

Learning Guide

Dementia

Level 3



26974 Describe interaction, supports, and reporting for people with dementia in a health or wellbeing setting	Level 3	8 credits
28563 Provide person-centred care when supporting a person with early-stage dementia in a health or wellbeing setting	Level 3	8 credits

Name:

Workplace:

Copyright © 2017 Careerforce

All rights reserved. Careerforce (Community Support Services ITO Ltd) is the owner of the copyright of this publication. Other than as permitted by the Copyright Act 1994, no part of this publication may be reproduced, copied or transmitted in any other form or by any means, without prior written permission of Careerforce, PO Box 25 255, Christchurch, 8144, New Zealand.

Contents

Introduction	1
What is dementia?.....	3
The impact of dementia on daily living	4
Understanding dementia.....	7
Functions of the brain.....	7
How dementia affects the brain.....	11
How it relates to what we do	12
What is ‘normal’ cognitive ageing?	13
It may not be dementia	14
Diagnosis of dementia	16
Stages of dementia	17
Supporting people to live to their full potential.....	20
Restorative practice.....	21
Choice and preference.....	22
Communicating with a person with dementia	23
Non-verbal communication	24
Verbal communication	24
Vocal communication	24
How you can help communication	25
Things to avoid.....	26
Observing and reporting.....	35
Providing support	36
Supporting family and whānau.....	36
Care for the family carer.....	36
Accessing additional support.....	37

Introduction

This learning guide is an introduction to dementia, and person-centred care.

How to use your learning guide

This guide supports your learning and prepares you for the unit standard assessment. The activities and scenarios should be used as a general guide for learning.

This guide relates to unit standards:

- 26974 Describe interaction, supports, and reporting for people with dementia in a health or wellbeing setting (level 3, 8 credits)
- 28563 Provide person-centred care when supporting a person with early-stage dementia in a health or wellbeing setting (level 3, 8 credits).

This guide is yours to keep. Make it your own by writing notes that help you remember things, or where you need to find more information.

Follow the tips in the notes column.

You may use highlight pens to show important information and ideas, and think about how this information applies to your work.

You might find it helpful to talk to colleagues or your supervisor.

Finish this learning guide before you start on the assessment.

What you will learn

This topic will help you to:

- describe dementia and its effects on a person with dementia.
- interact with a person with dementia.
- describe support services available for people with dementia.
- describe reporting requirements related to changes in people with dementia, in a health or wellbeing setting.
- describe the early warning signs and impact of early-stage dementia on a person.
- provide person-centred support to a person with early-stage dementia to promote their wellbeing.



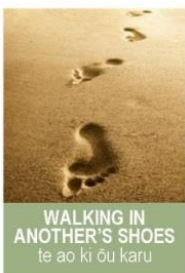
More info

There is a dementia-related Learning Guide at Level 4 that you may find useful.

Additional support

You may also attend a workshop lead by a trainer as part of the project:

Open Minds - Open Doors - Supporting people with dementia



Careerforce has partnered with Alzheimers New Zealand and Walking in Another's Shoes for this project. The training workshop has been developed by the Canterbury District Health Board.



The Careerforce website has an online resource about dementia that you will find useful. Go to www.ilearn.careerforce.org.nz

Ask your supervisor for help if you need to.

What is dementia?

Dementia is an umbrella term used to describe a group of diseases that happens when there are physical changes in the brain. These physical changes can lead to a loss of functions controlled by that part of the brain.

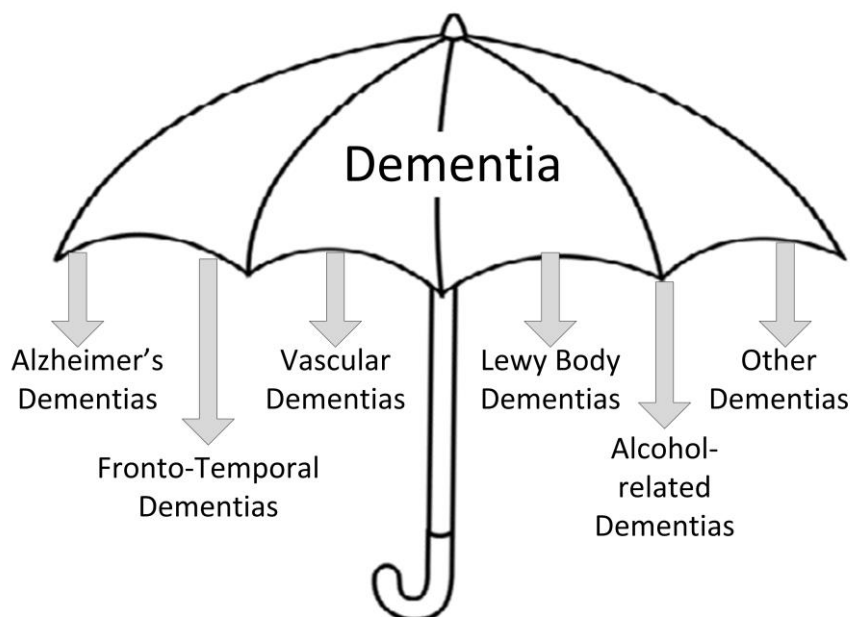
The damage caused by all types of dementia leads to the progressive loss of brain tissue, which in turn will affect a person's:

- memory.
- thinking.
- behaviour.
- emotions.
- perceptions.
- physical functioning.

Because it is progressive, the symptoms will gradually get worse over time.

Dementia is not a normal part of the ageing process. As we grow older we do become more forgetful and our brains just don't work as sharply or as well as they did when we were younger, but that doesn't mean we have Alzheimer's or any other sort of dementia.

There are many forms of dementia. Dementia is an overarching or umbrella term for various dementias.



Different forms of dementia

The impact of dementia on daily living

Memory impairment, especially short-term memory, is often the first symptom to be noticed. Someone with dementia may be unable to remember ordinary information, such as their birth date and/or their address, and may be unable to recognise friends and family members or recall recent events. However, while memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia.

The ability to think and reason (called cognitive ability) also declines and can affect decision making, judgement, speed of reaction time, problem solving, verbal communication including ‘word finding’ difficulty, and orientation in time and space (eg may get lost in familiar surroundings).

For those caring for someone with dementia it is important to keep in mind that the care and sensitivity you use to interact and communicate with a person with dementia can make a huge difference to their wellbeing and sense of self-worth.

Characteristic of dementia	Examples of the impact on daily living
Cognitive	May result in: <ul style="list-style-type: none"> • difficulty recognising people. • difficulty remembering PIN numbers. • difficulty finding their way home.
Functional	May result in: <ul style="list-style-type: none"> • difficulty completing activities of daily living independently. • difficulty handling money. • difficulty keeping safe with electricity. • difficulty knowing what to do next, especially if out of routine. • problems following social cues. • difficulty finding words or loss of verbal skills. • slower reactions.

Behavioural	<p>May result in:</p> <ul style="list-style-type: none"> • a loss of social skills • overactive response to changes or stimuli in the environment. • repetitive behaviours and patterns.
Psychological	<p>May result in:</p> <ul style="list-style-type: none"> • irritability. • changing moods • anxiety. • depression.

Here are some scenarios of people with dementia.

Decision making (poor judgement)

Alan was found at 4am wandering along the banks of the Avon river in his pyjamas. He was cold and confused. He couldn't tell the policeman where he lived or why he was there.

Decision making (slower reactions)

Jeremy lives on his own in a small flat. His support workers have noticed some changes in Jeremy over the past few months. He seems to have difficulty deciding what daily tasks need doing. Some legal documents require his signature, but he seems to keep putting this off. They have also noticed that some of his reactions are slower. For example, when the phone rings, Jeremy seems bewildered by the sound and takes a few moments to realise that he needs to answer it.

Being lost in familiar surroundings

Jim knows he lives in a street called Puhara, and even the house number, 41. But when he goes out for a walk on his street he often can't remember which is his house.

Carrying out everyday tasks

Allison often confuses the order she does things. She usually gets up and gets herself dressed. Today you noticed that she put her underwear on over her trousers and her socks over her shoes.

Performing familiar tasks

Wiremu used to keep in contact with his whānau by phone. But now when he uses the phone he often rings the wrong number and gets frustrated when he doesn't recognise the voice on the other end of the phone.

Memory change

Bill is in a residential dementia unit and is 78 years old. Recently Bill started getting up at 5am in the morning and getting dressed. He would get distressed when he couldn't find his gumboots. Bill believed he had to get his gumboots to go and milk his cows.

Memory loss

When Brian took his son to visit his father Ted, who was in the dementia unit, Ted thought the little boy was his other son. His family were upset because Ted did not recognise his grandchild.

Personality changes

Jenny gets ready to go to the supermarket. She puts on her dressing gown and slippers. Normally a gentle and quiet person, Jenny yells at her husband when he asks her to put on something more appropriate.

Ability to solve problems

Mereana used to work as an accountant. Now she finds it hard to do any maths in her head. She struggles to work out what change she needs when she has bought something.

Understanding dementia

Physical changes occur within the brain cells which cause disruption of the electrical charges and the cells' ability to connect or 'communicate' with other cells. The destruction or changes in the cells causes a loss of brain function controlled by those cells.

The signs and symptoms experienced are closely linked to the area of the person's brain that is affected. With Alzheimer's disease, the most common form of dementia, nerve cells in the area of the brain that deals with thinking and memory become damaged and die off. As the disease progresses, the parts of the brain affected begin to lose tissue and the brain shrinks.

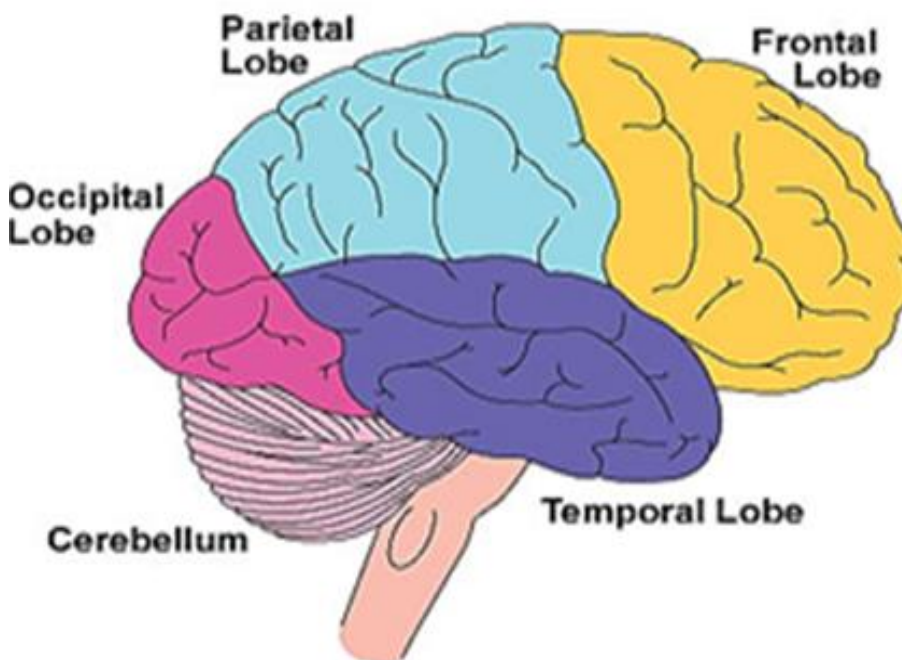
Functions of the brain

The brain is made up of many parts, such as the cerebellum, basal ganglia, brain stem and the lobes. There are four lobes that relate to cognition:

- 1 frontal lobe.
- 2 occipital lobe.
- 3 parietal lobe.
- 4 temporal lobe.

More info

Cognition means the mental processes involved in gaining and applying knowledge and comprehension. These processes include thinking, knowing, remembering, judging and problem-solving, and encompass language, imagination, sensory perception, planning and the initiation or inhibition of behaviour.



Parts of the brain

Functions of the frontal lobe

The frontal lobe is involved in:

- motor function, attention and concentration.
- planning.
- abstract thinking.
- motivation.
- problem solving.
- reasoning and judgement.
- insight.
- spontaneity.
- memory.
- language.
- initiation.
- impulse control.
- social and sexual behaviour.

Functions of the occipital lobe

The occipital lobe is involved in:

- vision.
- processing all the information our eyes are sending to the brain.
- helping us to make sense of visual information and understand it.
- recognising colours.
- movement.
- visual-spacial processing.

Functions of the parietal lobe

The parietal lobe is involved in:

- regulating and processing our five senses.
- helping us feel sensations of pressure, touch, temperature and pain.
- helping us process the taste of food and drink.
- movement.
- orientation.
- recognition of objects.
- speech.

Functions of the temporal lobe

The temporal lobe is involved in:

- processing auditory information.
- receiving sensory information from the ears and helping us comprehend and understand meaningful speech. Helping us to make sense of all the different sounds and pitches transmitted from the sensory receptors of our ears.
- speech and language.
- processing new information and forming long-term memories especially visual and verbal memories.
- helping us to interpret smells.



Write

In your own words, write an example of each function of the frontal lobe and how that relates to an activity of daily living. The first one is done for you.

Motor function

The ability to perform complex muscle and nerve acts that produce movement. This includes fine motor skills like writing, gross motor skills like walking, balance and co-ordination such as putting your clothes on.

Attention

Planning

Abstract thinking

Problem solving

Reasoning and judgement

My notes 

Insight

Spontaneity

Memory

Language

Initiation

Impulse control

Social and sexual behaviour

How dementia affects the brain

There are some fundamental differences between the brain of a person with dementia and of a person without dementia.

Nerve cells

In a person with dementia	In a person without dementia
Many nerves cells in the brain cease to function properly, may lose connections with other nerve cells and eventually die.	Normal ageing doesn't result in damage to or loss of nerve cells in the brain.

Plaques and tangles

In a person with dementia	In a person without dementia
Plaques and tangles can accumulate between and within the nerve cells of the brain. Plaques contain clusters of an unusual protein with some damaged nerve cells. Tangles consist of clusters of twisted filaments within nerve cells that contain a particular protein. Plaques and tangles accumulate in the brain and cause other nerve cells to gradually wither and die.	Proteins function normally, and assist in the normal functioning of the nerve cells and the movement of proteins within the nerve cells. There is no twisting or blockage resulting in the collapse of transport systems with the nerve cells.

Messaging

In a person with dementia	In a person without dementia
Messages between brain cells are disrupted preventing the brain from working efficiently. This leads to the characteristic symptoms of dementia such as loss of memory, impaired judgement and out-of-character behaviour.	There is normal flow of information and messages, and there are no marked changes to normal behaviour and mental functioning.

How it relates to what we do

What do the brain functions mean in relation to everyday activities in daily living?

Writing a shopping list -	
requires me to	requires my brain to
<ul style="list-style-type: none"> • get paper and pen. • look through the cupboards and fridge to see what I need. • write down the items needed. 	<ul style="list-style-type: none"> • remember it is shopping day and plan the steps i need to take. • initiate the task – to get started. • orientate to my kitchen, recognise pad, pen and food items. • use judgement to decide items required and quantity. • maintain concentration and attention so I can complete the task and avoid distractions. • interpret sensory information (smell, taste, touch, vision) to decide if the current food items are still edible. • use impulse control so I choose food items within my budget and of nutritious value. • use language skills to read product information and write the shopping list. • use motor skills to move around the kitchen and manipulate a pen.

Our brain is very busy for what we would generally think to be a simple task. When our brain is functioning normally, it quickly ‘translates’ what we want to do and sends appropriate signals to parts of our body. Just think, what it would be like if one of the functions of the brain was not working. How would that impact on the whole task?

For example, if my memory and attention is impaired:

- how successfully will I be able to write a shopping list?
- could I get easily distracted and not complete it?
- would I remember that I needed to write it?
- would I remember what to include on the list?

If my usual habit is to go to ‘Pak’n Save’ for groceries, but I am taken to an unfamiliar supermarket - will I be able to find the grocery items as easily? Probably not. Just think how this would impact on a person with dementia.

What is ‘normal’ cognitive ageing?

When you make a cup of tea, use the internet or read a book, you're using your cognitive abilities. Cognitive abilities are the mental skills you need to carry out a task. These mental skills include attention, information handling, memory and reasoning.

Throughout adulthood our cognitive abilities do gradually change. A certain amount of cognitive decline is a normal part of ageing. Some people will have more cognitive decline as they age than others and some people will start to show cognitive decline at a younger age than others.

One of the major changes is that we process information more slowly as we age. This table shows some of the things that change with age and some that stay the same.

What normally doesn't change	What normally becomes more difficult with age
<p>Being able to focus on one task (like reading a handout).</p>	<p>Being able to focus on one task while ignoring something else (like watching a movie while the people behind you are talking to each other), or being able to focus on more than one thing at a time (like getting tea ready while talking on the phone).</p>
<p>Being able to remember general factual information like general knowledge and words.</p>	<p>Being able to remember personal experiences like whether you took your medication this morning.</p>
<p>Being able to remember how to do things that you don't need to think about – like riding a bike</p>	<p>Being able to do complex tasks that require taking in complex information then analysing it (like the cost of some grocery items and subtracting the discount).</p>

It may not be dementia

Dementia is not a part of normal ageing. Dementia is a group of symptoms affecting cognition, behaviour and social abilities severely enough to interfere with daily functioning. Dementia indicates problems with at least two brain functions.

A person may have signs of what can appear to be dementia, but it may not be dementia. Check what else is going on for the person. For example, the person may have moved home and changed where they live and this change of environment can lead to confusion.

There are many possibilities other than dementia.

1 Normal ageing

Most of the change in cognitive function occurs because we process information more slowly as we age. People can start noticing normal cognitive changes as early as middle age.

This can have an effect on our ability to focus, remember, and complete complex tasks. Encourage people to use memory aids (like using a notebook, diary, calendar or whiteboard). Many older people will already be using these.

If someone is having difficulty with a cognitive task it's not always because of ageing. Problems with hearing or vision, being unwell or depressed, or being stressed can all make it more difficult to succeed on a task.

2 Acute confusion/delirium

This refers to a sudden change in cognition and is usually related to illness; infection or other medical reasons. The cognitive change tends to be dramatic and sudden.

3 Depression

Depression can also cause some changes to cognition. In particular it can affect a person's concentration, attention, motivation and ability to recall information. It will also be accompanied by negative thoughts, increased irritability, changes to appetite and sleep. Doctors will often wish to rule out a depression before diagnosing dementia.

4 Side effects of medication

Certain medications can have a negative effect on a person's cognition. If someone has begun a new medication and you are noticing recent changes to their cognition it is important to report this back.

5 Taking a longer time to process information

Whilst this could be a sign of dementia it is also a result of normal aging and would need to be accompanied with another sign or symptom before it could be considered as being suggestive of a dementia. Pace the task more slowly for the person. Tie in with their past experience as older people have years of accumulated knowledge and experiences.

6 Attention seeking behaviour

Aggression, resistance to cares, reverting to childhood.

These are labels often used to describe a person's behaviours and they represent some of the stigmatisation that can occur for people living with dementia. It is important to recognise that there are always reasons why a person behaves in a particular way.

Behaviour:	Could mean the person is:
Attention seeking.	Lonely.
Aggressive.	Frightened.
Resistance to cares.	Independent.
Reverting to childhood.	Responding to a parental approach.

7 Not intentional behaviour

When we observe a fluctuation in functional abilities we can make the mistake of believing that certain behaviour is intentional or being 'put on'. It is important to recognise that other factors can impact on the brain's ability to function such as fatigue, interest, anxiety, hunger, dehydration, pain. So what may look like intentional behaviour can be a reflection of the type of dementia or additional factors impacting on that person.

8 Not a complete loss of function

It is important to recognise and promote a person's ability to maintain function.

A common mistake is to decide that with a diagnosis of dementia comes a complete loss of function, when in actual fact we can 'de-skill' a person living with dementia by not providing them with opportunities to use the skills they continue to have.

9 Not hopeless

Reinforce the message that people living with dementia can indeed continue to live full and productive lives. The role we have in supporting them can enhance their quality of life and ability to function. Celebrate the fact that this work can be extremely satisfying and rewarding.

Diagnosis of dementia

Making a diagnosis can be difficult, especially in the early stages of the condition. Sometimes, a period of monitoring over several months can be necessary before a diagnosis is made. Reporting any changes in a person is a helpful first step.

Family and health professionals should be involved. Discussing concerns with a doctor is usually the first step as it will help rule out other conditions or illnesses that have similar symptoms to dementia and can mean that illnesses such as depression can be identified and treated.

The doctor may refer the person to a specialist consultant. Assessments can include conversations with the person being diagnosed and those close to the person; a physical examination; memory tests; and/or brain scans.

If you are supporting the person being diagnosed, it is useful to:

- write down any questions or worrying signs beforehand to ask the doctor as it can be difficult to remember everything you want to ask during a consultation.
- write down any important points the doctor makes during the consultation.
- ask for an explanation of medical terms, words or phrases used if you do not understand them.
- find out what supports are available in the community.

Follow up may be needed with consultants (for example, psychiatrists, neurologists, geriatricians or a specialist team). Explaining the diagnosis is an important step.

Support from family or others may be needed to ensure the person is fully but sensitively informed about the condition and its progress, using language and terms which can be understood. This can help the person experiencing dementia to plan for the future.

While there is currently no cure, there are a number of drug treatments available for people with mild dementia. These drugs can help lessen some of the common symptoms, and may help improve general functioning for some people.

A diagnosis of dementia can have a significant impact on a person's wellbeing and it is understandable they will experience a range of emotions including shock, disbelief, fear, shame, guilt, anger, and sadness. There will be real concern of what the future holds, a sense of isolation and being cut off. However for some the diagnosis may bring a sense of relief.

Telling someone that there is no need to feel sad, or there is nothing to worry about doesn't help as they are likely to think that you simply don't understand how they feel or what they are going through.

In talking with the person:

- try to be sensitive to what the person may be feeling.
- reassure them and confirm that you are there for them whatever happens.
- pay attention to non-verbal signs of emotion.
- help the person to identify their emotions by commenting (at an appropriate time) on how you think they may be feeling, for example, by saying, 'you look quite sad' or 'you seem worried'.
- allow time for your comment to sink in and for the person to react.
- if the response confirms your impression, acknowledge the feeling.

Stages of dementia

The rate that dementia progresses vary greatly and can be affected by other health conditions. There are usually three stages of dementia – mild (or early-stage), moderate and advanced.

The earliest changes can occur up to 20 years or more before a diagnosis is made. The onset of dementia is very gradual, and it is often impossible to identify the exact time it began.

Mild (early-stage) dementia

In the mild stage of dementia, often called early-stage dementia, mental abilities decline and mood swings occur. The person can live independently for the most part, with adequate personal hygiene and relatively intact judgement but there can be impaired social activities or employment difficulties.

Loss of memory, declining physical health, inability to concentrate and growing confusion can lead to greater dependency on family and carers. Inevitably, this will impact on relationships and affect the way in which partners relate to each other, both physically and emotionally.

Similarly for family carers, the emotional effects of a partner's increased dependency and the need for physical care might change the relationship.



More info

Early-stage dementia is different to young-onset dementia which describes a person who develops dementia at between 40 to 50 years of age.

An example of mild dementia

Harvey is 72 years old and has recently had a stroke. He had worked for a local engineering company all his working life. As well as working in the workshop as an engineer, he was responsible for hiring staff and monitoring their performance.

Since retirement he has continued to visit his former workplace on the last Friday of each month for morning tea (the boss' shout) to catch up with his workmates.



Harvey does not have any immediate family as he and his wife married late in life and did not have any children. His two brothers both died over the last ten years, and since his wife died five years ago he has lived alone.

Recently his niece insisted that he went to the doctor because she had noticed that her uncle found simple tasks that he had previously done every day were becoming increasingly difficult. For example, he struggled with jobs in his workshop at home, often leaving the light on at night and occasionally he'd have an accident with a piece of machinery.

Getting money from the money machine was also difficult as he couldn't remember how to work the machine and often put in the wrong PIN number.

When Harvey drove to the same supermarket he had shopped at for five years, he often had to stop on the side of the road as he couldn't remember how to get there and did not know where he was. He struggled with knowing how much money to hand over to the check-out operator and would get increasingly frustrated because he thought the check-out operator was short-changing him.

The doctor sent Harvey for an assessment and he was diagnosed with dementia.

Although he still lives at home, he now only works in his workshop when his nephew helps him. He has dinner at the local tavern and his friends walk him home afterwards. He has made some new friends, enjoys their company, and has taken up playing darts and bowls.

On most days Harvey goes to a day-care centre based at a nearby residential facility.

Harvey often appears quietly in the staff office of the centre and staff are becoming concerned about confidentiality of other people's records. He also inappropriately listens to the conversations of other people. It seems he still thinks he is in a position where he is responsible for staff performance.



Write

What is a sign of dementia?

Circle the phrases that indicate signs of dementia.

I don't know the date	I am slower to think	I can no longer tell the difference between pants and a top	I feel restless	My family think my personality has changed dramatically	I didn't take any Panadol today	I forget people's names	I am forgetting what numbers are and what needs to be done with them
I have started frequently misplacing personal items in the house and keep finding things in strange places	I can't use my cheque book anymore.	I often lose my car keys	I can't understand my pill blister pack anymore	I like to remember the past	I feel bored	I leave the tap running sometimes	I don't always recognise members of my family anymore
I occasionally have problems finding words.	I make a bad decision once in a while	I now have problems in social situations that used to be comfortable for me	I don't want help to shower	I don't always feel like socialising.	I keep getting lost when driving a familiar route	I now have difficulty following or initiating a conversation	I get lost easily
I have difficulty balancing my budget	I can no longer operate the television remote	I have never been able to save money	I have a favourite shirt I like to wear.	I have started having difficulty judging when it is safe to cross the road when out walking.	I take longer to do things	I don't recognise my car keys or know what they are used for	I fell out with my neighbour
I forget where I am going	I have been wearing the same clothes for three days	I now find it hard to concentrate when cooking and have burnt five pots	I no longer initiate doing things I used to enjoy	I can't find my way home	I am tired of housework	I am confused about what activities to do at certain times of the day	I refuse to take prescribed medication
I am losing weight and feeling sick	I say I am eating but no food is being used	I am confused by my new cell phone	I think someone keeps breaking into my house and messing it up	I am paying less attention to my physical appearance.	I lose my balance in the shower	I have trouble finding the right words sometimes	I do not remember going to the doctor this morning

Supporting people to live to their full potential

Historically dementia has been seen in the medical model of ‘treating’ people with dementia. It has focused more on the physical changes that happen in the brain and the best ways to ‘manage’ it.

A **person-centred** approach requires us to respect the person and treat them as individual, focusing on their needs, abilities and achievements. It takes into account the ‘whole person’s needs’ including social, physical, emotional and spiritual.

This approach means valuing who they are, what they are interested in and what they can still do. You support the person to maintain the abilities they have and offer a choice of activities within their capabilities.

Help the person to maintain relationships with family and whānau and with friends. Talk about and acknowledge their ‘life-story’ and their past life, friends, family and whānau.

This person-centred approach is likely to include a ‘care pathway’ to help the person progress through the health and social services in a coordinated way.

A person-centred approach is respectful, interested, relaxed, kind.

Sometimes we are so busy in our work that we take a **task-focused** approach. We do the task in an efficient way for the person we care for. We work to our job description and the service plan for the person. A task-focused approach could be seen as a busy and efficient carer.

Both the task-focussed and person-centred approach, when caring for a person with dementia, is ‘doing to’ or ‘doing for’ the person.



Restorative practice

- Honours the strengths of a person.
- Enhances independence and autonomy.
- Supports active participation based on agreed goals.
- Focusses on 'doing with' rather than 'doing to'.
- Builds confidence and self-esteem.
- Empowers and enables.
- Improves wellbeing and quality of life.
- Supports the person 'to do' rather than 'doing for'.

Another way is the **restorative approach** or 'doing with' the person. Here your role is as a companion, encouraging, relaxed, enabling, and working in partnership with the person.

The fundamental premise of restorative practices is that people are happier, more cooperative and productive, and more likely to make positive changes when those in authority do things 'with them', rather than 'to them' or 'for them'.

The restorative approach may require people who are providing care to think, act and work in a different way.

Both the person-centred approach and the restorative approach focus on the **wellbeing** of the whole person. Wellbeing involves feeling good and functioning well and having a **good quality** of life.

Quality of life refers to how much we are able to fully enjoy our life and the people in it. This includes the activities we choose to pursue; the people we connect with; and the experiences that give us pleasure.

Choice and preference

Each person with dementia needs to be treated as an individual, respecting their personal needs, preferences and choices. It is important to be empathetic and see things from the person's point of view.

Think about all the things you did this morning. You will have made many choices: what time to get up; what to wear; what to eat; which radio station to tune into; what tasks to do before leaving home and what can wait until you return later; to make your lunch or to buy it on the way; to walk, catch a bus or drive. You will have made many choices and exercised your personal preferences many times as you prepared for your day.

Just for a minute, imagine if you could not express your preferences or make a choice. How would it feel having someone else choose what you would wear, and what you would do for the day? People denied the opportunity to express their preferences and choices quickly lose confidence, have low self-esteem and can become depressed.

Remember that promoting the independence and self-worth of a person is important so that, and where able, the person can make decisions and have some control over their life. Be aware of personal likes and dislikes and preferences. This helps the person feel valued and respected and reduces stress.

Consider some of the daily activities a person may be supported to do:

- undressing/dressing.
- showering/bathing.
- grooming – brushing teeth, doing hair, shaving, applying make-up.
- meal management.
- medication management.
- house cleaning.
- grocery shopping.

How would you feel if you were asked to do these daily activities without any consideration for your habits and routines?

When supporting a person with dementia, it is essential to be supportive and positive. Don't assume you know what the person thinks or wants. Ask them.

You need to work together. Be helpful, kind, caring and compassionate. Being supportive in your communication and interactions helps the person with dementia to feel valued, supported and respected.

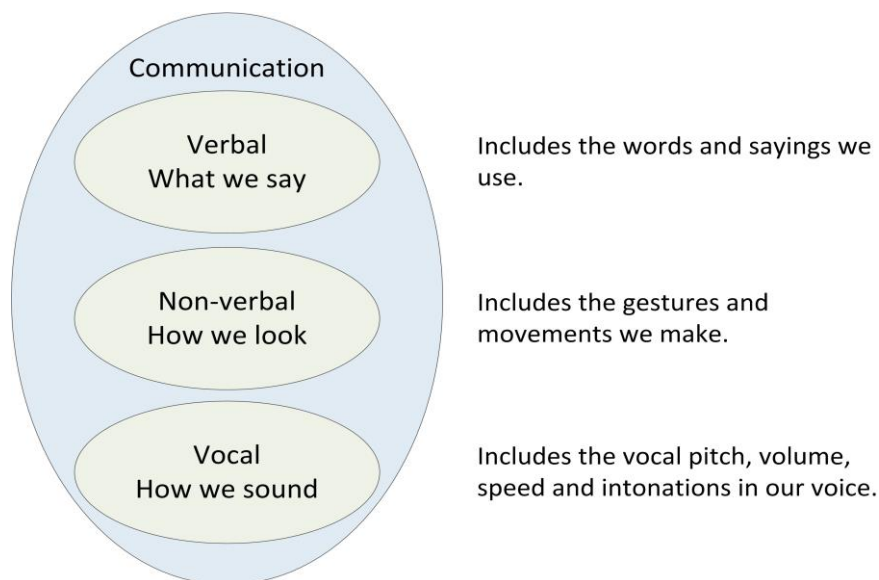
Communicating with a person with dementia

People with dementia often experience a gradual decrease in their ability to communicate and interact with other people as their dementia progresses. They may find it more and more difficult to express themselves clearly to others and to understand what others are saying to them.

This not only can make someone frustrated, upset and anxious, but it can also lead to feelings of isolation, fear and poor self-esteem. Communicate in a positive way to help the person maintain good self-esteem.

Create one-on-one time, making sure the person feels included and can participate in the interactions. Listen to what the person says and/or shares. This helps the person express their feelings, needs and emotions. Listening also demonstrates the respect you have for the person. It is important to be empathetic and see things from their point of view.

It is really important to take the time and effort to listen and speak carefully, to do your best to understand and to do what you can to make interaction and communication as easy and as rewarding as possible. Effective communication can significantly improve the quality of life of someone with dementia.



Communication

Communication is made up of the words we say, how we say them and our body language and gestures. When we communicate, all three parts of communication make up the message we send: **what we say, how we sound and how we look.**

Non-verbal communication

Non-verbal communication is made up of our body language and gestures. Gestures may be a movement of the head or hand, to express a meaning or emphasise what is being said. Body language is our main non-verbal method of communication.

Think about a time when you have some great news or a surprise for someone. You haven't said a word because you don't want to spoil the surprise, yet the person says to you: "What's up?" Somehow, even with your best efforts to remain 'normal', you have transmitted your excitement to the person without a word being spoken.

By observing the body language and gestures of people you gain insights into their mood or state of wellbeing. You will need to consider:

- what is going on now?
- what is a person's body language telling you?
- what happened before you arrived?
- who has spent time with the person?

Verbal communication

Verbal communication is the words we use. To be effective when speaking with a person with dementia:

- break down what you say to a single message. Convey each message one at a time.
- speak clearly, at a moderate pace and volume.
- repeat the message.
- re-word the message and repeat.

Vocal communication

Vocal is how we sound. It includes:

- pitch - the degree of highness or lowness of our voice.
- volume - quantity, or power of our voice, degree of loudness.
- intonations - the rise and fall of our voice when speaking.

As an example, try saying this sentence in the three different ways indicated:

- "It is really great to meet you" (friendly and enthusiastic tone).
- "It is really great to meet you" (sarcastic tone with a roll of the eyes).
- "It is really great to meet you" (said in a distracted tone, while looking at your cell phone).

How you can help communication

You can help a person with dementia to communicate. Here are some tips.

- ‘Check in and check out’ with the person you support. This involves saying ‘hello’ when you come in and ‘goodbye’ when you leave. This helps the person to orient to time and place, and supports cognitive abilities that the person retains.
- Approach the person from the front. Get the person’s attention. Use the person’s name.
- Face the person, be at the same eye level and make eye contact, if culturally appropriate.
- Be calm and gentle. Remember that facial expression, body language and the tone of voice become extra important.
- Use touch to help draw and keep the person’s attention, as well as to communicate feelings of affection.
- Avoid talking when there is background noise like TV or radio.
- Use short and simple sentences, and make one point at a time.
- Use familiar ideas rather than new or complex ideas.
- Allow time for the person to understand the information and to respond.
- Use simple questions with short answers. Do not ask questions that rely upon the person having a strong memory.
- If you repeat a question or any information, try to use the same words.
- Use activities like music and singing to communicate.
- If you have not been successful, try again later.

Ensure that people who are significant in the person’s life are also encouraged to interact effectively, respectfully, and in a dignified and personalised time together.

Some people will have a **communication book**. This is used to record anything about the situation, and can be seen by everybody. It may record what is happening, what is noticed, for example, changes, important information, and reminders. It provides a continuity of information flow for all those people supporting the person with dementia as well as for the person themselves.

Things to avoid

Never talk about people in front of them as if they are not there.

Avoid patronising or talking down to the person.

Avoid arguing with or contradicting people with dementia. Tell the person what they can do, rather than what can't be done.

Avoid coercing or giving orders or telling the person what to do. It is important to calmly and gently encourage the person to do what you want.

Interactions

Taking the example of Harvey (earlier pages), here are some ways to be supportive when interacting with him. Note how communication skills are used to manage Harvey's needs and also to manage the concerns which staff had about some of Harvey's behaviour.

Promotion of:	Environmental	Physical	Social	Spiritual	Emotional	Cultural
Supportive interaction with the person you support	Accompany/assist Harvey to the lounge, check he is comfortable and that he has someone to talk to.	While assisting Harvey with dressing or grooming allow extra time to respond to a request.	Ensure Harvey knows the activities that he can attend today.	Sit and listen to Harvey's story about the loss of his wife.	Check that Harvey has something to occupy him when other residents have visitors.	Make sure Harvey has the opportunity to socialise with other men.
	Encourage Harvey away from staff areas of the facility. Accompany him to a resident's area and sit with him until he is settled.	Verbal prompts or instructions are given one step at a time.	Reintroduce Harvey to other residents taking part in the facilities activities.	Look at and talk about the photos of his wife and brothers that Harvey has in his room.	Sit and listen without correcting when Harvey talks about being fine if he could just go home.	Arrange for a member of his former darts team to visit him.

Promotion of:	Environmental	Physical	Social	Spiritual	Emotional	Cultural
Communication skills used to interact with the person you support.	Reintroduce yourself each time you interact with Harvey.	Give verbal instructions simply and one step at a time.	Explain to Harvey what is happening. Show Harvey how he can take part.	Make sure Harvey has a 'quiet time' when he can talk about the things that are important to him.	Be aware of Harvey's body language and/or behaviour; respond by making time to talk with him.	Organise a volunteer to spend time with Harvey sharing his interest in engineering and darts.
	Explain clearly but firmly that the office is for staff only. Show Harvey the staff only sign on the door.	Check that Harvey has understood the message/instruction. Use open questions.	Explain to Harvey who each person taking part in the social activity is. Name stickers may help.	Use active listening skills to assure Harvey that you are interested in his story.	When Harvey is moved away from residents with visitors, explain carefully that they need to be alone. Take time to be with him and talk to him about his interests.	While sitting with Harvey show him books about engineering and encourage him to comment about the photos.



Read the following scenario and then answer the questions.

Jennifer

Jennifer is a support worker who is meeting Mary for the first time. She has been asked to work with Mary who has been showing signs of cognitive impairment and needs somebody to support her with meals. Jennifer's first session with Mary is at breakfast time.

Jennifer has been told Mary can no longer prepare her breakfast safely and has burnt two elements in the electric jug due to turning it on without water in it.

Mary tells Jennifer she really wants to make her own breakfast as nobody makes it taste as good as she does. She is not that happy about having a stranger in her home.

Jennifer firstly acknowledges how difficult it must be for Mary and asks if she would be willing to teach Jennifer her secret to a tasty breakfast. She discovers that Mary loves hot toast and a cup of tea. Her favourite spread is peanut butter.

Jennifer notices that Mary is well oriented to her kitchen and can put the bread in the toaster, tea bag in the tea cup. She has no difficulty with reading or writing. She does however have difficulty problem solving if the toaster is not turned on at the wall. She also has some trouble finding the items for her toast as her pantry is very cluttered.

Jennifer tells Mary she is looking forward to learning from her and in turn she may have some ideas that could help avoid problems with the jug and the toaster.

Mary identifies a place on the kitchen bench to keep her favourite spreads so they are easier to locate. Jennifer puts a sign by the toaster where Mary can see it which says 'Am I turned on at the wall?' She puts another sign by the jug that says 'Fill me with water.'

Jennifer's presence and the written cues help Mary complete the steps required to make her breakfast safely and independently. She now says she is looking forward to Jennifer's visits and is working hard to get Jennifer to produce the perfect cup of tea!

Mary

When the doctor told me somebody was going to have to come and cook me my meals I couldn't understand it. I know my memory is not as good as it used to be but the thought of a stranger coming into my house and cooking me the breakfast I had been making for 40 odd years was devastating to me.

I've always been an independent woman and don't suffer fools easily. When my husband and I were on the farm I would have produced breakfast for about 50 shearers before day break so why anyone had to come and make my simple toast and tea didn't make sense.

It just felt wrong. But the kids seemed worried and I hate to see them that way so I bit my tongue and agreed.

To be honest that toaster had been annoying me. It was so temperamental and there was that business with the element in the jug burning out. I guess in my heart of hearts I knew that had more to do with me than the electronics... it is so hard getting old.

When Jennifer arrived she wasn't at all what I expected. Nancy down the road said she felt like a visitor in her own house when her support worker started coming. But Jennifer wasn't like that. She seemed to understand how hard all this was for me and I never ever got the feeling she thought I was losing my marbles.

In fact it looked like I had a few things to teach her and all. Together we were able to sort out all the troubles like the toaster; the jug and the things that kept going missing in the pantry. A couple of months in and guess what. I am still making my own breakfast.

It's all been such a relief and life is so much smoother than it was pre-Jennifer. The kids are more relaxed, the doctor is off my back and these memory problems seem to have come to nothing!

Based on the scenario, **answer the following questions.**

What were Mary's fears before meeting Jennifer?

If you were in Mary's shoes would you feel the same?

How did using a restorative approach make Mary feel?

What was it about this approach that helped Mary feel the way she did?



Write

Read the following scenario and answer the questions.

Mrs Lee migrated from China to New Zealand in 1989. Her husband died four years ago and her only son has recently had to move away for business. She was very involved in the Chinese community when her husband was alive but in recent months has become increasingly isolated. Her son visits her once a month and during his last visit he was very concerned that she had lost weight and didn't seem to be eating. He took her to her GP who is treating her with an anti-depressant. He did query whether or not she may have a dementia but was unwilling to make a diagnosis at this stage. He has recommended a support worker start working with Mrs Lee to help her re-connect with her community and assist with meal planning and preparation.

Mrs Lee

"My name is Mrs Lee. I like to be called this because it reminds me of my husband. I was so excited to marry him and become Mrs Lee. He was everything to me and I cannot adjust to life without him. He did so much for me: paid the bills and got the shopping in and took care of the business side of things. When he knew he was dying he tried to teach me some of those things. He was clever – could use the computer and pay bills on the line. I never got the hang of that.

And just lately when the bills come in I find it harder and harder to make any sense of them. The numbers and words don't mean anything anymore. You may think it is because English is my second language. But I was so clever with languages. I can speak four different languages you know. Cantonese; Mandarin; English and French. Although these days it makes me exhausted speaking in English or French and it can be harder to find the words I am looking for. It was crazy the other day. I was speaking to my son on the phone and all of a sudden I couldn't find the word I was looking for in any of my language. Imagine that, four languages and not one of the words I wanted would come to me.

They think I am depressed because I don't eat and I don't go out. The truth is I am scared to go out much now. I panic in group situations. I feel everybody notices that I am not following conversation so well; I can't keep up at the games of bridge anymore and I am still not over the embarrassment of getting lost on my way home that last time.

I do get hungry and I think I want to eat, but then I just don't know where to start. The oven confuses me at times and I seem to have all the wrong ingredients in the house. Too many bananas for one thing and never any garlic or ginger. I must remember to put that on the shopping list next time I go shopping.

That is the other thing, I don't remember when I last went shopping and it seems easier to wait till my son comes to visit and he can help.

My son and the doctor have said that someone will come to help me. They think the company will make me happier and more confident. I am not sure anybody can help me."

Answer the following questions.

From the information you have read, what are some of the signs of dementia being experienced by Mrs Lee?

What parts of the brain may be affected?

What tells us that they are actually signs of dementia and not just Mrs Lee's usual function?

As Mrs Lee's support worker what will be important for you to consider in regards to your approach when working with her?

If Mrs Lee is diagnosed with dementia what potential impact will this have on her son? Consider emotional and social impacts.

What else could be impacting on Mrs Lee that we need to consider?



Read the following scenario and answer the questions.

You have been asked to begin working with Martha. Her family has recently requested a change of support worker due to Martha's frequent complaints. Martha requires assistance with medication management and security checks. The family are anxious you build a good relationship with Martha as they are concerned that she may refuse to have anyone enter her home if this doesn't work.

Martha

"Let me tell you that getting old is no fun. These young girls march into my house like they own it and ask all sorts of nosey questions about my private business. They do not know the meaning of respect. I tell you when I was their age I knew my place and would not have dreamt of trying to tell somebody who was three times my age what to do.

Yes the GP thinks my pills have become a bit complicated for me to manage alone and I admit I got them a bit mixed up a few months ago and took the wrong thing at the wrong time. You know if he hadn't mucked around with my prescriptions and kept changing them all the time it wouldn't have been a problem.

And then there was the business of leaving the door open when I went out. My daughter got all upset and thought I was going to get robbed. She tries to tell me that it is not as safe around here as it used to be and maybe she is right.

So yes I agree that maybe I do need someone to come in and help with these things but that doesn't mean anyone has got the right to boss me about and ask me about my private matters. Is it any of their business why I am taking the pills I am taking? And they don't need to go into my bedroom without asking first! She said she was checking if my window was shut. The cheek of it! Do I look so incapable that I can't shut my own window?

Well I've finally got rid of her and now I'm expecting a new person tomorrow. Let's hope they come with a good set of manners".

Answer the following questions.

Martha is very clear about her needs. Using a **restorative practise** model, identify the key beliefs you would use to help build a relationship with Martha.

Uses communication that is positive, not judgemental or challenging.

Provides an individualised approach

Honours the strengths of a person.

Enhances independence and autonomy.

Supports active participation based on agreed goals.

What are the risks if we don't practise in a restorative way?

Observing and reporting

If you observe changes in a person with dementia, you need to report these changes to ensure that the person continues to get the level of support that best meets their needs.

You should talk to your supervisor, or other health professionals and find out what form your report should take. It may be a verbal report, or there may be a standardised written form for you to fill in.

Make sure that when you report changes that you limit your report to facts only.

- Report what you have observed.
- **Don't** pass judgement.
- **Don't** give opinions on what you think is the underlying cause of the change.

Review the section 'What is dementia' and ask yourself the following questions.

- What are the observed indicators (visible signs) for the types of changes in physical abilities that need to be reported?
- What are the observed indicators for the types of changes in behaviour that need to be reported?
- What are the observed indicators for the types of changes in cognitive (thinking) abilities that need to be reported?
- What are the observed indicators for the types of changes in emotional states that need to be reported?
- What are the observed indicators for the types of changes in social abilities that need to be reported?

Ensure that your final report covers all these points.

Providing support

Supporting family and whānau

Loss of memory, declining physical health, inability to concentrate and growing confusion can lead to greater dependency on family and carers. Inevitably, this will impact on relationships and affect the way in which partners relate to each other, both physically and emotionally.

Similarly for family carers, the emotional effects of a partner's increased dependency and the need for physical care might change the relationship.

You can act as a resource by knowing how and where to refer the family member to the place or person that can answer such questions as:

- what supports are available to them?
- what does a diagnosis of early stage dementia mean?
- what do the whānau need to know?

Assist the whānau to still see their family member as the person they are, rather than someone with a dementia. For example, activities the family have always done together can still be done, with adaptations.

Support family/whānau to adapt their behaviour and responses so as to support their family member thereby making their behaviour less challenging, eg, agree, go with it, have patience, go with what works.

Ensure all communication with family/whānau is within your scope of practice and is accurate and caring.

Care for the family carer

Know how to look after yourself so that you remain well. Take breaks, eat well, keep up your fluids to stay hydrated and have regular gentle exercise.

Ensure you maintain some of your own personal interests.

Ensure you are integral to the wider multi-disciplinary team and all information is explained and shared.

Assist your family member to maintain activities they enjoy and can still participate in so as they are occupied and have a sense of worth.

Accept help from other family members, people or support networks and source outside help and support as soon as you need it. Refer to www.alzheimers.org.nz and/or www.carers.net.nz

Recognise when you need a break and understand that this does not mean you have failed or let anyone down. It means you are acting responsibly so that you are better able to provide the best possible care for your family member.

Accessing additional support

Support services

Local and national support and advocacy services are available for family/whanau and support workers who care for a person living with dementia. The main ones are given below.

Alzheimer's NZ

Alzheimer's New Zealand's aims and objectives are to provide information and promote high standards of education for people with dementia, their carers, families and health professionals.

There are 23 member organisations of Alzheimer's throughout New Zealand that provide support and education for all people living with dementia, their family and their caregivers in their local areas.

The regional member organisations may offer all or some of the following services:

- support through group 'get-togethers' for the person diagnosed with dementia
- support group meetings for carers and family members.
- home visits by member organisation staff or field workers.
- carer education programmes.
- volunteer services.
- day-care programmes.
- regular newsletters.
- library books and audio resources.
- extensive resource information.

They may be contacted through a local branch of Alzheimer's New Zealand or contacting the national organisation for local information.

Age Concern

Age concern offer national and local services and provide information on activities that make it easier for people to improve their lifestyle, health and wellbeing, in particular for home-based services.

Residential services

Residential services that provide support to people with dementia include:

- **Rest homes**, who aim to provide home-like environments with registered nurse supervision and care staff able to support residents with daily living activities.



More info

For more information, refer to their website at www.alzheimers.org.nz

- **Dementia care units**, which aim to provide care for people with specific dementia care needs. They usually have people in small clusters in a secure setting. They have 24-hour security access with registered nurse coverage, access to medical specialists, and staff with specialised dementia and Alzheimer's training.

Support in difficult situations

A difficult situation could be where a person with dementia is being cared for at home by family members and the family may need a break from the caring. Support services exist to provide relief for the carers. Alzheimer's New Zealand can assist with providing details of available relief services. Examples of support services include:

Relief services

- a member of the psychogeriatric or rehabilitation team at a local hospital referred by a GP.
- social workers responsible for aged care such as church agencies or a district nurse.
- a GP, social worker or service coordinator from a public hospital if the person with dementia has been a patient.
- the local Alzheimer's New Zealand organisation or the national office of Alzheimer's New Zealand.

Sexuality and sexual behaviour

- qualified sexuality counsellors.
- a GP, social worker, district nurse or member of psychogeriatric or rehabilitation team at the local hospital.
- local member organisation of Alzheimer's New Zealand.

Abusive behaviour

- elder abuse and neglect prevention services are established throughout the country.
- a GP, social worker, district nurse or a member of the psychogeriatric or rehabilitation team at a local hospital referred by a GP will provide contact details.
- local member organisation of Alzheimer's New Zealand.

Safety

- the occupational therapy department at your local District Health Board will assess the safety needs of the person with dementia, and assess the home the person lives in and advise on what needs to be done.
- a GP, district nurse or social worker can provide contact details.
- local member organisation of Alzheimer's New Zealand.