

## DEMENTIA CARE CONNECTIONS | FAQ's

### Understanding dementia

#### **What is dementia?**

Dementia isn't a single disease, but a term used to describe the symptoms of a range of illnesses which cause a progressive decline in the ability to think and perform everyday tasks. It can also lead to changes in personality and behaviour. While there is no cure for dementia, it's important to keep in mind that it is possible to continue to maintain a good quality of life for many people. Continuing to do the things that are meaningful is the key to living well with dementia. Life may change, but finding ways to focus on physical and mental wellbeing makes dealing with the progression of the disease more manageable.

<https://www.opalhealthcare.com.au/about-aged-care/dementia/what-is-dementia>

#### **What are the different types of dementia?**

There are many types of dementia but the most common causes include Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies. While it is more commonly experienced in older people, dementia can sometimes occur in those under 65 years of age. This is known as younger onset dementia. One in ten people over the age of 65 experiences dementia, while three in ten are affected once they reach 85 years of age. Understanding the symptoms associated with each type of dementia can help in ensuring each person's care needs are met.

<https://www.opalhealthcare.com.au/about-aged-care/dementia/types-of-dementia>

#### **What are the symptoms of Alzheimer's disease?**

In the early stages of Alzheimer's disease symptoms may be very subtle. You may notice lapses in memory and difficulty in finding the right words for everyday objects appear as the first noticeable symptoms. Other symptoms may include forgetting well-known people or places, deterioration in social skills, loss of enthusiasm for previously enjoyed activities and emotional unpredictability. Symptoms may fluctuate from day to day and often become worse in times of stress or if the person is unwell.

#### **What are the symptoms of vascular dementia?**

Vascular dementia is the broad term which describes dementia associated with problems of circulation of blood in the brain. Symptoms vary, depending on the part of the brain where blood flow is impaired. Symptoms often overlap with those of other types of dementia, especially Alzheimer's disease and include confusion, difficulty with concentration and memory, restlessness, agitation and depression. Sometimes an increase in symptoms occurs following a series of strokes but they may also progress in a gradual steady decline.

### **What are the symptoms of frontotemporal dementia?**

Frontotemporal dementia is a term used to describe disorders that primarily affect the frontal and temporal lobes of the brain which causes them to shrink or atrophy. These areas of the brain are generally associated with personality, behaviour and language. Some people with frontotemporal dementia have dramatic changes in their personality and may become impulsive, lack inhibition and have repetitive compulsive behaviours such as tapping or clapping together with difficulty with speech and language.

### **What are the symptoms of dementia with Lewy bodies?**

Lewy body dementia is the second most common type of progressive dementia after Alzheimer's disease. Protein deposits, called Lewy bodies, develop in cells in the areas of the brain involved in thinking, memory and movement. People with dementia with Lewy bodies may experience visual hallucinations. Other symptoms include rigid muscles, slow movement, walking difficulty and tremors similar to those experienced in Parkinson's disease.

### **What impact does dementia have on carers and families?**

Dementia has a huge impact not only on the person who has been diagnosed, but also on those closest to them. Often children of someone living with dementia find roles have been reversed as they become the caregivers. Some of the feelings commonly experienced by carers include guilt, grief, loss and even anger. Rest assured that if you are feeling any of these things you are not alone. Even if your loved one isn't ready to move into long-term care, feel free to arrange for a chat with our knowledgeable team who'll be happy to offer advice or put you in touch with other carers who are going through the same thing and can offer support and understanding.

## **Preparing for future care**

### **How do I know it's the right time to think about residential care for my loved one?**

Thinking about the move into residential care is never easy and can bring up all sorts of emotions. It's time to start the conversation about moving into care when you have concerns that your loved one isn't coping well with day-to-day activities or if you feel safety is a concern. They may be forgetting to do things like turn off the stove or even finding the way home when out for a walk. The earlier you start the conversation, the more time everyone will have to consider options and make informed decisions.

### **I am struggling with the decision to move my loved one into residential care.**

It's natural to feel apprehensive about making such a big decision. It's important to remember that you're not alone. Our team understand that it can feel overwhelming and they can provide direct support and suggest strategies to make things easier.

### **What steps can I take to make the transition to care a smooth one?**

Think about a short stay in respite care to start with. Perhaps arrange to go and have lunch or participate in an activity that your loved one enjoys. This will give you both you a chance to find out if the Care Community feels like a good fit and it will give you both confidence in your decision.

### **What are some of the challenges I might expect?**

Moving house is among the most stressful life events. When moving house is combined with a big life change like moving into residential care, it can have a significant impact. Often the move into care comes about as a result of a traumatic event such as a fall rather than a considered decision process, so the circumstances around the move can feel overwhelming and out of the person's control. Sometimes the person moving into care can take out their frustrations on their family if they don't feel in control. It's important to ensure that your loved one feels a part of the decision-making process. If this happens, try not to take it personally. Our team are here to help and support both you and your loved one through this time.

### **What should my loved one bring with them when they move into care?**

Home is not simply somewhere to live, it is a haven from the outside world and symbolic of who we are. Letting go of possessions accumulated over a lifetime which trigger memories of our past can lead to feelings of loss. It's important when someone moves into care that they choose some things to bring with them that provide comfort and help to ease the transition to their new surroundings by providing security and familiarity. That might be things like soft furnishings, artwork or ornaments with special sentimental value. Speak with our leadership team to discuss the sort of things that might make your loved one feel at home.

## **Establishing a new home**

### **How long will it take for my loved one to settle into the new environment?**

Everyone's different but on average you can expect most people to start feeling more comfortable and at home in around two to six weeks. It's a big adjustment so try not to get disheartened if it seems to take a while. The most important thing is to just take each day at a time and speak with our leadership team if you have any concerns.

### **What should I do if my loved one seems unhappy and asks to go home?**

Each day will be different. Sometimes just being aware that there will be good days and bad days means it can be easier to manage when things get tough. It's a good idea to check in with the care team before your visit. Find out how your loved one's day has been and the things they've enjoyed doing. That way, if they are feeling negative you can redirect the discussion to talking about the highlights of their day. Ensure that the care team are aware of the things that your loved one likes to do so they can be included in their daily activities. This will go a long way to creating positive feelings and helping them to feel at home.

### **I feel guilty for bringing my loved one into care. How can I deal with this feeling?**

It's normal to feel emotions like guilt, loss and even grief when your loved one moves into long-term care. You've probably been putting your loved one first and the rest of your life on hold for some time now. Remember that you've done the very best for your loved one. Dementia is a progressive disease and as the symptoms increase, caring for someone living with dementia becomes a full time job. Many people find they experience a feeling of relief when their loved one moves into care. They are finally able to resume a more natural relationship and enjoy spending time with each other without the burden of constant care. They are also able to connect with other families who are going through the same thing often providing a wonderful support network.

## **Maintaining relationships**

### **My parent doesn't seem to recognise me.**

It can be very difficult when someone you love stops recognising you. There are things you can do to keep your connection with your loved one. Even if they may not recognise your face, they do remember how you make them feel. It may be that they are living in a different time in their life, perhaps a time before they had children. Try entering their world and engaging with them in the memories they do have. Sharing photos of that time in their life can provide the basis for reminiscence. Although it's difficult, don't try to get the person to remember you but focus on sharing positive memories together.

### **My mother thinks I am her husband. How do I deal with that?**

Try using reminiscence and look at photos of the past that are meaningful and connect you both, helping to tell a narrative of your lives together. This can help orient the person in time and reset their perception of your relationship. Do not pressure them person to remember who you are or force them to participate in the relationship role of the relationship if they are not comfortable. Remember the care team are always there to support you

**My loved one seems to be angry at me when I visit.**

It's likely that they're not actually upset at you, but may be having difficulty in communicating how they are feeling. Talk to the team to find out how your loved one is doing prior to your visit. They'll be able to work with you to find out what may be triggering these feelings and come up with ways to alleviate and redirect these emotions. You may also consider your time of visit. Try to time your visit when your loved one is well-rested and ready to join you in doing an activity that you can enjoy together.

**My loved one is no longer able to speak. I don't know how to communicate with them anymore.**

Even though your loved one may no longer be able to verbalise it's still possible to have meaningful interactions. Observe body language and non-verbal cues to understand how they are feeling. Touch and eye contact are both good ways to engage and connect closely with each other. If your loved one enjoys the experience, a hand massage with soothing cream can be a wonderful way to spend time together. You may consider more frequent visits as other ways of communicating are no longer open to them. Ensure that all family understand how they can still contribute to positive engagement.

## Meaningful Life

**I'd like to take my loved one on an outing but I'm worried that I can manage this.**

Talk to the care team and understand the risks and how they can be managed. Find a place that's not too crowded or busy which can reduce potential for overstimulation. Start small. Go somewhere familiar like a small café or the park. Consider taking other family members for support and think about the time of outing and ensure that the person is not tired or near medication time. Most of all, try to relax and enjoy spending time together.

**My mother tells me she's bored and has been in bed all day every time we speak but the team tell me a different story. How should I handle this?**

Talk to the team before you visit to get an understanding of what she's done during the day. You can then frame your conversation around that. It may be that she cannot remember. Ask a team member to take photos so that when you come in you can share the photos together and prompt conversation.