a dementia fall into three categories, those that step up and help a lot, those that find it difficult to help, which can include reasons of living a long way away, and those that avoid contact with their parent entirely, which can often be to do with other family dynamic reasons.

The children of an elderly person with dementia are often the “squeezed middle”, they are in their 40’s and 50’s, with young children or children just entering adulthood, and often they are busy working and/or busy caring for the household and children, with all the responsibility this entails. This leaves them limited time and resources to take on the major role of caring for their parent, for which they then feel guilty.

Children worry about their parent being taken advantage of, if their parent is alone. They can also worry about the cost of care and how this will impact on their inheritance from their parent, although many don’t and would rather ensure that the money their parent has is used for their benefit.

On very rare occasions, biological children of people with dementia turn their backs on their family member and do not step forward to become a carer, either because they don’t have the time, the mental energy, or

they have a bad relationship with their parent because of past events.

Tim was the son of an army general, George, and he was also serving in the military and worked away a lot. He liaised with me when there was an issue that required someone to attend to the situation in person. Tim had discussed the situation with his father and arranged for George's house to be set up with cameras strategically placed in a couple of rooms, so that he could check on him remotely. The care agency that Tim had arranged to come and visit George had an app, and Tim checked the app daily to see what the carers had done for George. When Tim was home, he would stay with his father and take him out to the places that they loved to go. Tim told me that he worried all the time about his father, and he would occasionally check on the cameras and watch George sleeping to see if he was still breathing. Caring takes a huge amount of mental energy and emotional resources.

## **2.6 What the wider family thinks**

Sometimes members of the extended family can be very close to the person with dementia and so have similar feelings of concern, horror, fear and shame etc that close family feel, but often their perspective is more distant. They feel sadness that the person has a terminal illness and is facing an uncertain future, but it is not their problem and they can get on with their lives.

If they meet the person with dementia or their immediate family, they are usually kind and show concern, but then they get on with their lives, and their thoughts and good wishes are short lived. They are just not close enough to the person to feel the emotional impact.

Occasionally there is shame associated with the disease and the family don't want their immediate community to know that a relative has dementia.

Often, unless the family member has previous experience of being a carer for a person with dementia, they do not know what to do or how to help, and they often do nothing. This leads to the loneliness that people with dementia have reported that they feel.

The answer to this situation, is just to be kind. Smile, say a kind hello, offer to help, be warm and understanding. This will have a positive impact.

## **2.7 What people want to know and what they don't want to know**

What people with dementia want to know is the diagnosis, although it is likely that they have put off finding out about their health issue for a while, for fear of what the answer might be. Then they will know that they are facing a currently incurable and deteriorating disease. They dread the loss of their dignity, with the loss of their mind and thought abilities, as well as loss of physical abilities, particularly to do with their toileting.

The diagnosis does answer the question regarding “what is wrong?”. The first response for a lot of people is to then assimilate this information, which can take days, weeks or months. In the short term they don’t want to know anything more than the confirmation of the diagnosis.

People will have individual questions about their own situation that might not be universal, but the key thing that people want to know is where to go for help when they do get a question. There are common questions about what the stages of dementia will look like and the time frame of deterioration. This information is very hard to provide, as although there are statistics around overall life expectancy, there are always people on the far sides of each set of statistics, so all that can ever be provided is generic basic information. People then have to adapt to living with the element of uncertainty.

This acceptance of uncertainty and knowing that there will be problems in the future is a key mindset to understand. Expect issues to arise and then when they do, at least you knew that they were going to happen, which means that getting over the shock of an issue arising isn’t part of the issues that need sorting out.