Learning Guide

Dementia: Support and safe practice

23920 Describe dementia, support and safe practice to support people living with dementia in a health or wellbeing setting

<table>
<thead>
<tr>
<th>Level</th>
<th>Credits</th>
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</thead>
<tbody>
<tr>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

Name:

Workplace:

Issue 3.0
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Introduction

This learning guide explains how to describe dementia and how to support a person living with dementia in a health or wellbeing setting.

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 the following unit standard:

- 23920 Describe dementia, support and safe practice to support people living with dementia in a health or wellbeing setting (level 4, 6 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 mark 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:

- define dementia and distinguish it from the normal ageing process.
- understand dementia and how it affects the brain.
- understand the features and different types of dementia.
- describe dementia in relation to its stages.
- describe dementia in terms of co-existing conditions.
- describe dementia in terms of its impact on daily living.
- describe support for people living with dementia in a health and wellbeing setting.
- describe the importance of meaningful activity for a person living with dementia.
- use safe practice when supporting a person living with dementia.
- define categories of restraint used when supporting a person living with dementia.
- identify and apply the maintenance of the person’s rights during restraint practice.
- identify and apply organisational policies and procedures that comply with national standards for restraint minimisation.
What is dementia?

Dementia is an overarching term used to describe a chronic disorder of mental functioning caused by physical changes in the brain as a result of disease or injury. These physical changes can lead to a loss of the functions controlled by specific sections of the brain.

The damage caused by all types of dementia leads to the progressive loss of brain tissue and the symptoms will gradually get worse over time.

There is a wide variety of physical symptoms associated with the decline in memory or cognition that directly impacts a person’s ability to perform everyday tasks.

Memory impairment, especially short-term memory, is often the first symptom to be noticed. Someone living 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 remember 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. This can affect:

- decision making.
- judgement.
- orientation in time and space (e.g., the person may get lost in familiar surroundings).
- speed of reaction time.
- problem solving ability.
- verbal communication (for example, the person may have difficulty with finding words).

Other changes may affect behaviour or activity – for example, the person may show changes in:

- personality (e.g., inappropriate responses, lack of emotional control).
- eating, dressing, toileting (e.g., becomes incontinent and is unable to dress without help).
- interest level (e.g., may lose interest in their surroundings, hobbies, etc.).
- ability to perform routine household tasks.
- behaviour (e.g., the person may become agitated and perform repetitive actions, or experience delusions and hallucinations).

More info

For more information on dementia refer to the learning guides for unit standards:

23921 Dementia: Person-centred support

23922 Dementia: Effects of providing support

23923 Dementia: Related behaviours

You can also find additional resources on the Careerforce website: http://ilearn.careerforce.org.nz
Dementia and the brain

Dementia is a progressive neurological disorder, with increasing brain dysfunction. Physical changes occur within the brain cells, disrupting the electrical charges in the cells and the cells’ ability to connect or ‘communicate’ with other cells. The destruction or changes in the cells causes a loss of the brain function controlled by those cells. This affects memory, thinking, behaviour, emotion and physical functioning.

A person living with dementia experiences it in their own individual way. However, there are some common features. The way a person develops dementia and the signs and symptoms they experience are closely linked to the area of the person’s brain that is affected.

There are many forms of dementia. Dementia is an overarching term for various forms of dementias, including Alzheimer’s disease, vascular dementia, fronto-temporal dementias, Lewy Body dementias and alcohol-related dementias.

There are also some key differences in the symptoms of the different types of dementia. In advanced Alzheimer’s disease the cortex shrinks dramatically. This is especially so in the hippocampus, which is the part of the brain that deals with new memories.

Different forms of dementia

There are usually three stages of dementia:

- early/mild.
- moderate.
- advanced/severe.

The earliest changes can take place for 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.
Understanding the brain

The healthy brain has over 100 billion nerve cells (neurons) that communicate with each other and many other nerve cells in the body to form interlinking networks. These networks are ‘organised’ to do special things, such as thinking, learning, remembering, seeing, hearing, smelling and controlling muscle movements.

Brain function is carried out by the network of nerve cells (neurons) and connections throughout the brain. Electrical charges or ‘messages’ travel through these networks to ‘control’ our actions, behaviours, memories, thoughts and feelings.

With dementia, physical changes within the brain cells disrupt 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 the brain function that is controlled by those cells.

The signs and symptoms of dementia 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 that are affected begin to lose tissue and the brain shrinks.

Parts of the brain

The brain is made up of different parts that need to function together.

The cerebrum fills most of the bony skull. It is the part involved in remembering, problem solving, thinking and feeling. It also controls movement.

The cerebellum sits at the back of the head, underneath the cerebrum. It controls coordination and balance.

The brain stem sits underneath the cerebrum in front of the cerebellum. It connects the brain to the spinal cord and controls automatic functions such as breathing, digestion, heart rate and blood pressure.

The brain has a wrinkled surface. This is a specialised outer layer of the cerebrum called the cortex.
The brain is also divided into two halves – the left half controls movement on the body’s right side, while the right half controls the body’s left side. The ‘language centre’, the area of the brain that controls speech, is on the left side of the brain in most people.

The brain is made up of four lobes that relate to cognition:

- the frontal lobe.
- the occipital lobe.
- the parietal lobe.
- the temporal lobe.

The brain is a very complex thing, so it is not possible to truly localise specific functions of the brain to just one lobe.

**Frontal lobe**

**Functions of the frontal lobe**

- Motor function.
- Attention and concentration.
- Planning.
- Abstract thinking.
- Motivation.
- Problem solving.
- Reasoning and judgement.
- Insight.
- Spontaneity/initiation.
- Memory.
- Language.
- Impulse control/social and sexual behaviour.

**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.
Occipital lobe

Functions of the occipital lobe
- Vision (shared with the parietal lobe).
- Processing all the information our eyes are sending to the brain.
- Helping us to make sense of visual information and understand it.
- Recognising colours.
- Seeing and tracking movement.

Parietal lobe

Functions of the parietal lobe
- 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.
- Feeling and sensing movement.
- Orientation.
- Recognition of objects.
- Speech and language (shared with temporal).
- Visuo-spatial tasks.

Temporal lobe

Functions of the temporal lobe
- Processing auditory information.
- Receiving sensory information from the ears and helping us comprehend and understand meaningful speech.
- Helping us differentiate sounds and pitches transmitted from the sensory receptors to our ears.
- Speech and language.
- Processing new information forming long-terms memories especially visual and verbal.
- Helping us to interpret smells.
Fundamental brain differences

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

**Nerve cells**

<table>
<thead>
<tr>
<th>In a person without dementia</th>
<th>In a person living with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal ageing doesn’t result in damage to or loss of nerve cells in the brain.</td>
<td>Many nerves cells in the brain cease to function properly, may lose connections with other nerve cells and eventually die.</td>
</tr>
</tbody>
</table>

**Plaques and tangles**

<table>
<thead>
<tr>
<th>In a person without dementia</th>
<th>In a person living with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>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 that would result in the collapse of transport systems with the nerve cells.</td>
<td>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.</td>
</tr>
</tbody>
</table>
Reactions and decision making

<table>
<thead>
<tr>
<th>In a person without dementia</th>
<th>In a person living with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is normal flow of information and messages, and there are no marked changes to normal behaviour and mental functioning.</td>
<td>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 behaviour that is out of character.</td>
</tr>
</tbody>
</table>

Memory changes

<table>
<thead>
<tr>
<th>In a person without dementia</th>
<th>In a person living with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory loss is not an inevitable part of the aging process. The person is able to function independently and carry out activities of daily living. The person is able to recall and describe incidents of forgetfulness. They may occasionally not be able to find the right word, but can carry on a conversation. Judgement and decision making are not affected.</td>
<td>Symptoms that indicate dementia could be an inability to perform simple tasks, unable to recall or describe specific instances. The person may get lost or disoriented or be unable to follow directions. Words can be forgotten or misused and it is difficult to hold a conversation. Judgement and decision making are affected.</td>
</tr>
</tbody>
</table>
Normal ageing versus dementia

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 disease or any other sort of dementia.

‘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, the ability to handle information, 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.

<table>
<thead>
<tr>
<th>What normally doesn’t change</th>
<th>What normally becomes more difficult with age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being able to focus on one task (such as reading a handout).</td>
<td>Being able to focus on one task while ignoring something else (such as 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 (such as getting tea ready while talking on the phone).</td>
</tr>
<tr>
<td>Being able to remember general factual information like general knowledge and words.</td>
<td>Being able to remember personal experiences (such as whether you took your medication this morning).</td>
</tr>
<tr>
<td>Being able to remember how to do things that you don’t need to think about – such as riding a bike.</td>
<td>Being able to do complex tasks that require taking in complex information then analysing it (such as adding the cost of some grocery items and subtracting the discount).</td>
</tr>
</tbody>
</table>
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 a person’s daily functioning. Dementia indicates problems with at least two brain functions.

A person may show signs of what can appear to be dementia without actually having dementia. Check what else is going on for the person – for example, they may have moved home. This change of environment can lead to confusion.

There can be other reasons why a person’s ability to perform daily activities can decline. A diagnosis of dementia would not be made before other possible conditions were ruled out.

Acute confusion or 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.

Depression

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

Side effects of medication

Certain medications can have a negative effect on a person’s cognition. If someone has begun a new medication recently and you notice changes in their cognition, it is important to report this back.

Taking a longer time to process information

While this could be a sign of dementia, it is also a result of normal aging and needs to be accompanied by another sign or symptom before it could be considered as suggestive of a dementia. Pace the task more slowly for the person. Tie it in with their past experience, as older people have years of accumulated knowledge and experience.
Attention-seeking behaviour

Aggressions, resistance to care and reverting to childhood are labels often used to describe a person’s behaviours. Such labels 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.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Could mean the person is</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention seeking.</td>
<td>Lonely.</td>
</tr>
<tr>
<td>Aggressive.</td>
<td>Frightened.</td>
</tr>
<tr>
<td>Resistance to care.</td>
<td>Independent.</td>
</tr>
<tr>
<td>Reverting to childhood.</td>
<td>Responding to a parental approach.</td>
</tr>
</tbody>
</table>

The behaviour is not necessarily intentional

When we observe a fluctuation in a person’s 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, such as fatigue, interest, anxiety, hunger, dehydration and pain, can affect the brain’s ability to function. What may look like intentional behaviour can be a reflection of the type of dementia the person has, or of other factors that may be affecting them.

Dementia doesn’t mean a complete loss of function

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

A common mistake is that a diagnosis of dementia means 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.

The outlook is 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.
Scenarios of people living with dementia

**Decision making (poor judgement)**

Alan was found at 4 a.m. 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 Jeremy seems to have difficulty in 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 house is his.

**Carrying out everyday tasks**

Alison often confuses the order in which she does things. She usually gets up and gets herself dressed. Today you notice that she has 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.

**Memory change**

Bill is in a residential dementia unit and is 78 years old. Recently Bill has started to get up and dressed at 5 a.m. He gets distressed when he can’t find his gumboots as he thinks he needs them 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 be an accountant but now finds it hard to do any maths in her head. Out shopping, she can’t to work out what change she will get.
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 has been done for you.

**Motor function**

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

**Attention**

**Planning**

**Abstract thinking**

**Problem solving**

**Reasoning and judgement**
Insight

Spontaneity

Memory

Language

Ability to initiate

Impulse control

Social and sexual behaviour
Types of dementia

Dementia can be described as reversible or non-reversible.

Certain conditions can cause reversible dementias. Examples of reversible dementias include medication interactions, depression, vitamin deficiencies, thyroid abnormalities or infections. The effect of these problems is usually short term and can be reversed when the cause is removed. It is important that these conditions are identified early and treated appropriately so that the symptoms can be improved.

<table>
<thead>
<tr>
<th>Cause</th>
<th>What happens</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Unwanted reactions between drugs cause effects that mimic dementia.</td>
<td>Confusion. Hallucinations.</td>
</tr>
<tr>
<td>Depression</td>
<td>Major life stresses can affect the chemical balance in the brain.</td>
<td>Low mood. Low energy levels.</td>
</tr>
<tr>
<td>Vitamin deficiency</td>
<td>Insufficient B vitamins such as folate, niacin, riboflavin and thiamine are available for good brain function.</td>
<td>Confusion. Change in mental state.</td>
</tr>
<tr>
<td>Thyroid abnormalities</td>
<td>Low or high thyroid levels, or other endocrine abnormalities can cause effects that mimic dementia.</td>
<td>Confusion.</td>
</tr>
<tr>
<td>Infections</td>
<td>Changes can affect the brain when infections are developing.</td>
<td>Confusion.</td>
</tr>
</tbody>
</table>

The irreversible dementias are known as degenerative dementias. The most common form of irreversible dementia, accounting for 50–60% of all diagnoses, is Alzheimer’s disease.

Alzheimer’s disease leads to nerve cell death and tissue loss throughout the brain. Over time, the brain shrinks dramatically, affecting nearly all its functions. The brains of people living with Alzheimer’s disease have fewer nerve cells and connections than a healthy brain does. As a result, people living with Alzheimer’s disease lose functional nerve cells in the areas of the brain that deal with thinking and memory. They also experience a build-up of abnormal proteins in some brain cells.

Other common forms of dementia are:

- vascular dementia (multi-infarct, transient ischemic attack (TIAs) and small strokes).
- dementia with Lewy Bodies.
- frontal temporal lobe (including Pick’s disease).
- Creutzfeld Jakob’s Disease (CJD).
<table>
<thead>
<tr>
<th>Degenerative and progressive dementias</th>
<th>What happens</th>
<th>Symptoms</th>
</tr>
</thead>
</table>
| **Alzheimer’s disease**               | Physical changes in the structure of the brain. Cells die and the brain shrinks. Plaques and tangles develop in the brain tissue and disrupt the messages throughout the brain, especially in the areas that control memory and mental functions. | • Increasing difficulty in managing complex or new tasks.  
• May forget the names of people and places, appointments and recent events.  
• Shows lack of initiative or withdrawal from usual activities.  
• Emotional and personality changes.  
• Frustration.  
• Anxiety, sadness, irritability, suspicion and loss of confidence.  
• Difficulty in finding the right words or understanding what is said. |
| **Vascular or multi-infarct dementia** | Cells in the brain die when the oxygen supply is cut off, often because of a blockage in the network of blood vessels that supply oxygen to the brain. Related to multiple strokes (also called multi-infarct dementia). | • Onset can be:  
  – sudden when caused by a stroke.  
  – gradual when caused by a number of very small strokes.  
• Other characteristics are similar to those of Alzheimer’s disease. |
| **Lewy Bodies dementia**              | Abnormal clumps of protein develop in the nerve cells in the brain of people living with Lewy Bodies dementia, Alzheimer’s disease and Parkinson’s disease. These clumps disrupt normal functioning and act like a road block for messages travelling within the brain. | • Fluctuation in intellectual functioning, especially alertness and attention.  
• Poor hand–eye coordination.  
• Symptoms similar to Parkinson’s disease (slowness, muscle, stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of voice).  
• Prone to falls.  
• Sometimes visual hallucinations and delusions. |
| **Frontal and temporal lobe dementias (including Pick’s disease)** | Damage occurs to the frontal lobe and/or the temporal lobes of the brain. These areas are responsible for behavioural control, judgement, emotional responses and language skills. | • Personality changes such as apathy and indifference.  
• Inappropriate behaviour.  
• Poor insight and social judgement.  
• May not be forgetful (unlike Alzheimer’s disease).  
• Loss of ability to initiate, organise and follow through on simple plans and familiar activities.  
• In the early stages may be misdiagnosed as stress and/or depression.  
• Difficulties with language. |
Dementia, delirium and depression

Although some of the features of dementia, delirium and depression are similar, there are some key differences between them. It is not unusual for a person living with dementia to also experience either depression or a period of delirium.

**Dementia** is a progressive cognitive decline.

**Delirium** is a temporary state of confusion.

In **depression** there are changes in thinking and reasoning linked to mood.

Because signs and symptoms overlap, it can be difficult to decide what the problem is. An accurate assessment is important so that the correct treatment can be started.

<table>
<thead>
<tr>
<th>Features</th>
<th>Dementia</th>
<th>Delirium</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Onset</td>
<td>Slow</td>
<td>Sudden</td>
<td>Gradual or sudden</td>
</tr>
<tr>
<td>When does it happen</td>
<td>Progressive over time. ‘Sundown syndrome’ occurs late in the day with increased agitation and anxiety</td>
<td>At night and/or upon waking up</td>
<td>Usually worse in the morning or following certain situations</td>
</tr>
<tr>
<td>How long does it last</td>
<td>Months to years</td>
<td>Anything from days up to a month</td>
<td>Months to years</td>
</tr>
<tr>
<td>Alertness</td>
<td>Generally alert</td>
<td>Fluctuates</td>
<td>Normal</td>
</tr>
<tr>
<td>Attention</td>
<td>Generally normal</td>
<td>Impaired and can fluctuate</td>
<td>Easily distracted</td>
</tr>
<tr>
<td>Memory</td>
<td>Recent and past memory impaired</td>
<td>Recent and immediate memory impaired</td>
<td>Patchy memory</td>
</tr>
<tr>
<td>Thinking</td>
<td>Difficulty with words and poor judgement</td>
<td>Disorganised speech</td>
<td>Puts self down and shows signs of hopelessness</td>
</tr>
<tr>
<td>Sleep</td>
<td>Fragmented</td>
<td>Disturbed sleep pattern or sleep–wake cycle is reversed</td>
<td>Usually wakes early, restless</td>
</tr>
<tr>
<td>Other features</td>
<td>Personality changes and lack of insight into condition</td>
<td>Can be associated with acute illness</td>
<td>May neglect self and spend long moments in deep personal thought</td>
</tr>
</tbody>
</table>
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 is necessary before a diagnosis can be made. Early diagnosis is very important, as it will help rule out other conditions or illnesses that have similar symptoms and can help the person experiencing dementia to plan for the future.

Discussing concerns with a doctor is usually the first step. This can mean that illnesses such as depression are identified and treated. The doctor may refer the person being diagnosed to a specialist consultant. Assessments can include conversations with the person being diagnosed and others close to them, a physical examination and memory tests and/or brain scans.

Several types of scan are available to help decide if there are changes occurring in the brain. The most common are:

- computerised tomography (CT) or computerised axial tomography (CAT) scans, which take pictures of the brain using X-rays and a computer.
- magnetic resonance imaging (MRI) uses a computer to create an image of the brain using radio signals produced by the body in response to the strong magnet in the machine.

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 if you do not understand them.
- find out what support is 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 that the person is fully but sensitively informed about the condition and its progress in language and terms they can understand.

While there is currently no cure, there are a number of drug treatments available for people living 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. They will feel real concern about what the future holds as well as a sense of isolation and being cut off. For some, however, 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 will not help, as they are likely to think that you simply don’t understand how they feel or what they are going through.

When talking with the person:

- try to be sensitive to what they 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.

Remember!

- It is not your role to diagnose a person living with dementia.
- You have to report back any changes.
- Usually the person to speak to would be your coordinator, district nurse, registered nurse or manager who may then contact the family/whānau and/or health professionals or GP to let them know about the changes.
- Dementia doesn’t just affect the person living with it but also the lives of the family/whānau and friends who are close to that person.
- A diagnosis of dementia can have a significant impact on a person’s wellbeing. It is understandable that they will experience a range of emotions, including shock, disbelief, fear, shame, guilt, anger and/or sadness.
- They will feel real concern about what the future holds as well as a sense of isolation and being cut off.
- For some, the diagnosis may bring a sense of relief.
Risk factors

The possibility of acquiring dementia increases with advancing age. Also, as people live longer, dementia is becoming more common. Age is the greatest risk factor for developing dementia, but dementia is not a consequence of ageing. Dementia predominantly occurs in the second half of people’s lives, often after the age of 65.

Those who have a parent, brother, sister or child with Alzheimer’s disease are more likely to develop it. The risk increases if more than one family member has the illness. When diseases tend to run in families, heredity (genetics), environmental factors, or both may play a role.

<table>
<thead>
<tr>
<th>Incidence of moderate to severe dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of onset</td>
</tr>
<tr>
<td>Up to 70 years</td>
</tr>
<tr>
<td>Over 90 years</td>
</tr>
</tbody>
</table>

Researchers believe that most people develop dementia because of a combination of different risk factors rather than from a single cause. Factors that may increase the risks of developing dementia are:

- a previous head injury. Dementia pugilistica can develop from a head injury.
- smoking.
- high blood pressure.
- diabetes.
- high blood cholesterol.
- alcohol. Alcohol-related dementia is known as Wernicke Korsakoff Syndrome.
- other substance abuse.
- Down syndrome.
- Human Immunodeficiency Virus (HIV).

People living with Down syndrome are more at risk of developing dementia in adult life and this risk increases as they prematurely age. Research suggests that over half of the people living with Down syndrome and who are in their 60s have Alzheimer’s disease.

HIV can cause healthy brain cells to break down, releasing damaging enzymes. These enzymes can then attack the healthy neurons, resulting in dementia symptoms. Over 20% of HIV patients develop some symptoms of dementia.
Stages of dementia

The rate of progress of dementia varies greatly and can be affected by other health conditions. There are usually three stages of dementia:

- early/mild.
- moderate.
- advanced/severe.

Early/mild dementia

In the mild stage of 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 they may experience difficulties with social activities or employment.

In early/mild dementia there may also be problems related to memory, language and other cognitive functioning. Symptoms may include:

- difficulty in remembering people or names.
- difficulty in recalling words or carrying on a conversation.
- often forgetting appointments, conversations or experiences.

An example of mild dementia

Rachael has recently been diagnosed with dementia. She went to the doctor because she found that simple tasks that she had done every day for the last 40 years were becoming increasingly difficult for her.

She struggled to cook her evening meal, and when she did cook she would leave the stove on and the taps running. Getting money from the money machine was difficult, as she couldn’t remember how to work the machine and often put in the wrong PIN number.

When Rachael drove to her local supermarket she often had to stop on the side of the road as she couldn’t remember how to get there and she did not know where she was. Rachael struggled with knowing how much money to hand over to the checkout operator, and would get frustrated because she thought she was being short-changing.

The brain during the early/mild stage of dementia. The highlighted area shows the parts of the brain that are affected.
Moderate dementia

In the moderate stage of dementia, behavioural disturbances develop and employment is usually no longer possible. Independent living is likely to have some risks and require more supervision, meaning that the person may no longer be able to live alone. They may not be able to cook, clean or manage the home.

The person is likely to be very forgetful of recent events. Memory of the distant past may be better, but some details may be forgotten or confused. Problems become more disabling and the person experiences difficulties when away from familiar surroundings. Families may become upset when their names are confused, or they may become anxious when unusual behaviour, personal neglect or wandering are reported.

An example of moderate dementia

Mereana’s whānau has asked for some home support because they are worried about her safety and her ability to carry out everyday tasks for herself. Mereana often misplaces her house keys, her telephone and her purse. She puts things down in a logical place, but then can’t remember the logic she used to place the object, or even what she is looking for. This makes her frustrated and she often cries.

Mereana is avoiding seeing people and talking with her whānau. She has difficulty in finding the right words and even remembering what she was talking about is increasingly difficult. Mereana often repeats herself or becomes embarrassed when she uses the wrong word. She also finds that she is struggling to remember the names for things and people. She confuses family members and at times can’t remember who they are. She finds shopping overwhelming, as she gets tired easily and can’t remember what she is shopping for, or often cannot remember where to get the item she needs.

The brain during the moderate stage of dementia. The highlighted area shows the parts of the brain that are affected.
Advanced/severe dementia

Physical problems are dominant in the advanced stage of dementia. The person may lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement, leading to the need for total care.

The person living with this stage of dementia may be unable to remember even something that occurred just a few minutes ago – for example, eating a meal. They need help with personal hygiene, toileting, washing and dressing. The person may lose the ability to understand or use speech, no longer recognise family, friends or familiar objects, and need assistance with all daily living activities, including mobility. The frustrations of living like this can lead to outbursts of aggressive behaviour, agitation and physical restlessness.

Although many abilities are lost as the disease progresses, other abilities will remain. The person may maintain the senses of touch and hearing, as well as the ability to respond to emotions.

People at the end of life with dementia have significant health needs which have been found to be comparable to those of a person with advanced cancer.

Later in dementia care becomes a combination of aged care, palliative care and dementia care.

An example of advanced dementia

Ron has recently moved into Aroha Residential Care because he can no longer look after himself. He has become dependent on others to support him. He has no memory of recent events, does not recognise members of his family and has become incontinent. He communicates through grunts and is unable to walk without support. He also needs help with eating and all his personal care.

The brain during the three stages of dementia - early/mild, moderate and advanced/severe. The affected areas have been shaded.
Co-existing conditions

The New Zealand Framework for Dementia Care is a response to the growing proportion of the elderly in the population and the increasing number of people living with dementia now and in future years.

Dementia has traditionally been treated as a medical issue. However, the medical model does not maximise a person’s overall wellbeing and independence, and so there has been a shift to a more integrated approach that includes both the health and social aspects of care.

Dementia is very often accompanied by one or more other serious medical condition. Healthcare professionals often struggle with complex interactions between dementia and other serious medical conditions, as medication and various other treatments can have an adverse effect on the cognitive status of the person. In the elderly in particular, it may be difficult to recognise the appearance of dementia and the co-existence of other medical conditions.

Chronic medical conditions

Research has shown that many people affected by dementia also have the following chronic medical conditions:

- hypertension.
- coronary artery disease.
- chronic obstructive pulmonary disease (COPD).
- osteoarthritis.
- stroke.
- other chronic, terminal or life-limiting conditions.
- diabetes.
- cancer.
- chronic renal problems.
- multiple sclerosis.
- obesity.
- Parkinson’s disease.
- respiratory disease.

Acute medical conditions

People living with dementia may also have the following acute medical conditions:

- pneumonia.
- skin ulcers.
- hip fractures.
- septicaemia.

Many people living with dementia have more than three co-existing medical conditions that include arthritis and/or visual or hearing impairments.
Co-existing medical conditions may also be an issue with the many people living with dementia (over 50%) who live at home, with or without formal care. The relationship between dementia and co-existing conditions is a challenging one and the difficulties it creates for supporting a person may not be entirely understood.

This frequency of co-existing medical conditions has important implications for you as the support worker. These conditions can make the cognitive and other symptoms of dementia worse. Dementia can also complicate the care of a co-existing condition.

**End of life care**¹

Towards the end of life the most common clinical issues may include:

- infection.
- eating problems.
- pain.

The most common infections in advanced or late stage dementia involve the urinary tract, respiratory tract, skin or eyes. These are almost inevitable due to immobility, incontinence and a reduced immune response. Infections can be treated with antibiotics. Keeping the person comfortable and pain free may be more appropriate.

Pain is often under recognised and under treated as identifying and measuring pain in people with dementia is difficult, especially if their communication skills are limited or non-existent. Evaluation for possible pain should be made when any behaviour change is seen. It is important to observe, record and report the effect of pain relief, not just that it has been given to the person.

Swallowing difficulties can lead to aspiration and the risk of developing respiratory infections. Eating issues include difficulties in chewing, swallowing, refusing food, and weight loss.

As the disease progresses the person with dementia may be disinterested in food and unwilling to eat. It is important to offer food the person likes, for example, melted chocolate or ice cream.

The person may not be able to eat and drink without assistance. Good oral hygiene and mouth care is important.

A person with advanced stage dementia at the end of life may be unable to swallow food or water safely. The family may think that the person is dying because they are not being cared for properly and are being starved. The family need to be aware that the person is dying from the disease or the condition. The inability to eat or drink is a result of the advanced stage of the disease.

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¹ Content adapted from Hospice New Zealand Fundamentals of palliative care programme
Support when there are co-existing conditions

People living with dementia generally need supervision and assistance. This is very often provided informally by family members, friends or acquaintances. It is important to understand that you, as a support worker may not be able to provide the specific services their conditions need; links to professional services may be required.

As a support worker you need to be aware of the likelihood of dementia based on the risk factors, as well as recognisable symptoms and the possibility of a chronic or an acute medical condition that could also be associated with the risk factors. For example, an older person who has been diagnosed with dementia is also a life-long smoker and has now developed respiratory disease.

As a support worker you need to ensure that:

- all co-existing conditions are included in the assessments you conduct for the person you support.
- their personal care plan documents the conditions.
- any changes in any of the conditions, separately or together, are documented and reported immediately.

A co-existing medical condition could have significant impact on the treatment, informal care and overall outcomes for a person living with dementia. This, in turn, may have a direct impact on you as a support worker, and your ability to manage stress and the burden of maintaining the health and safety of the person you support.

People living with dementia have diverse needs and require effective systems to link them to support services. As a support worker you could be the linking system to help refer people living with dementia to service providers – for example, dementia specialists, psychiatrists and other similar providers in the community.

As a support worker, your care is based on a holistic approach and should consider the whole person, not just their dementia. It is for this reason that you must consider and include links to services or sources of information about services for co-existing medical conditions.

Family, friends and others who support a person living with dementia may not understand or be aware of the treatment of problems associated with dementia and the impact of treatable co-existing conditions on the person’s cognitive and self-care abilities. Therefore it is important to understand your role and responsibilities in the care of co-existing conditions.
Please describe the personal and professional impact of the following combinations of conditions on you as the support worker. A short example is provided for you.

<table>
<thead>
<tr>
<th>Co-existing conditions</th>
<th>Personal impact</th>
<th>Professional impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia and diabetes</td>
<td>Emotional impact of witnessing cognitive and physical deterioration resulting from diabetes; increased stress burden of continuous analysis of co-related symptoms and management.</td>
<td>Increased demands of providing strict processes and timelines for managing diabetes and also reducing stress and anxiety for the person being supported, ensuring health links remain appropriate to the individual’s holistic needs.</td>
</tr>
<tr>
<td>Dementia and hypertension</td>
<td></td>
<td></td>
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<tr>
<td>Dementia, cancer and pneumonia</td>
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</tbody>
</table>
**Person-centred care**

Historically, dementia has been seen through a medical model of ‘treating’ people living with dementia, focusing mainly on the physical changes that happen in the brain and the best way to ‘manage’ them. This approach did not consider the person before the condition, how they feel now and the influence of their social and physical environment on their experience.

‘Person-centred care’ is a concept based on the work of the late Professor Tom Kitwood, of Bradford, England. He describes person-centred care as “implying recognition, respect and trust based around the personhood or status bestowed upon one human being by others”. Personhood places an emphasis on wellbeing and recognises a sense of self, who the person is, the person’s individuality, and how the person can interact positively with other people.

Person-centred care is holistic. It focuses on the wellbeing of the whole person, including their relationships, communication and individuality as well as the needs, feelings and abilities that they retain. The person living with dementia is at the centre of any plans that are made, and the assessment plan takes into account the ‘whole person’s needs’ – their social, physical and emotional needs. It is likely to include a ‘care pathway’ to help the person progress through the health and social services in a coordinated way.

Overall, person-centred care means being more flexible about the way services are delivered. This requires a ‘needs-led’ service based on what the person’s needs are at the time and the way these needs are met.

Organisations that use a person-centred approach are more likely to retain and recruit suitable people who enjoy their role and work more effectively. It also benefits the person living with dementia, as it helps them to feel accepted:

- listened to.
- understood.
- informed.
- involved; especially in making decisions and choices.
- empowered.
Individualised care and support, which is the foundation of person-centred care, builds on a person’s abilities and strengths rather than on any deficits or deadlines. It is about:

- treating people with dignity, respect and understanding.
- listening and actively acknowledging what is important to each person.
- recognising strengths and retained abilities and offering choices within their capabilities.
- maintaining privacy during care and support.
- making sure that services are of a high standard to help the person live a meaningful life.
- ensuring that people experiencing dementia and the people who care for them are kept fully supported and informed.
- making sure that those who support a person living with dementia are trained and supported in their role.
- understanding and supporting carers and using their expertise and experience to improve the care and support that is offered.

Loss of memory, declining physical health, inability to concentrate and growing confusion can lead to a person’s 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.

The more we know about an individual and their whanau, the more creative options we can identify to adapt:

- the physical environment, to help them participate in activities.
- our interactions and communication, to help the people we support to participate in activities.

As dementia progresses we need to focus on support in terms of reacting to changes in condition, changes in a person’s needs and changes in a person’s quality of life.
Personal support through stages of dementia

Each person for whom we provide care is unique. This means that their conditions are also unique and will impact each person differently. The type of dementia; its effect on behaviour, cognition and physical ability; the varying rate of progression; and the person’s symptoms, environment and access to proper care all impact the person being supported and how you, as a support worker, will provide care for them.

There is no common ‘manual’ for dementia. However, how we respond to changes through the stages of dementia for the person we are supporting can be managed.

A person living with dementia has to deal with the social, emotional, psychological and practical effects of the condition; this can be a tremendous burden.

As a support worker you have the ability to influence their experience by how you respond to and support changes in their condition, their personal needs and their quality of life as the condition progresses. Essentially, the keys to success are individualised (person-centred) care, attention to and respect for the person, and providing links to appropriate support.

Providing support for changes

Providing support for changes in condition, personal needs and quality of life through the stages of dementia can significantly impact the person’s relationships, communication, individuality, emotions and behaviours, physical abilities, independence and overall wellbeing. It is important to remember that not all people progress at the same rate and they may not experience every stage of dementia. Below are a few examples to help you identify how to manage change as it occurs.

Relationships

Changes: People progressing through the stages of dementia may go from being comfortable and jovial around family to forgetting recent events or the names of family members, to not recognising family members or becoming irritable around them.

Support for these changes could include:

- identifying methods of communicating and meaningful activities.
- identifying prompters or indicators, such as objects or music, which could trigger recognition.
- focusing on controlling stress and anxiety over visits.
- finding help for the family by providing links to social services for support to manage the emotional burden.
Communication

Changes: People living with dementia may experience difficulties in communicating. This in turn can cause them to lose confidence and avoid interacting with others socially. As the condition progresses they could start to withdraw completely from any form of social interaction or be unable to communicate or remember to communicate their needs at all.

Support for these changes could include:

- helping the individual learn how to communicate through behaviour and body language, such as gestures, eye contact or facial expressions.
- ensuring they are included in familiar and comfortable activities in which they enjoy engaging in conversation.
- listening to their needs, however trivial, without intimidating them or making them feel unimportant.

Once the condition progresses it may be necessary to destress each situation by avoiding sudden movements or tense expressions that could be confusing.

Independence

Changes: A person living with early dementia may no longer be able to do routine jobs or may lose interest in hobbies and activities. In moderate dementia they may easily become lost if away from familiar environments. As they progress to severe dementia they may not be able to locate their own room and bed.

Support for these changes could include:

- allowing the person to maintain as much independence as possible rather than just taking over.
- ensuring that the person’s overall wellbeing is increased, their dignity is maintained and their confidence and self-esteem are built rather than making them feel helpless.
- focusing on things they can do rather than on what they can’t do.
- offering help in a supportive way.
- remaining patient and adjusting to needs as they occur.

It may be necessary for you to recognise when it is time to recommend or request additional care or transfer to a professional facility.
In the table below write how you would support changes in condition, personal needs and quality of life through each stage of dementia for:

- individuality.
- behaviour.
- physical ability.

<table>
<thead>
<tr>
<th>Individuality</th>
<th>Stage of dementia</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Early</td>
</tr>
<tr>
<td>Support changes in condition</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Stage of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early</td>
</tr>
<tr>
<td>Support changes in personal needs</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal ability</th>
<th>Stage of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Early</td>
</tr>
<tr>
<td>Support changes in quality of life</td>
<td></td>
</tr>
</tbody>
</table>
The impact of dementia on daily living

Memory impairment, especially of short-term memory, is often the first symptom to be noticed. Someone living with dementia may be unable to remember ordinary information, such as their birth date and/or their address, and 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 the ability to find words) and orientation in time and space (e.g., the person may get lost in familiar surroundings).

When caring for someone living with dementia you need to keep in mind that the care and sensitivity you use to interact and communicate with them can make a huge difference to their wellbeing and sense of self-worth.

The various characteristics of dementia can affect the activities of daily living (ADL) and will have a direct impact on the type of support that is provided by the support worker and the family/whānau.

Some examples of how the characteristics of dementia will change a person’s daily activities are given below.

**Cognitive effects:** The person may not recognise familiar people and places, numbers, dates and PIN numbers. The person living with dementia will be at an increased risk of harm and falls; they may wander and have difficulties with nutrition. They may require a plan for facility support, home services or services to help manage finances. These requirements may change with time and will depend on their stage of dementia. People living with dementia may also have difficulty in communicating.

**Functional effects:** The person living with dementia may find it difficult to carry out routine household tasks and managing hygiene, which may in turn lead to unsafe living conditions. Addressing basic needs, including housing, meals and physical care, may be necessary as the person progresses through the stages of dementia.

**Behavioural effects:** People living with dementia may begin to change their behaviours and may find it difficult to adjust to their surroundings or the people around them. The confusion created by cognitive changes may make them restless or agitated. They may become suspicious of others or act out to try to convey messages, as they may also have difficulty in communicating. Behaviours may become increasingly challenging for the support worker and family/whānau.
**Psychological effects:** A person living with dementia may experience a range of emotions. Loss of faculties such as memory or clarity of thought may lead to emotional outbursts. Psychologically, a person living with dementia may react to their loss of independence by losing confidence and self-esteem, which could lead to depression and anxiety. The multidisciplinary team may need to discuss therapies or medicinal treatments to help support the person.

Below are examples of how the effects of dementia can impact a person.

<table>
<thead>
<tr>
<th>Effects of dementia</th>
<th>Impact on the person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive effects</td>
<td>• Difficulty in:</td>
</tr>
<tr>
<td></td>
<td>– recognising people and places.</td>
</tr>
<tr>
<td></td>
<td>– remembering PIN and phone numbers</td>
</tr>
<tr>
<td></td>
<td>– remembering where they live and finding their way home.</td>
</tr>
<tr>
<td></td>
<td>• Poor short-term memory.</td>
</tr>
<tr>
<td></td>
<td>• Easily confused and muddled.</td>
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<tr>
<td></td>
<td>• Poor concentration, attention and easily distracted.</td>
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<tr>
<td></td>
<td>• Unable to think clearly or solve problems.</td>
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<tr>
<td></td>
<td>• Difficulty in learning new things.</td>
</tr>
<tr>
<td>Functional effects</td>
<td>• Difficulty in:</td>
</tr>
<tr>
<td></td>
<td>– completing the everyday tasks and activities of independent living.</td>
</tr>
<tr>
<td></td>
<td>– handling and managing money.</td>
</tr>
<tr>
<td></td>
<td>– keeping safe with appliances, e.g., gas and electric cooking, ironing, boiling kettles, etc.</td>
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<tr>
<td></td>
<td>– knowing what to do next, especially if out of routine.</td>
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<tr>
<td></td>
<td>• Problems following social cues.</td>
</tr>
<tr>
<td></td>
<td>• Word finding difficulty or loss of verbal skills.</td>
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<td></td>
<td>• Slower reactions.</td>
</tr>
<tr>
<td>Behavioural effects</td>
<td>• Loss of social skills.</td>
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<tr>
<td></td>
<td>• Overactive response to changes or stimuli in the environment.</td>
</tr>
<tr>
<td></td>
<td>• Repetitive behaviour patterns.</td>
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<tr>
<td></td>
<td>• Physical or verbal aggression.</td>
</tr>
<tr>
<td></td>
<td>• Inappropriate responses or behaviours.</td>
</tr>
<tr>
<td>Psychological effects</td>
<td>• Irritability.</td>
</tr>
<tr>
<td></td>
<td>• Mood swings.</td>
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<tr>
<td></td>
<td>• Frustration and anger with self and others.</td>
</tr>
<tr>
<td></td>
<td>• Changes in personality.</td>
</tr>
<tr>
<td></td>
<td>• Anxiety.</td>
</tr>
<tr>
<td></td>
<td>• Loss of motivation.</td>
</tr>
<tr>
<td></td>
<td>• Depression.</td>
</tr>
</tbody>
</table>
Think about a person living with dementia who you are supporting. For each of the headings in the table, list two ways in which the person’s dementia has affected their daily living.

<table>
<thead>
<tr>
<th>Psychological</th>
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<td></td>
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<table>
<thead>
<tr>
<th>Cognitive</th>
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<table>
<thead>
<tr>
<th>Behavioural</th>
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<table>
<thead>
<tr>
<th>Functional</th>
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</table>
Meaningful activity

Activities are everything we do in our lives, from getting up in the morning to going to bed at night. Activities can include an occupation or role; leisure activities such as sport, hobbies and relaxation; and self-care activities such as showering, dressing and preparing and eating food.

Doing things that are enjoyable helps us to feel good about ourselves. Research has shown that while people living with dementia may not remember a particular activity they have participated in, they still retain the feelings created by doing the activity.

Meaningful activity is activity that is relevant to the person. It requires some detective work to build a picture of what was and is important to that person. Knowing the person really well is a big help in understanding what is meaningful for them.

Meaningful activities can:

- maintain existing skills.
- stimulate the senses.
- provide pleasure.
- calm the atmosphere.
- provide a routine.
- improve physical skills.
- provide a sense of success.

Activities can be:

- **active** – the person is ‘doing something’ (for example, knitting, singing, playing bingo).
- **passive** – the person may just sit, watch or listen to music, the radio, TV or movies.

Some activity is done **alone** or on an individual basis, in **small groups** of two or three people, or in **larger groups**.

**Unstructured activity** does not require the person to be closely supervised and enables them to participate as and when they choose.

**Structured activity** requires involvement from other people – staff or family members.
Some care facilities provide planned activities to satisfy people’s needs for enjoyable pastimes, either alone or with others. In a home environment, activities are less formal but no less important. Including activities as part of the daily routine makes living more pleasant for people living with dementia. Showing them that others enjoy their company can build a person’s self-esteem.

People living with dementia can fluctuate in their abilities from day to day. Supporting them to function to their potential requires flexibility, patience and the ability to change plans according to individual response. Often there is a need to balance safety and independence, using practical and sometimes clever solutions to minimise the risks. Whatever the activity, it will probably need to be broken down into simple, achievable steps. It also needs to be enjoyable for the person.

**Examples of activities**

Ideas for activities that are meaningful and selected by the person themselves can and will differ according to the time of the day and the person’s mood, the wellbeing and level of energy. It is the ‘doing’ that is important.

Activities frequently involve social events, daily living activities and maintaining a person’s skills and interests. Different types of activity include:

- **arts and crafts** – handcrafts, making gifts or decorations.
- **hobbies** – gardening, writing, music, singing.
- **physical activity** – bowls, croquet, walks, exercise, dancing.
- **mental activity** – board games, pet therapy, reading.
- **quiet activity** – calm music, aromatherapy, looking at a pleasant view.
- **sensory activity** – with items to touch, smell and feel (for example, wool, pine cones, feathers, flowers), a garden area, or a musical instrument to play such as a piano.
- **reading** – with books or magazines left open at interesting pictures, (for example, recipes or sports pictures). This type of activity benefits from an area with good light and comfortable and inviting chairs to sit in.
- ‘**half done**’ activities, where a carer leaves some part of a task unfinished. This provides an incentive for the person to complete something. Examples include clothes left to be folded and warm soapy water in the sink with cups and saucers stacked ready to wash. This can cue the person living with dementia to take the next step and helps the person retain the skills and abilities for familiar tasks.
You can help the people living with dementia whom you support by talking to them about upcoming events. Let them know what is involved in the activity and remind them about it frequently. Make sure people are prepared for the activity. You may also need to assist them when they are participating in the activity.

**Music therapy**

Music therapy is the creative use of music to connect and communicate with a person.

Music is perceived by many different ways and by different parts of the brain. For example, rhythm, pitch and melody are all processed in different parts of the brain. This means that music can reach various functional sections of the person’s brain and may bring a response from even the most severely affected person. Even when all other modes of communication fail to make any impact, music can still bring some social, emotional or cognitive connection.

Music and singing are ways of stimulating and encouraging social interaction. They can improve a person’s mood and enhance feelings of relaxation and confidence. It can also enable the person living with dementia to express their inner feelings more easily. Music and singing can:

- enhance a person’s long-term memory.
- improve recall – for example, familiar songs that a person can relate to.
- maintain or even improve social or emotional functioning.
- help with mental processing.
- improve physical health and motor skills.

It is important that the person providing the therapy knows the individual preferences of the person and significant events in their life story. How familiar the person is with the piece of music, whether they like it and the significance or memories it has for them are important factors for using music effectively.

Unfamiliar music does not have the same effect. Familiar music can bring positive responses such as tapping fingers and feet to the tune, humming, rhythmic movement of the body or a change of expression on the face. It also helps to retrieve both positive and negative memories from the past.

Therapy can be individual to the person, such as playing their preferred music as part of a night-time routine. Or it may be part of a wider quality-of-life programme used in a group setting – for example, wartime songs in reminiscence sessions, the music used in a strength and balance programme or background recorded music.
**Write**

Think about a person living with dementia whom you are currently supporting. In the table below, list the activities you support that person with. Explain the purpose of these activities, how you support the person with the activities, and how the activities are meaningful to the person.

<table>
<thead>
<tr>
<th>The activities</th>
<th>What is the purpose of the activity?</th>
<th>How do you support the person with this activity?</th>
<th>How is this activity meaningful to the person?</th>
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**Restraint**

Sometimes people’s behaviour or actions become so difficult or unsafe for them and those around them that special measures such as restraint are required to protect them. Restraints limit a person’s freedom of movement and are used to keep people safe.

Restraints should only be used when all other interventions have been unsuccessful and there is risk of harm to people if restraints are not used.

The Health and Disability Services (Restraint Minimisation and Safe Practice) Standards (NZS 8134.2.2008) have been developed and revised to provide guidelines to the health and disability sector, so that the use of restraint is recognised and reduced. If restraint is necessary the standards recommend using the least restrictive kind, in a safe and respectful manner.

The use of restraint is a serious clinical decision. The situation must be fully assessed and health professionals must decide that restraint is needed.

Ethical principles guide the care given to people in health and disability settings. These principles remind us to:

- act in the person’s best interests.
- not harm the person, and to keep the person safe.
- respect the person’s dignity and rights.

Factors that influence the use of restraint include:

- the person’s general physical and mental health.
- the gender of the person.
- the person’s culture.
- the risk to the person, those around them and to the environment.
- the person’s experiences during their life.
- the effect that restraint may have on the way the person reacts in the future.
- possible alternatives to restraint.
Your organisation will implement policies and procedures to keep the person safe during a restraint episode. You will need to follow the restraint policies and procedures of your organisation – for example, you must:

- observe the person carefully.
- monitor the person’s condition and activity.
- record what you saw and what you did.
- report the effect of the restraint.
- make sure the person is adequately supported while being restrained – for example, supplied with food and fluids and their toileting needs and comfort attended to.
- communicate with the person.
- maintain dignity and privacy of the person in the way you care for them during restraint.

**Types of restraint**

Any use of restraint must be strictly in accordance with the Health and Disability Services (Restraint Minimisation and Safe Practice) Standards and your organisation’s policies and procedures. It must also be within your scope of responsibilities. Legal and ethical practice must be adhered to at all times.

The different types of restraint include personal restraint, environmental restraint, physical restraint, seclusion and chemical restraint.

**Personal restraint** is when you use your own body to intentionally restrict the movement of a person – for example, holding a person’s arm when a blood test is being taken.

**Physical restraint** occurs when equipment or furniture is used to limit the person’s normal freedom of movement – for example, when a person is unable to get out of a chair independently because of the design of the chair (such as a ‘fallout chair’), a belt is used to keep the person seated or a table or fixed tray is placed so that it prevents the person from leaving the seat.

**Environmental restraint** intentionally restricts a person’s normal access to the environment – for example, by means of locking devices on doors, windows or gates, or by denying the person’s normal means of independent mobility (such as a wheelchair).
Seclusion is a kind of restraint that can be legally undertaken only under the Mental Health Act. A person may be placed for a period of time alone in a room or area from which they cannot leave. This is usually to prevent them from causing injury or harm to themselves or others or endangering other people or property.

Clinical restraint is when a drug is given to ensure compliance to prevent a person harming themselves or others. It may restrict the freedom of movement of a person, make them incapable of resisting and, in some cases, sedate them. This type of restraint, like the others, is a clinical decision. Medication should only be used for the purpose it has been prescribed for and not as a form of chemical restraint, which would be against Restraint Minimisation and Safe Practice Standards.

Enablers

Enablers are equipment, devices or furniture that a person chooses to use. Use of enablers follows an assessment of a person’s needs and should be the least restrictive option for that person and should be voluntary. The intention should always be to promote or maintain the person’s independence and safety – for example, a raised bed rail to assist mobility in bed, help position pillows for comfort or prevent the person falling from the bed.

Equipment or furniture is used in the physical positioning of a person without limiting their normal freedom of movement. These interventions are not considered a form of restraint, but rather are a normal component of the person’s day-to-day life.

Enablers may become restraints – for example, if a person is confined to a bed unwillingly, or is unable to get out of bed because of the bed rails, then this becomes a restraint.

If person is unable to get out of a chair independently because the position of a table or fixed tray prevents them from leaving the seat, then this becomes a restraint.

Enablers may become restraints

Bed rails may keep a person safe, to prevent them falling out of bed. But they can become a restraint if people are confined to bed unwillingly.
Restraint and the person’s rights

Restraint reduces or removes the person’s rights to freedom of movement. It can be a stressful experience for many people, especially when it is associated with memory loss and confusion. Inability to communicate thoughts, feelings and emotions heightens a person’s anxiety and frustration.

Communication

Positive communication during restraint is essential to reduce the person’s agitation and anxiety and to make them feel safe and secure. Depending on the kind of restraint, the person may feel more anxious or sometimes may feel greater security and safety through being restrained. Your body language will communicate your respect and care for the person, who may be feeling vulnerable. Remember that it is the tone and pitch of your voice (rather than the words you say) that will help the person make sense of the world around them.

Touch can also be a useful way to communicate with the person, convey care and concern and provide reassurance in a confusing world. Make sure that touch is culturally acceptable for the person with dementia.

If it is decided that restraint is the best option, the person being restrained will need a full explanation about what is happening and why. The explanation should be within the person’s ability to understand. You may need to repeat the information several times so that they understand.

When talking to people about restraint, you and your organisation will need to:

- involve them in discussion and all aspects of the restraint process as much as possible.
- involve them in the decision making as much as possible, within their level of understanding. Clear, simple and short sentences are usually the most helpful.
- involve family/whānau or their advocate (with consent). Family/whānau and advocates have an important part to play in ensuring that the person’s best interests are considered.
- obtain informed consent. Consent can only be obtained when full information is given and understood. Consent needs to be gained from the person, if they are able to give it, or from their representative.

Keeping the person informed throughout restraint is an important responsibility for the organisation.
Support

The person’s care plan will guide the support required during restraint. The person is likely to have an increased need of support because they no longer have freedom of choice, and in some cases are unable to express their own needs.

You will need to be more aware of the person’s need for:

- physical support for food, fluids, regular exercise, rest and toileting. This means that the restraint should be removed at regular intervals and constantly reviewed to see if it is still needed.
- cultural safety, especially for people whose culture sees restraint as having a negative impact on their perception of themselves and their health, value and worth.
- health and wellbeing, especially if a person is unable to express pain and discomfort or where restraint can cause harm – for example, damage fragile skin.
- reassurance, comfort and support, including time spent one-on-one with the person.
- dignity and privacy for the person under restraint.

Dignity and privacy

Dignity is about the sense of pride and respect we have for ourselves and extend to others.

Restraint reduces our dignity by cutting down our choices and making us rely on others to meet our needs for food, fluids, toileting, comfort and care. Support workers who are supporting a person who is being restrained will need to make sure that they are continually aware of the person’s dignity.

Support workers can promote a person’s dignity by:

- always being respectful towards them.
- using a gentle, calm approach, employing all the strategies previously described to reduce stress.
- providing an ongoing explanation of what they are doing.
- implementing the person’s individual care plan.
- thinking about other ways to minimise the need for restraint.

Privacy of the person’s personal information is important during any health care service. Personal information should be stored securely, and should not be accessible to people who are not authorised to see it.

Conversations with and about the person and discussions with their family about their care needs should always be held where others cannot overhear.
Safety

Safety during restraint is assisted when you:

- follow your organisation’s policies and procedures for using restraint.
- are trained in the use of restraint.
- document the use of the equipment.

During restraint, you will be expected to monitor the use of the restraint. For example, you may need to monitor the restraint every 15 minutes, especially if the restraint is being used for the first time. Monitoring may become less frequent when the person becomes more used to the restraint and remains safe using it.

Cultural and spiritual needs

Considering the person’s cultural needs is also relevant when restraint is used. Sometimes it is necessary to remove items that are culturally significant to the person in order to keep the person safe. Having such items taken away – for example, removing a Māori person’s ‘taonga’ – can affect a person’s psychological health. In this situation it is important to return such items as soon as possible after restraint.

The person also has the right to spiritual support during restraint just as in all other parts of life – for example, giving a Catholic person their rosary beads.

The person may also benefit from having familiar items, such as photos, trinkets or other meaningful possessions, around them.

Organisational compliance

Restraint is always a planned process. Your organisation will have policies and procedures about how restraint is used and what your responsibilities are in using it. These strictly follow the Health and Disability Services (Restraint Minimisation and Safe Practice) Standards. Review your organisation’s policies and procedures and the standards to understand the processes for the use of restraint in your workplace.

The approval process

This is the way in which your organisation controls the use of restraint. It will also describe which health professional is responsible for implementing restraint and who must agree that restraint is necessary.

Documentation is an important way of showing what care and support has been given to the person and how this has been monitored during restraint. For example, each time you provide support you must record this in the manner your organisation requires. This may be by signing a record sheet, completing a progress report, or ticking boxes on a checklist to show that the person under restraint has been monitored.
Assessment
Assessment is always undertaken before any treatment is started. Restraint is a form of treatment that needs to be considered as one among a range of possible options and so the need for and risks of restraint must be assessed for each person.

Assessment will consider the person’s general health, the risk to others and what the end goal of restraint should be. Assessment will also look at the strategies that can be used, which may mean that other effective actions can be taken so that restraint is not required.

Informed consent
Informed consent is always sought when treatments of this kind are used. If a person living with dementia is unable to understand the significance of restraint, then a welfare guardian is asked to sign the consent, after being given all the information. In an emergency, your organisation may permit the use of restraint before a signed consent is obtained. This decision will need to be fully documented.

Care and monitoring
Personal plans include all aspects of the person’s care, including restraint. Your organisation will decide how support during restraint should be described – it may be part of the main plan or in a separate document. You will need to know where to find the information about your responsibilities for providing care and support during restraint use.

Reporting and recording
Reporting and recording are an important part of a support worker’s role. Your organisation’s policies will describe what observations, monitoring and unexpected changes you need to record during restraint, and how often this needs to be done.

Evaluation and review
Evaluation and review is about determining the effectiveness of the restraint that has been used. Evaluation will look at the history of the restraint episode through the records that you and others have kept. It is the chance to look at whether restraint was the correct decision and achieved the result that was intended, or whether some other intervention would have been safer for the person.

For example, high bed sides may make the person more unsafe if the person tries to climb over the sides and then has a fall, making the risk of using a restraint greater than not using a restraint. A mattress on the floor may be a safer option for this person.

Evaluation also considers whether the restraint used was the least intrusive for the person. A review process decides whether there should to be any changes in the process if restraint is required in the future.
Legislation

New Zealand has legislation that recognises people’s basic rights. People living with dementia have the same rights as other people. There are core Acts, codes and regulations that have an impact on your work practice and how you interact with the people you support. The main Acts and codes are shown in the diagram below.
The Human Rights Act 1993 specifically promotes and protects human rights, the basic rights and freedoms that all people are entitled to. This includes freedom from discrimination. The intention of the Act is to help ensure that all people in New Zealand are treated fairly and equally.

The Privacy Act 1993 and the Health Information Privacy Code 1994 have the same purpose – the promotion and protection of an individual’s privacy and personal information. The Privacy Code applies specifically to the area of health.

The Health and Disability Commissioner Act 1994 created the Office of the Commissioner of Health and Disability. One of the Commissioner’s first tasks was to find out what people expected from service providers in terms of quality of care and then to define these expectations by means of legally enforceable rights.

A regulation established the Code of Health and Disability Services Consumers’ Rights (1996). It is often simply called ‘the Code of Rights’ or ‘the Code’. The Code was created to promote and protect the rights of health and disability service users.

The Code tells consumers how they can expect to be treated when they receive a health or disability service. It also sets out the procedure for a consumer to make a complaint if these rights were not being met.

The Code is available in many different formats, including pamphlets and posters.

You need to know where to get a copy of the Code – there may be times when the people you support want to check their rights, or when you need to check what your duties are in a particular situation. The way you behave at work must reflect the legal obligations set out in the Code of Rights.

If you are unsure of where to find a copy of the Code in your workplace, ask your supervisor. You can also obtain a copy of the Code from the Health and Disability Commissioner’s office or website (www.hdc.org.nz).
How do you, as a support worker, promote rights for people experiencing dementia?
Making decisions for a person living with dementia

Advanced dementia will decrease life expectancy.

‘Specific needs of residents with end stage dementia seem to arise not only because they have a prolonged disease trajectory and uncertain prognosis but also because poor cognition impairs their ability to express their wishes, verbalise their feelings of pain, discomfort and emotional anguish.’


Advance care planning

Decisions about end of life will need to be made at the onset of dementia, whilst the person still has the mental capacity to make their wishes known before their health deteriorates further.

Advance care planning (ACP) is a way to help a person to think about, talk about and share their thoughts and wishes about their future health care. It is focused on and involves both the person and the health care professionals responsible for their care. It may also involve whānau/ family and/or carers if that is the person’s wish.

There are several ways to do this:

-   enduring power of attorney.
-   advance directive, also called a ‘living will’.
-   end of life directive, which is proposed in a Member’s Bill for End of Life Choice, currently (2015) before the NZ Parliament.

Enduring power of attorney

Enduring power of attorney is also known as EPA. An EPA is a legal arrangement in which a person chooses another person to make decisions for them for when they may no longer be capable of doing so themselves.

There are two types of EPA:

-   for property.
-   for personal care and welfare.

In your workplace it is likely that you have experienced supporting a person who has an EPA for their personal care and welfare. The person who has the power of attorney is usually a close family member or friend of the person living with dementia.
When the person living with dementia can no longer make decisions for themselves, the person holding EPA will make decisions such as:

- where the person experiencing dementia will live.
- the diet they will be given.
- the types of clothing they will wear.
- consent (or refusal) for medical treatment or procedures.

However, it is imperative that you understand the following conditions of an EPA.

- It does **not** take effect until a person ceases to have the ability to make decisions about their own health and welfare.
- It does **not** take effect until the person is assessed by a qualified person – for example, a general practitioner, psychiatrist or a member of a mental health team.
- A form 5 (Health Practitioners Certificate of Mental Health Capacity/Incapacity) must be completed before the person who has been appointed with EPA can take over any decision-making powers.
- The appointed EPA **cannot** make decisions without the EPA being activated.

**Form 5**

Form 5 is the health practitioner’s certificate of mental incapacity to activate an EPA in relation to a person’s personal care and welfare.

The Mental Health (Compulsory Assessment and Treatment) Act 1992 defines mentally incapable as:

- lacking the capacity:
  - to make a decision about a matter relating to personal care and welfare; or
  - to understand the nature of decisions about matters relating to personal care and welfare; or
  - to foresee the consequences of decisions about matters relating to personal care and welfare or of any failure to make such decisions; or
- lacking the capacity to communicate decisions about matters relating to their personal care and welfare. (s.94(2)).

**Absence of an EPA**

If the person being supported has not appointed someone with EPA for them, the person (or the facility) may apply to the Family Court to be appointed as a Personal Care and Welfare Guardian and a Property Manager. However, this process is complicated and can be quite costly and time consuming. It can take several months before it is granted.
Advance directive

An advance directive is another way in which people can make decisions about their care ahead of time. A person can use an advance directive to tell medical professionals what kind of medical care they would like to receive.

An advance directive may include:

- whether a person wants CPR (cardiopulmonary resuscitation) to be performed if their heart stops beating.
- whether the person wishes to be kept alive on a ventilator if they are unable to breathe without assistance.
- whether the person wants to be kept alive by tube feeding.
- whether the person wants to be given fluids.
- what kind of drug therapy the person wants – for example, they might choose to be given pain relief but not antibiotics to fight an infection.
- what the person wishes to happen about organ or tissue donation.

The person can carry a card to tell medical professionals what they want. The information will also be in their personal plan.

For each person you support, you need to know if they:

- have an advance directive.
- carry an advance directive card.

Although there is no standard format for advance directives, the New Zealand Medical Association’s website offers information and sample forms for use http://nzma.org.nz/patients-guide/advance-directive
Boundaries: what you can and can’t do

As a support worker you must know and understand your boundaries and the personal and professional limits to providing care. You can only provide support you have been trained or are permitted to give. Knowing your limits will help you to feel safe in your role. You should know where your role ends and where someone else’s begins.

Working within the limits of your role may also be called your ‘scope of practice’. This means that you support a person in the way that’s set down in your job description and in the person’s personal plan. Your workplace will have policies and procedures about your scope of practice. They may also have a staff handbook that gives you important information about professional guidelines.

Special note

If the person you support has an EPA that has been activated, the final decision rests with the person’s general practitioner. The GP will take into account the opinion of the appointed EPA, but will make the final call. For example, if the person you support has a chest infection and the EPA says “Don’t treat him,” the GP may say that the person still has a good quality of life and has the right to decide to treat them with antibiotics and other medication. This is because the GP must always act in the best interests of the person, not the person’s EPA or family.

If you are ever faced with this situation, it is important for you to know that you must follow all medical orders, not the EPA’s direction.

For example, Mrs Smith’s family member (her appointed EPA) tells you not to give antibiotics. You must follow the GP’s orders at all times. However, it would be good practice to notify your supervisor and arrange for the GP and EPA to speak to one another to resolve any conflict.
Read the following scenario and answer the questions.

Scenario: Edna

A few months ago Edna started to show signs of memory loss and confusion. Her doctor advised that she should choose who should have an EPA for her and she chose her nephew, John. Last week Edna left the stove on and nearly started a fire, but John was visiting and noticed in time. She also had a fall in the night and became very frightened when she couldn’t remember the way back to her bedroom.

John decided that he needed to use his EPA to move his aunt into residential care. At first, Edna wasn’t happy to leave her home but she soon settled in at the rest home and is much safer there.

How would you find out about Edna’s EPA?

Does John have the right to use his EPA to move Edna to a care facility?

What steps should John take to get Edna the help she needs?