Module 1

Understanding Dementia

- Outline
- What is Dementia?
- Signs and Symptoms of Dementia
- Causes of Dementia
- Common Types of Dementia
- Stages of Dementia
- Impact of Dementia
- Summary
- Review Activity
Outline

Aim

In this module you will learn about the causes and different types of dementia. You will also learn about the impact of dementia not only on a person, but also on the staff and family providing care.

Learning outcomes

At the end of this module you will be able to:

• explain what dementia is
• recognise the signs and symptoms of dementia
• describe how dementia is caused
• list the most common types of dementia
• explain the progression of dementia
• describe the impact dementia can have on a person
• describe the impact dementia can have on caring for residents.

Resources required

To complete the training for this module you will need:

• access to the Aged Care Channel satellite program Understanding Dementia.
What is Dementia?

Definition

Dementia is a general term used to describe problems with memory and thinking, which leads to a decline in social skills and behaviour and indicates that something is wrong with the brain.

What happens to the person?

When a person has dementia, little by little they lose the ability to remember, to think and to deal with more than one piece of information at a time. They gradually lose the ability to relate to people, communicate and to care for themselves.

Focus

You need to remember that people have dementia. It is very important to focus on the uniqueness and individuality of each person.

Take note…

Remember, you are caring for and assisting a person with their own personality, their own interests, their own likes and dislikes who happens to have dementia. Dementia affects individuals in different ways.

Consider this…

Experiential Activity – this will be explained by your trainer.

Question: Is this where you can buy ice cream?

A ‘care worker’ is sitting at a table with a stack of reward cards. If you approach the ‘care worker’ and ask this question correctly you will be given a card.

Only one of the following forms of communication will be acceptable:

- Written
- French
- German
- Spell out loud
- Written backwards
- Sign Language
- Singing
- Pidgin English
- Chinese

How did this activity help you understand what it must be like for a person with dementia?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Source: Adapted from Experiencing Dementia – Gaunson, Horgan, Walker
How many people have dementia?  
In 2004 around 170,000 Australians over 65 years of age are living with a diagnosis of dementia. Many of these people live in the community, some independently.

Who gets dementia?  
Dementia can happen to anyone. It can affect people in their 30s, 40s and 50s. However:
- it is more common over the age of 65
- one in four people over the age of 85 have the condition.

Consider this…

The Australian population is ageing. This means more Australians are living to an older age.
- In 2004 Over 170,000 people have dementia
- By 2051 About 650,000 people may have dementia

How might this affect people like you who are working in aged care?

Normal healthy ageing

Dementia does NOT mean a normal part of ageing. It is caused by a number of different illnesses. It is important to remember that three out of four people over the age of 85 do not have dementia.

As part of the normal ageing process people may become more forgetful but it does not affect their daily living activities like dementia does.

<table>
<thead>
<tr>
<th>Normal Ageing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory loss</td>
<td>May gradually lose vision, hearing, touch and smell</td>
</tr>
<tr>
<td>Memory loss</td>
<td>Retrieval of information can be slower</td>
</tr>
<tr>
<td>Ability to think</td>
<td>Unaffected</td>
</tr>
<tr>
<td>Self-care</td>
<td>Usually able to perform all self-care tasks</td>
</tr>
</tbody>
</table>

Consider this…

Divide into groups of three and complete the following exercises:

**Visual Losses.** Put on eye goggles and either:
- take a walk with a partner up a flight of stairs, or
- take two pills out of a pill container

**Hearing Losses.** Place earplugs in your ears and:
- carry on a conversation with the rest of the group

**Touch Losses.** Put on thick rubber gloves and
- count out money from a purse

How did you feel?
__________________________________________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________
Signs and Symptoms of Dementia

**Group of signs and symptoms**

Dementia describes a group of signs and symptoms and is not the name of the disease or illness that causes them. A collection of signs and symptoms is called a syndrome. Dementia is a syndrome that may be caused by a number of different illnesses.

**Various signs and symptoms**

Signs and symptoms will vary between people and can occur at different times for the one person.

In the beginning common signs and symptoms can include:
- memory loss, particularly recent memory
- confusion
- mood and personality changes
- withdrawal
- poor judgment
- taking longer to do everyday tasks.

Then over time a person with dementia may:
- lose their communication skills
- become disorientated to time, place and people
- lose the ability to do everyday tasks
- lose control of their bowel/bladder
- wander and pace around
- hallucinate or have delusions
- behave in a way that is a challenge to manage.

It is important to remember that a person with dementia still retains a number of abilities until the end stage of dementia.

**Consider this…**

Clive had just turned 70. He thought he was losing his memory. Sometimes he would drive into town and he’d forget the turnoff or where he’d parked the car. He couldn’t remember names of people he had known for years. Simple tasks like mowing the lawn started to take longer. He was clumsy and kept dropping things. He started to feel depressed and withdrawn. He had a feeling things weren’t quite right, but couldn’t put his finger on the reason why. When Clive tried to talk about it to his doctor he couldn’t find the right words and he couldn’t make sense of what the doctor was saying.

Clive was diagnosed with Alzheimer’s Disease, a form of dementia.

Clive moved in with his daughter and lived with her for 10 years. He loved wandering around the garden. He gradually lost the ability to speak and perform everyday tasks like bathing and dressing. When he needed total care he moved to a nursing home nearby.

How many signs and symptoms of dementia did Clive display?

Underline them as you go.
Causes of Dementia

Syndrome

Remember, dementia is a syndrome that may be caused by a number of different illnesses.

Range of causes

Dementia may have a number of different causes.

<table>
<thead>
<tr>
<th>Cause of Dementia</th>
<th>Type or Form of Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plaques, tangles and transmitter defects to brain</td>
<td>Alzheimer’s Disease</td>
</tr>
<tr>
<td>Strokes (many and small)</td>
<td>Vascular Dementia</td>
</tr>
<tr>
<td>Multi infarcts</td>
<td>Parkinson's Disease</td>
</tr>
<tr>
<td>Transmitter Damage</td>
<td>Lewy Body Disease</td>
</tr>
<tr>
<td>Physical Damage</td>
<td>Brain Injury</td>
</tr>
<tr>
<td></td>
<td>Brain Tumour</td>
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<tr>
<td></td>
<td>Hydrocephalus</td>
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<tr>
<td>Toxic Damage</td>
<td>Korsakoff’s Syndrome</td>
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<tr>
<td></td>
<td>Alcohol Related</td>
</tr>
<tr>
<td></td>
<td>Wilson’s Disease</td>
</tr>
<tr>
<td>Genetic Disorder</td>
<td>Huntington’s Disease</td>
</tr>
<tr>
<td></td>
<td>Wilson’s Disease</td>
</tr>
<tr>
<td></td>
<td>Pick’s Disease</td>
</tr>
<tr>
<td>Infections</td>
<td>AIDS</td>
</tr>
<tr>
<td></td>
<td>Syphilis</td>
</tr>
<tr>
<td></td>
<td>Creutzfeldt-Jakob Disease (Mad Cow)</td>
</tr>
<tr>
<td>White Matter Damage</td>
<td>Binswangers Disease</td>
</tr>
</tbody>
</table>

Consider this…

What do you think is the most common type or form of dementia?

__________________________________________________________
Common Types of Dementia

**Most common types** The most common types of dementia are:

- Alzheimer's Disease – approximately 50-70%
- vascular or multi-infarct dementia – approximately 20-30%.

Other less common forms of dementia include:

- neurological damage - Lewy Body Disease, Parkinson's Disease
- fronto-temporal lobe dementia
- alcohol-related - Korsakoff’s Syndrome
- genetic – Huntington’s Disease, Wilson’s Disease, Pick’s Disease
- infection – AIDS, CFJ, Syphilis.

![Types of Dementia](image)

**Conditions that look like dementia** Some conditions present like signs and symptoms of dementia. These may be reversible and include:

- depression
- acute confusion/delirium (caused by infection, dehydration, constipation)
- anxiety
- tumours
- vitamin deficiencies.

**Consider this…**

Why do you think it is important to diagnose the type of dementia correctly?
Alzheimer’s Disease

**Cause:** A physical disease which causes brain cells to die. Tangles and plaques disrupt messages within the brain.

Alzheimer’s Disease is the most common form of dementia. The person gradually becomes more forgetful, confused and unable to sequence their activities. They develop problems with speech and communication and become lost, even in familiar surroundings.

Vascular Dementia

**Cause:** Multiple little strokes have damaged particular areas of the brain.

Vascular or multi infarct dementia is the other common form of dementia. A person’s abilities usually deteriorate after a stroke and then stabilise until the next stroke.

Lewy Body

**Cause:** Abnormal lumps called Lewy Bodies develop inside nerve cells in the brain. It is thought these cause the degeneration and death of brain cells.

Lewy Body dementia is often diagnosed as other forms of dementia and is only proven on autopsy. People with Lewy Body dementia often have visual hallucinations and delusions as well as tremors and stiffness like Parkinson’s Disease.

Frontal Lobe

**Cause:** Damage starts in the front part of the brain, the reason for this is unknown.

Damage to the frontal lobes leads to alterations in personality and behaviour, changes in the way a person feels and expresses emotion, and loss of judgement.

Korsakoff’s Syndrome

**Cause:** Too much alcohol over a long period of time, especially when combined with a poor diet which is low in Vitamin B1 leads to irreversible brain damage.

It affects the most vulnerable parts of the brain which are used for memory, planning, organising, judgement, social skills and balance.

Parkinson’s Disease

**Cause:** Parkinson's disease is a progressive disorder of the central nervous system.

This disease is characterised by tremors, stiffness in limbs and joints, speech impediments and difficulty initiating physical movements. Late in the course of the disease, some people may develop dementia.

Huntington’s Disease

**Cause:** Inherited, degenerative brain disease which affects the mind and body.

Dementia is usually an inevitable part of the deterioration.

AIDS Complex Dementia

**Cause:** Infection to the brain from the HIV virus.

Not everyone with AIDS will have dementia.
Stages of Dementia

Progressive stages

Dementia is progressive in most cases. The speed with which dementia can progress varies between individuals. Sometimes a massive decline can occur rapidly over a few months, in other cases it may happen over a number of years. Although the major signs and symptoms are the same, each person will have a unique and different way of expressing them.

There are three general stages of dementia.

Dynamic process

The dementing process is dynamic – it is always progressing and changing. It can vary from day to day but over longer periods it will progressively make the person more disabled.

Example of progression

A person with Alzheimer's Disease was asked to copy the drawing of the house on the left over a two year period.

Source: “The Dementia Booklet” published by ADARDS New Zealand inc, 1993
Consider this…

Scenario
Josie had cared for Mrs Baker for just on four years. Lately she had noticed that Mrs Baker had stopped speaking. Bathing and dressing had become increasingly difficult as Mrs Baker ceased helping with any of the tasks. During the past week she had stopped feeding herself at meal times, even when prompted. Mrs Baker seemed completely flat and withdrawn into a world where Josie couldn’t make contact with her. Josie noticed differences in Mrs Baker.

What differences or changes had Josie noticed?
__________________________________________________________
__________________________________________________________
__________________________________________________________

What do you think is happening to Mrs Baker?
__________________________________________________________
__________________________________________________________
__________________________________________________________

What would you do?
__________________________________________________________

Take note…
It is very important to report ‘changes’ or ‘differences’ to your Team Leader or Supervisor. Document them!
Impact of Dementia

Person Centred Care

The impact of dementia varies between individuals. It is very important to try to get to know the person behind the illness. Put the person at the centre. This is called ‘Person Centred Care’.

Common care issues

The most common areas that people with dementia may need assistance with include:

- Memory Loss
- Disorientation
  - Time, Place, People
- Behaviour
- Communication
- Maintaining Self-Care
- Going to the Toilet
- Eating & Drinking
- Wandering
- Safety Issues

Impact on the person

Increasingly a resident will need more assistance as the dementia progresses. This has a huge effect on the person and their lifestyle.

Impact on the care worker

Your role as a care worker is to support and assist the person who has dementia to manage everyday activities. This is not an easy task at times and will require lots of understanding and patience.

Discover and focus on abilities

When you assist a person with dementia in their everyday life you will most likely follow a resident care plan. This plan will be based on the assessment of the resident and the areas of their lives where you need to assist them. Remember that assessment is a ‘process of discovery’. This means discovering what a resident can and cannot do. When helping residents with tasks they can no longer do remember to encourage and support the abilities they still have.
Memory loss

Gradual memory loss is a feature of dementia. Short term memory is affected first and as the disease progresses long term memory may be impaired.

**Impact on the person:**
- The person may not be able to learn or retain new information easily.
- The person may be frustrated because they cannot remember things.

**Impact on those caring for the resident:**
- You need to be patient and repeat ‘new’ information constantly.
- You may need to draw on the resident’s long term memory to improve the ways you communicate with the resident.
- You may need to prompt the resident with verbal cues and/or visual cues such as pictures, or cues from the environment.

Can you think of any more?

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**Take note…**

Remember to discover what they can still remember and use this to help them!

Disorientation

The resident may not know who you are, what time period it is, where they are, why they are there, or any combination of these things.

**Impact on the person:**
- The person may feel lost and insecure.

**Impact on those caring for the resident:**
- You may need to constantly orientate and reassure the resident either verbally or by having clear signs in their environment.

Can you think of any more?

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**Take note…**

Remember to discover what verbal phrases or visual cues will help residents orientate themselves!
**Communication**

The resident may be unable to tell the carer verbally what they need or want.

**Impact on the person:**
- The person's needs and wants may not be met.
- The person may become very frustrated.

**Impact on those caring for the resident:**
- It may be difficult to know what the resident needs or wants.
- You need to use and respond to body language and other types of communication.
- You need to slow down, 'listen' and observe. Give the resident time to respond. **Go at their pace!**

Can you think of any more?

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**Take note...**

Remember to discover what words, phrases, music, pictures, smells, tastes the person responds to and helps them with communication.

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**Self-Care**

The resident may forget how to do tasks of everyday living such as getting dressed or brushing their hair.

**Impact on the person:**
- The person’s personal cleanliness and appearance may decline.
- The person may forget to eat.
- The person may become ill as a result of poor hygiene or lack of food and drink.

**Impact on those caring for the resident:**
- You may need to prompt or support the resident with their everyday living tasks. It is important not to ‘take over’ the task but to support where possible.

Can you think of any more?

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**Take note...**

Remember to discover what self-care tasks or what part of self-care tasks they are still able to do. Assist by prompting and encouraging them.
Safety

A resident with dementia may be at risk because they no longer recognise dangers such as traffic, fire, electricity, boiling water or poisons.

Impact on the person:
- The person may be injured.

Impact on those caring for the resident:
- You need to make sure the environment is safe by removing hazards.
- You need to supervise residents closely if the environment is not secure.

Can you think of any more?

__________________________________________________________
__________________________________________________________

Take note…

Remember to discover what they can do ‘safely’ and let them do that. Do not think if it is a danger for one person then no-one can do it. Tailor your safety interventions to the individual!

Wandering

Some residents with dementia wander as a means of activity, whilst others have a strong sense of purpose to be somewhere such as their childhood home.

Impact on the person:
- The person needs to walk or they become agitated.
- Walking and wandering gives the person a sense of space and activity.

Impact on those caring for the resident:
- You need to provide a safe and secure space where the resident can wander, such as a walking track through the garden.

Can you think of any more?

__________________________________________________________
__________________________________________________________

Take note…

Remember if you have a safe and secure area encourage residents to use it. Think about how you can make these areas more attractive.
Eating and drinking

A person with dementia may forget to eat or drink.

**Impact on the person:**
- The person may suffer malnutrition and lose weight.
- The person may suffer dehydration which can lead to an increase in dementia symptoms.

**Impact on those caring for the resident:**
- You may need to prompt the resident to eat and drink.
- You need to look out for residents who are losing weight and take notice of the food and drinks they have.
- You may need to provide a resident with lots of little nutritional snacks and drinks throughout the day rather than meals at set times.

Can you think of any more?

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**Take note…**

Remember to discover what an individual resident can still do on their own or with minimal assistance!

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Going to the toilet

Residents may forget how to find their way to the toilet, how to undo their clothing, or how to use the toilet. They may not even recognise the urge to go to the toilet.

**Impact on the person:**
- The person may have frequent accidents which may be embarrassing for them.
- The person’s skin condition may be affected.

**Impact on those caring for the resident:**
- You may need to prompt the resident to go to the toilet.
- You may need to take the resident to the toilet frequently.
- You may need to clean the resident/environment following an accident.

Can you think of any more?

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**Take note…**

Remember to discover what an individual resident can still do on their own or with minimal assistance!
Behaviours

There are many possible unusual behaviours that people with dementia can show that care workers and families may find challenging. But we need to remember that even if we find a behaviour challenging it always has meaning for the resident. It often indicates that something is wrong or they have misunderstood what’s happening around them. Sometimes a person’s behaviour is the only way they can express themselves or get a message across.. Behaviours that may cause concern include:

- Aggression
- Resistance to care
- Abusive language
- Taking things and hiding them
- Verbal outbursts
- Suspicion and accusations
- Agitated or repetitive acts
- Sexual behaviour

Is the person trying to get a message across?
For example: I’m tired, I’m scared, I’m unhappy, I want control.

Impact on the person:
- The person may become isolated and fearful.
- The person may harm themselves.

Impact on those caring for the resident:
- You may find the behaviour very difficult to manage because it is irrational and unpredictable.

Can you think of any more?

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______________________________
______________________________

Take note…

Remember to discover the types of behaviour and situations that you need to encourage and support and the types of behaviour and situations that you need to manage!

Do not take what a person with dementia does or says personally.
Summary

What is Dementia?
- Dementia is a general term used to describe problems with memory and thinking, which leads to a decline in social skills and behaviour and indicates that something is wrong with the brain.
- Approximately 25% of people over the age of 85 have dementia.
- Dementia is NOT part of the normal ageing process.

Signs and Symptoms of Dementia
- The most common signs and symptoms of dementia include:
  - memory loss, particularly recent memory
  - confusion
  - personality changes
  - withdrawal
  - poor judgment
  - loss of ability to do everyday tasks.

Causes of Dementia
- Dementia is a syndrome that may be caused by a number of different illnesses.
- There are a range of causes that may result in a form of dementia. These include:
  - plaques, tangles and transmitter defects to the brain e.g. Alzheimer's Disease
  - strokes and multi infarcts e.g. vascular dementia
  - transmitter damage e.g. Lewy Body, Parkinson's Disease
  - physical damage e.g. tumours, head injury
  - toxic damage e.g. alcohol abuse
  - genetic disorder e.g. Huntington's Disease
  - infections e.g. AIDS, syphilis, Creutzfeld-Jacob Disease
  - white matter damage e.g. Binswangers Disease.
Common Types of Dementia

- The most common types of dementia are:
  - Alzheimer's Disease
  - vascular dementia.

- Other less common forms of dementia include:
  - Lewy Body Disease
  - Pick's Disease
  - Korsakoff's Syndrome
  - Parkinson's Disease
  - Huntington's Disease
  - AIDS Complex Dementia

- Some medical conditions mimic dementia and can be treated. Consequently the dementia may be reversed. These include:
  - depression
  - acute confusion/delirium (caused by infection, dehydration, constipation)
  - anxiety
  - tumours
  - vitamin deficiencies.

Stages of Dementia

- Dementia is progressive and goes through stages.

Impact of Dementia

- People with dementia may need assistance with:
  - Memory loss
  - Disorientation
  - Communication
  - Self-care
  - Safety
  - Wandering
  - Eating and drinking
  - Going to the toilet
  - Behaviours

- Try to discover the person behind the illness.
- Do not take what a person with dementia does or says personally. Dementia is the disease, not the person.
Take Home Messages

Try to see the person behind the illness.

Don’t take what a person with dementia does or says personally.

Focus on what a person with dementia can do and assist them with what they can’t.
Review Activity

Activity 1

Decide whether these statements are True or False. Tick the box.

1. People with dementia have problems with memory and thinking which can lead to a decline in their social skills and behaviour.
   - True [ ] False [ ]

2. Everyone over the age of 85 has dementia.
   - True [ ] False [ ]

3. Dementia describes a group of signs and symptoms and is not the name of a disease.
   - True [ ] False [ ]

4. A sign or symptom of dementia is memory loss.
   - True [ ] False [ ]

5. Vascular dementia is caused by many little strokes in the brain.
   - True [ ] False [ ]

6. Alzheimer’s Disease is the most common form of dementia.
   - True [ ] False [ ]

7. Some conditions look like dementia but are reversible if treated, for example, depression.
   - True [ ] False [ ]

8. Dementia is a progressive illness and goes through stages.
   - True [ ] False [ ]

9. Dementia may change the way a person behaves and this can be challenging.
   - True [ ] False [ ]

10. A person with dementia may forget how to do everyday living tasks and may need help.
    - True [ ] False [ ]