

# GETTING A DIAGNOSIS OF DEMENTIA

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Because the diseases that cause dementia develop gradually, the early signs may be very subtle and vague and not that obvious. Early symptoms also depend on the type of dementia and vary a great deal from person to person. Often people just adapt to changes, thinking they are due to ageing and so the dementia diagnosis is not even considered. Sometimes a friend or relative who has not seen the person for a while notices that the person is not functioning as well as previously and raises the alarm.

## Why do we need to get a diagnosis at all?

For many years dementia was not spoken about openly, people avoided using the word, pretended it was just normal part of aging or the older person was just 'a grumpy old thing'. We now know better. We do not ignore and pretend about cancer anymore, so too with cognitive issues and dementia. Dementia is a declining neurological disease and people deserve to be assessed and diagnosed with any type of neurological disease, including dementia.

## Early symptoms might be:

- Poor short-term memory, especially for recent events. Missing appointments, losing track of what bills have been paid, losing things.
- Inability to carry out usual tasks, for example a great cook struggles to plan and prepare a meal.
- Personality changes: speaking or behaving in ways that are uncharacteristic e.g. a usually kind person makes hurtful remarks.
- Changed behaviour including apathy or disinhibition. Loss of interest in usual activities.
- Speech and language problems: difficulties finding words.
- Struggling to follow conversations or understanding what others say.
- Psychological changes: Depression and withdrawal, increased suspiciousness or irritability. Poor concentration.
- Difficulty with abstract thinking e.g. understanding concepts, handling numbers.
- Poor judgement: poor decision making
- Disorientation to time and place: forgetting what day it is, getting lost in familiar surroundings or not adjusting to new ones.
- Loss of spatial skills. The ability to judge distance, size and speed may diminish, making driving dangerous among other problems.

This list covers only the common symptoms. Different forms of dementia start with different early signs.

## Why is it so difficult to get a diagnosis?

### Potential Lack of Insight

Not everyone with changes in their cognition have insight into what is happening to them, or they may feel defensive and deny that there is an issue. This will often mean they will not bring the topic up with their GP or flatly deny there is a problem and avoid the GP altogether. It is extremely hard for family members, who know their person so well, to see the changes and have concerns, to override the persons wishes and seek medical help. This is particularly so when the person is very angry and hostile towards anyone who dares to mention their concerns.

### Reluctance of doctors to diagnose

Many family members feel frustrated by how complicated it is to get someone seen and assessed for their cognitive issues. In New Zealand there are many ways in which a person can be assessed and diagnosed with Dementia. For most people, their GP will make the diagnosis. Not all GPs feel confident to do this and will refer on to a specialist for an assessment. The person could be referred to a Geriatrician, a Psychiatrist of Old Age, a Memory Clinic or Team or a Neurologist (public or private). Some people will be diagnosed with dementia while they are in hospital for something else.

If there is not enough evidence to make a definitive call, the diagnosis may not be made straight away. The doctor may be erring on the side of caution, they wait to see if the person declines over time to confirm that this is dementia and not something else. However, this is not an excuse to let the doctor procrastinate, family members need to keep recording any concerns and revisit the doctor should they notice any further decline and insist on some action.

### What should you do if you are concerned about someone's cognition?

- Gently approach your family member about the things you have noticed. No one responds well to being confronted with the mistakes they are making. Talk to them about your concerns and suggest you go together to the GP for a "checkup". Depending on the situation it may be easier for a family member to talk to the GP alone first. When the GP sees the person it is important that someone who knows them well goes with the person.
- Let the GP know about your concerns prior to an appointment so they are engaged and prepared.
- When bringing the person in to see their GP book a double appointment for 30 minutes so there is less time pressure.
- Talk with the GP about the best way to proceed in the appointment. The GP may plan for the person to be seen by the Practice Nurse for a Memory Test while you talk through your concerns.
- Write down your concerns and any incidents that have occurred.
- Be honest and tell the GP what's really going on,
- Check if there is any blood or urine tests the GP would like done before the appointment.
- If the person with the cognitive issues refuses to go for a cognitive assessment, they may still go for other conditions e.g. a blood pressure check. Let the GP know in advance about your concerns and if you do not want the person to know you have contacted the GP. (They will bring up the issue in some other way.) It is vital that someone provides the doctor with additional information that the person may not disclose or even be aware of.

### How is the diagnosis made?

The GP will take a full history and will usually need to talk to someone who knows the person. They will examine them for any medical or psychological problems that could be causing these symptoms. The GP may get the Practice Nurse to do a memory test in another room (usually the 30-question Mini ACE test) or do it themselves in front of you. They will order some blood tests and maybe a CT head scan.

If things are not straight forward you can ask for a specialist referral - you can go public or private, going private may be quicker however the services offered in the public system are usually more comprehensive for the ongoing support, review and complexity of dementia along the way.

### Why is it important to get an early diagnosis

- It could be something else. There are treatable medical conditions that can look like dementia.
- As with any disease, the sooner a diagnosis is made the sooner the person and their family can get onto 'putting all their ducks in a row'.
- Early diagnosis allows the person time to adjust, come to terms with what is happening, plan for the future and set priorities as to how they chose to live in the next few years.
- Research shows that the earlier the diagnosis, the better the person with dementia and family cope. Often people are very relieved to understand why their relative has changed.
- Everyone can get support and education on how to cope with dementia. Dementia NZ offers support, advice, education and navigation through the journey of dementia.
- Medication and other activities (such as cognitive stimulation therapy) may slow down the progression.

- Family / whanau can do some future planning such as appointing an Enduring Power of Attorney, making an Advanced Care Plan.
- As you can both do the things that you've always meant to do, while you still can.

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Dementia New Zealand offers support, information and education.

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