Dementia New Zealand™

INFORMATION FOR FAMILY AND FRIENDS

To people Important to me …

The reason you are receiving this is because you are a friend or family member with whom I would like to share how my diagnosis of dementia impacts me. If you can learn about and understand more about dementia, it will support me and other members of my family. It will also improve community acceptance and understanding of dementia.

- While it may appear that I have no disability, something like memory loss does affect the way I go about my daily activities.
- Dementia affects my thought processing ability. It is a disease over which I have no control.
- It is not the end of the road in life's journey for me, however it does mean that the road has narrowed. Please continue to walk with me.
- I may need your support to help me exercise my rights to access support so that I can live as independently as possible and be engaged in my community as much as I choose to.
- If you are my EPOA, I may need you to be an advocate for me so that I get the information I need to participate in decisions that affect me as fully as possible- including care decisions throughout my dementia journey.
- I need lots of encouragement.
- Please keep a sense of humour and laugh with me!

I need you to …

- Continue to include me in conversations and activities – even when I appear reluctant.
- Give me time to understand what you are saying and respond.
- Use simple sentences and one step instructions.
- Focus on the things I am still be able to join in with.
- Write important things down for me, using support systems that work for me e.g. diaries/ calendar/ whiteboard.
- Accept that repetition is part of my illness.
- Speak directly to me – not through another person.
- Treat me with the same dignity and respect as other people. I still have thoughts and feelings. Remember that I am still me - The essence of who I am is still the same.

It is important for you to understand that …

- I may have difficulty with co-ordination or negotiating my environment.
- Short term memory loss will mean that recent memories or instructions may be the most difficult for me to recall.
- When I forget, it is the nature of my memory loss. It is not my fault, and it's not deliberate.
- Routine is an important help as I manage my day.
- Big groups and gatherings can make me feel vulnerable.
- It may be necessary to change some roles.
- Dementia New Zealand and affiliates have information sheets, books, videos, and other information available, which will help you to learn more about dementia.
- Your local affiliate may run educational courses, support groups, and other services for family and friends of people with dementia.

How can you help?

It may come as a shock when someone you know is diagnosed with dementia, but once the news has settled – there is the capacity to live life well. 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.

- If you are part of the extended family or a family friend, it is important that you continue to support both the person living with dementia and their main care partner. It is a sad fact that people with dementia and their family / whanau often feel abandoned by people they thought were friends. It is helpful to put yourself in their shoes to understand what it feels like to be them as they deal with the dementia process.

- Accept that being there will be difficult, especially as the condition progresses. There may be painful, embarrassing, frustrating and sad times, but there will also be rich times with periods of warmth, joy, satisfaction and a good deal of laughter.
- Listen to what the person with dementia and their care partner want.
  - o Sometimes it will be just listening, allowing people to let off steam.
  - o The carer might want someone to stay while he/she has a break.
  - o The person with dementia might want 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.
- Learn as much as you can about dementia and if you know what 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 affiliates.
- Feeling isolated can speed the course of depression so it is important that you develop your communication skills so that you can continue to connect with the person with dementia. Talk with the main care partner about this as they will have worked out some communication strategies that you can share.
- Encourage the person to make plans for the future. 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.
- Be patient and tolerant. You may feel 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. It's easy to feel concerned 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, however generally speaking, risks of developing dementia can be minimised by following a healthy lifestyle For more information, please refer to our *Genetics and Dementia* information sheet.

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 Māori proverb says it how it is:

He waka eke Noa.
We are all in this together.

Other useful articles.

- Thank you for being a friend! - Dementia Canterbury
- For families watching on ... Caring for the Care Partner - Dementia Canterbury
- A word to care partners - “Look after yourself” - Dementia Canterbury
- Genetics And Dementia | Dementia NZ
- One Pager - Top Tips Brain Health Awareness Month 2025

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