

INFORMATION FOR FAMILY AND FRIENDS

It comes as a shock when someone you know is diagnosed with dementia, but it doesn't mean the end of the world! The person with dementia is still the same person you have loved over the years, and this will never change. But, more than ever, they will need your continuing support as they face the future with a gradually progressive, debilitating neurological disease.

How can you help?

1. Offering support to the person with dementia and the person who will be their main carer. Tell them that you will stick with them through the course of the condition and mean it. It is a sad fact that people with dementia and their family / whanau are often abandoned by people they thought were friends. People who say that it is "too hard" for them to see someone in this state should try to imagine what it is like for the person! Accept that being there will be difficult, especially as the condition progresses. There is no doubt you will have painful, embarrassing, frustrating and terribly sad times, but there will also be periods of warmth, joy, satisfaction and a good deal of laughter.
2. Listen to what the person with dementia and their carer want: Sometimes it will be just listening, allowing people to let off steam. It might be that the carer wants someone to stay while he/she has a break or the person with dementia wants to do one of their usual hobbies - Walking on the beach, having a coffee or playing golf (you might have to keep the score). People with dementia and their carers don't always ask for help, so it is good if you can offer assistance when you see a need or at any other time.
3. Learn as much as you can about dementia and if you know what particular type of dementia your family member or friend has, find out about that. This will help you to understand what is happening and to anticipate difficulties that might arise. If you know which parts of the brain are affected, then you will also be aware of what is working well for the person and you can engage with them in that way. For example, singing and the ability to appreciate music are often preserved even when dementia is very advanced. You might want to read Dementia New Zealand pamphlets or attend an education session with your local Dementia New Zealand group.
4. Develop your communication skills so that you can continue to connect with the person with dementia. Being isolated can speed the course of the condition and cause depression. The main carer will have worked out some communication strategies that you can share.
5. Encourage the person to make future plans. This might include updating a Will, appointing Enduring Powers of Attorney, making an Advanced Care Plan or even deciding what to do with the dog if it gets too much to look after it. Different people have different things that matter to them. Over time, it is useful to have a discussion and perhaps write down what they might like to happen to them later.
6. Be patient and tolerant. You may be upset by what the person does or says, especially if it seems out of character. Remember that they have a physical disease of the brain and their behaviour is affected by this. They are not trying to annoy you! Being disapproving or trying to correct them is not helpful. Just take them as they are remembering they are still themselves, just in a different way.

Keep doing the things you used to enjoy together. Some people are bothered that the person with dementia does not always recall what they have done and wonder whether the activity was worth it. However, people do not have to remember, to enjoy things. (We enjoyed the meal we had last Tuesday because of the company we had, though we can't remember now what it was we ate). Emotions, be they happy or sad, can last a lot longer than the experience that caused them.

Inheriting dementia?

Family members often worry that they will inherit dementia. There are some very rare inherited forms of dementia. These usually start when the person is relatively young and family members can have genetic testing to see if they too are susceptible. However, for most people, dementia begins in late life and is so common that most people have an affected elderly relative. Some genes may make an individual a little more likely to get Alzheimer's disease.

However, other things like smoking, lack of intellectual stimulation and lack of exercise, high blood pressure, obesity and poor eating habits play a much larger role in developing dementia. The best way to reduce your chances of developing dementia is to live a socially-involved and healthy lifestyle.

Finally

The person with dementia is still the same person you know and love. Keep in touch, learn to go at their pace and in their way and encourage others to stay involved as well. That is the best thing you can do for your friend or family member.

This publication provides a general summary only of the subject matter covered. People should seek professional advice about their specific case. Thank you to Alzheimers Australia, Dr Chris Perkins, Dr Richard Worrell and Dr Tina Crownshaw for your input into this publication. 2023.