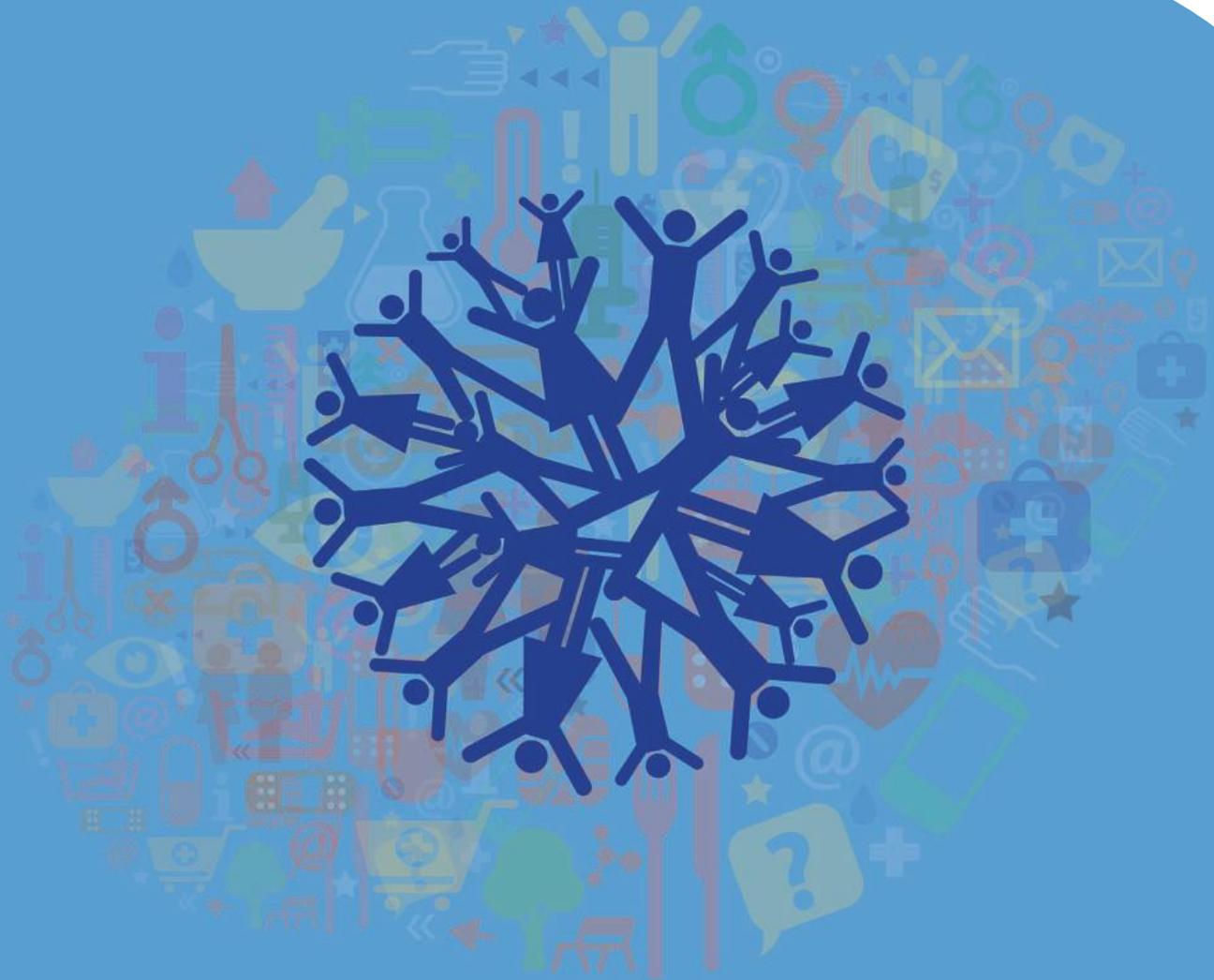


# CHCAGE005

## Provide support to people living with dementia

Release 2



*Learner guide*

CHCAGE005

# **Provide support to people living with dementia**

Release 2

Learner guide

Aspire Version 1.1



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### CHCAGE005 Provide support to people living with dementia Release 2

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First published April 2017

Cover design Rewind Creative

Printer Doculink Australia Pty Ltd, 1d/28 Rogers Street,  
Port Melbourne VIC 3207

e-ISBN 978-1-76059-754-2 (PDF version)

ISBN 978-1-76059-752-8

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## Before you begin

This learner guide is based on the unit of competency *CHCAGE005 Provide support to people living with dementia*, Release 2. Your trainer or training organisation must give you information about this unit of competency as part of your training program. You can access the unit of competency and assessment requirements at: [www.training.gov.au](http://www.training.gov.au).

## How to work through this learner guide

This learner guide contains a number of features that will assist you in your learning. Your trainer will advise which parts of the learner guide you need to read, and which practice tasks and learning checkpoints you need to complete. The features of this learner guide are detailed in the following table.

<b>Feature of the learner guide</b>	<b>How you can use each feature</b>
<b>Learning content</b>	<ul style="list-style-type: none"> <li>▶ Read each topic in this learner guide. If you come across content that is confusing, make a note and discuss it with your trainer. Your trainer is in the best position to offer assistance. It is very important that you take on some of the responsibility for the learning you will undertake.</li> </ul>
<b>Examples and case studies</b>	<ul style="list-style-type: none"> <li>▶ Examples of completed documents that may be used in a workplace are included in this learner guide. You can use these examples as models to help you complete practice tasks and learning checkpoints.</li> <li>▶ Case studies highlight learning points and provide realistic examples of workplace situations.</li> </ul>
<b>Practice tasks</b>	<ul style="list-style-type: none"> <li>▶ Practice tasks give you the opportunity to put your skills and knowledge into action. Your trainer will tell you which practice tasks to complete.</li> </ul>
<b>Video clips</b>	<ul style="list-style-type: none"> <li>▶ Where QR codes appear, learners can use smartphones and other devices to access video clips relating to the content. For information about how to download a QR reader app or accessing video on your device, please visit our website: <a href="http://www.aspirelr.com.au/help">www.aspirelr.com.au/help</a></li> </ul> <div data-bbox="1163 1328 1353 1610" style="text-align: right;">   <p style="font-size: 8px; margin-top: 2px;">V1234</p> </div>
<b>Summary</b>	<ul style="list-style-type: none"> <li>▶ Key learning points are provided at the end of each topic.</li> </ul>
<b>Learning checkpoints</b>	<ul style="list-style-type: none"> <li>▶ There is a learning checkpoint at the end of each topic. Your trainer will tell you which learning checkpoints to complete. These checkpoints give you an opportunity to check your progress and apply the skills and knowledge you have learnt.</li> </ul>

## Foundation skills

As you complete learning using this guide, you will be developing the foundation skills relevant for this unit. Foundation skills are the language, literacy and numeracy (LLN) skills and the employability skills required for participation in modern workplaces and contemporary life.

The following table outlines specific foundation skills noted for your learning in this learner guide.

Foundation skill area	Foundation skill description
Learning	<ul style="list-style-type: none"> <li>▶ Understanding your job role, organisational procedures and legal responsibilities</li> <li>▶ Managing your work and seeing how well you are going and making goals for yourself at work</li> <li>▶ Seeking professional development opportunities for continuous improvement</li> </ul>
Reading	<ul style="list-style-type: none"> <li>▶ Understanding how documents are presented and being able to navigate through documents</li> <li>▶ Understanding industry- and job-specific terminology</li> <li>▶ Interpreting key information in relevant documents</li> <li>▶ Understanding routine workplace checklists and documentation</li> </ul>
Writing	<ul style="list-style-type: none"> <li>▶ Planning, drafting and writing reports and documents</li> <li>▶ Communicating through written letters, email and online</li> <li>▶ Recording progress; reporting incidents</li> </ul>
Oral communication	<ul style="list-style-type: none"> <li>▶ Clarifying instructions</li> <li>▶ Providing information</li> <li>▶ Supporting others through encouragement, negotiation and conflict resolution</li> <li>▶ Using body language to model desired behaviour and responding to others' body language</li> </ul>
Numeracy	<ul style="list-style-type: none"> <li>▶ Calculating costs, weights, measurements of height and distance</li> <li>▶ Interpreting measurements</li> </ul>
Teamwork	<ul style="list-style-type: none"> <li>▶ Working well with other people by cooperating, collaborating, encouraging and building rapport</li> </ul>
Planning and organising	<ul style="list-style-type: none"> <li>▶ Planning your workload and commitments</li> <li>▶ Implementing tasks</li> <li>▶ Completing work on time</li> <li>▶ Knowing how to deal with hazards and risks</li> </ul>
Making decisions	<ul style="list-style-type: none"> <li>▶ Understanding and applying decision-making processes</li> <li>▶ Reviewing the impact of your decisions</li> </ul>
Problem-solving	<ul style="list-style-type: none"> <li>▶ Identifying problems</li> <li>▶ Working out how to fix a problem using problem-solving processes and reviewing the outcome</li> </ul>
Innovation and creation	<ul style="list-style-type: none"> <li>▶ Recognising opportunities to develop and apply new ideas</li> <li>▶ Generating ideas by thinking of new ways to do something</li> <li>▶ Making suggestions to improve work</li> </ul>

Foundation skill area	Foundation skill description
Technology and digital literacy	<ul style="list-style-type: none"> <li>▶ Efficiently using digitally based technologies and systems correctly and safely</li> <li>▶ Accessing, organising and presenting information</li> <li>▶ Using equipment correctly and safely</li> </ul>

## What do you already know?

Use the following table to identify what you may already know. This may assist you to work out what to focus on in your learning.

Topic	Key outcomes	Rate your confidence in each section
Topic 1 Prepare to provide support to those affected by dementia	1A Apply person-centred care approaches	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	1B Interpret the individualised plan	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	1C Identify and address the person's need for a stable and familiar environment	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	1D Recognise signs consistent with financial, physical or emotional abuse or neglect	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
Topic 2 Use appropriate communication strategies	2A Use verbal and nonverbal communication to maximise engagement	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	2B Gain cooperation and provide reassurance by using reality orientation	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	2C Use a range of validation strategies to relieve distress and agitation	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
Topic 3 Provide activities for maintenance of dignity, skills and health	3A Organise activities that aim to maintain independence	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	3B Organise activities that are appropriate to the individual	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident

Topic	Key outcomes	Rate your confidence in each section
	3C Ensure the safety and comfort of the person balanced with autonomy and risk-taking	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	3D Access information about the person's reminiscences and routines with family and carers	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	3E Provide support and guidance to family, carers and/or significant others	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
Topic 4 Implement strategies that minimise the impact of behaviours of concern	4A Identify behaviours of concern and potential triggers	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	4B Contribute to team discussions on support planning and review	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	4C Take action to minimise the likelihood and impact of behaviours on the person and others	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	4D Evaluate the implemented strategies to ensure effectiveness in minimising behaviours	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
Topic 5 Complete documentation	5A Comply with reporting requirements	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	5B Complete, maintain and store documentation	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
Topic 6 Implement self-care strategies	6A Monitor own stress level	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident
	6B Use appropriate self-care strategies	<input type="checkbox"/> Confident <input type="checkbox"/> Basic understanding <input type="checkbox"/> Not confident



## Topic 1

In this topic you will learn how to:

- 1A Apply person-centred care approaches**

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- 1B Interpret the individualised plan**

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- 1C Identify and address the person's needs for a stable and familiar environment**

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- 1D Recognise signs consistent with financial, physical or emotional abuse or neglect**

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## Prepare to provide support to those affected by dementia

Caring for someone with dementia or memory support needs, can be stressful and time consuming. Your understanding of dementia will help you find the best ways to communicate and care for a person who has dementia, as well as those connected to the person such as their family, carer and friends. As dementia is a condition that affects memory and thinking, developing rapport and a relationship of trust with people with dementia can be extremely challenging. It is helpful to approach your work with an understanding of the condition and an understanding of each person's individual needs. You must also understand the challenges and burdens that family members and carers face when someone close to them has dementia. The impact on the life of carers is significant and must be taken into account when planning and delivering support. People with dementia are also vulnerable to abuse and neglect. This means you must be observant and pay attention to the signs indicating something is not right.

# 1A Apply person-centred care approaches

When providing care for a person with dementia it is important to pay attention to the environment in which the care is being provided. Regardless of the environment (be it the person's own home, a day centre, social club or residential facility), you need to be aware of features of the environment that may cause the person to become distressed, confused or anxious. Tailor the environment to the person's individual needs so their surroundings are calming and familiar. Maintaining a stable and familiar environment for people helps prevent distress and minimise behaviours of concern.

To maintain a stable familiar environment:

- ▶ ensure there is a minimal amount of background noise, such as music or talking, as this can be distracting and confusing
- ▶ decorate facilities in soothing colours
- ▶ keep furnishings comfortable and simple
- ▶ ensure the person has their own familiar items around them, such as photos and ornaments that are meaningful to them and evoke retained memories of their past.

## A person-centred approach

When providing care for a person with dementia all aspects of their care and other activities should be adapted for each individual. Different people have different skills, preferences and histories. Some will take longer to do tasks than others. Some may need extra time to develop trust in you, each time you provide support. Tailor the way you communicate with the person; reassure them and provide support and activities based on their individual needs.

Below are the different factors to take into account when using a person-centred approach.

### Relationship

- ▶ You need to be considerate of the way you develop relationships with people who have dementia and their family members. Knowing about their interests, history, family and culture, etc. means that you can say and do things in a way that puts them at ease. Even though they may not remember who you are, showing that you know them and the things that are important to them will be reassuring when you are providing care. Understanding and acknowledging the challenges faced by the family members of people with dementia, and being available to discuss them, will provide support and help them in their role as carers.

### Control and choice

- ▶ Taking a person-centred approach means ensuring the person has as much control and choice as possible, while providing care that meets their needs in a safe and high-quality way. It means that the person is placed in the centre of the planning process. Their likes, dislikes, personal history, cultural and religious beliefs, skills and knowledge are central to the process of planning how their support will be delivered. It means adapting care and other activities to the person, rather than expecting the person to fit in with service models that are available.

## Environment

- ▶ Maintaining a stable and familiar environment for people can prevent distress and minimise inappropriate or challenging behaviours. This may mean ensuring there is little background noise, such as music or talking, as this can be distracting and confusing; or decorating facilities in soothing colours and keeping furnishings comfortable and simple. Ensure the person has their own familiar items around them, such as photos and ornaments that are meaningful to them. Tailor the environment to the person's individual needs so their surroundings are calming and familiar.

## What a support worker can do

How a person with dementia is supported and included in the community can affect their experience, level of comfort and maintenance of social connections. In the past, conditions such as dementia were treated using a medical model of care. The symptoms were treated and people were often placed into institutions with no thought given to how they may be supported to stay at home or be part of their communities. Health professionals now look at the person first, and their condition second. This is referred to as the social model of health. This model works from the expectation that, as far as possible, we should adapt the environment to enable people with dementia to participate in and access the community, rather than assume that their dementia is what is preventing them from doing so.

Here is further information about the different ways a support worker can adapt their approach to assist people with dementia.



### Recognition

Knowing that a person may not recognise you when you come to provide support will mean you must introduce yourself and reassure them of who you are and why you are there, every time – even if you have helped them many times before.



### Disorientation

If part of your role is taking the person with dementia out into the community, knowing the effects of dementia will mean you know to watch them closely, not let them wander off, and observe and manage their interaction with other members of the public.



### Communication

Knowing that a person with dementia may not be able to find the words to tell you what they want, or when something is wrong, will mean you communicate with them carefully and watch for other cues or signs to help you determine what is going on.



### Perception

It can be very distressing for a person with dementia as they struggle to understand what is going on around them. Ensure you are gentle, patient and reassuring in assisting them to function in their world.



### Individuality

As every person is different, it is important to acknowledge and support them as individuals – not just a person with dementia. You may need to try a number of different approaches before being able to provide assistance to each person.

## Example

### Apply a person-centered approach

Here are three examples of how to apply a person-centred approach.

#### The late sleeper

A person may have always slept in on a weekend. A service may have a model of providing support to those needing help to get up, showered and dressed in the morning, between 7.00 am and 9.00 am. For a person who has habitually slept in, it may be necessary to be flexible and assist them at a later time to accommodate their personal preferences.

#### The club member

A person may have been a member of a club all their life, but due to their dementia can no longer attend the club independently, and may have difficulty remembering names and faces. A worker may provide support to ensure they can still attend the club by providing transport, assisting with names, facilitating understanding from other club members and providing reassurance to the person.

#### The traveller

A person may have always dreamt of visiting America, but has recently been diagnosed with dementia. A service, in partnership with the person's family may arrange to have workers support the family to accompany the person on her dream trip, and provide support, reassurance and guidance while away. The workers may also be involved in putting together a 'book of memories' including photos and stories from the trip, so they can look over this in the future and see the parts of the trip they no longer remember.

# Practice task 1

1. What are some ways that you can provide a person-centred approach to a person with dementia?

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2. What are some ways that you can tailor the environment to a person with dementia when using a person-centred approach?

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[Click to complete Practice task 1](#)

# 1B Interpret the individualised plan

Every person living with dementia has individual needs and factors that should be taken into consideration when providing their care and support. The cause of the dementia, the stage of dementia, how the dementia is affecting the person and their individual support needs should be taken into account when developing and interpreting a person-centred support plan.

Individualised plans should include the needs and wishes of the person. This approach aims to enable the person with dementia to be independent and in control of their life as much and as often as they can be.



## Understand dementia

To provide the best support to people with dementia, you must first understand what dementia is, why it occurs and the impact it has on the person and their ability to manage their day-to-day lives. Developing this understanding is the basis on which you build the skills and approaches for providing support. Here is an overview of what dementia is, the symptoms and how a person should be treated.

### What is dementia?

The word dementia does not refer to a single illness or condition. It is used when a person's brain is affected by one or more diseases or conditions that cause cognitive functioning (memory and thinking) to get worse over time.

### Signs of dementia

There are many symptoms that a person may have dementia. These include memory loss, confusion, changes in personality, apathy (lack of interest) and withdrawal, and a loss of ability to perform everyday tasks.

### Treatment

Once a person has dementia, it cannot be reversed or stopped. The symptoms generally get worse over time. Each case of dementia is different. For example, dementia will progress at different rates in different people. For one person, it can go from being quite mild, with only some symptoms, to being severe, with many symptoms in a short period of time. Some skills are lost more quickly than others. Mood and personality changes will vary. You cannot predict how dementia will affect an individual or those around them.

### Support

Part of doing your job well means treating a person with respect, kindness and understanding. Families also need support and reassurance just as much as the person with dementia. It can be very upsetting for families to watch someone they love gradually lose their skills. You may need to refer families to your manager for assistance, or to support services such as counsellors or community services.

## Alzheimer's disease

Alzheimer's disease is the most common form of dementia in people aged over 65 years. It accounts for over half the diagnosed cases of dementia. It is named after Alois Alzheimer (1864–1915), a German physician who first described the disease in 1907. Alzheimer's disease is a progressive, degenerative illness that attacks the brain. As the brain cells shrink or disappear, there is a build-up of abnormal material called 'tangles' in the centre of the brain and 'plaques' outside the brain cells. Plaques and tangles cause disruptions in the messages in the brain and damage the connections between cells. As the brain cells die, the person's ability to recall information or form new memories decreases over time.

## Symptoms of Alzheimer's disease

The symptoms of Alzheimer's disease vary from person to person, and may change in an individual from day to day; however, they always worsen over time. In the early stages of the disease the symptoms can be difficult to detect. It often starts with memory lapses and difficulty in finding the right words for everyday objects. Other symptoms are listed below.

Other symptoms of Alzheimer's disease may include:

- ▶ ongoing memory difficulties, especially about recent events
- ▶ vagueness in normal conversation
- ▶ a loss of enthusiasm for activities the person has previously enjoyed
- ▶ taking longer to do everyday tasks
- ▶ forgetting well-known people or places
- ▶ being unable to understand questions and instructions
- ▶ changes in social skills
- ▶ emotional unpredictability.

## Vascular dementia

An example of vascular dementia is known as multi-infarct dementia. This type of dementia is caused by small strokes that happen over time. These small strokes are also called transient ischaemic attacks (TIA) and are temporary blockages in small blood vessels in the brain. Damage to the brain occurs when the vessels are blocked and oxygen does not get to parts of the brain, causing cells to die.

The symptoms of multi-infarct dementia and other forms of vascular dementia may appear similar to those of Alzheimer's disease and a mixture of both types of dementia can occur in some people. Knowing the causes and symptoms of multi-infarct dementia and other types of vascular dementia can help you to identify the best ways to provide support and assist you to observe changes in the person's abilities and skills.

## Huntington's disease

Huntington's disease is an inherited, degenerative disease of the brain that affects both the mind and the body. Symptoms of Huntington's disease are most usually first seen between the ages of 30 and 50. Symptoms include intellectual decline; irregular movement (twitches or jerking) of the arms, legs and facial muscles; personality changes; memory loss; slurred speech; impaired judgment; and some psychiatric problems. A person will only get Huntington's disease if one of their parents has the disease. There is no cure.

Knowing about the causes, symptoms and effects of Huntington's disease can help you provide support to those people with the disease, and monitor the progression of symptoms and the effect on the person's abilities. Knowing about Huntington's disease may also affect the approach you take in communicating with and providing support to family members.

## Parkinson's disease

Parkinson's disease is a progressive neurological condition that causes a person to have less and less ability to control their movements, body and emotions, and is strongly associated with Lewy body dementia.

The cause of Parkinson's disease is unknown; however, it is known that abnormal proteins called Lewy bodies develop inside neurons and that the brain also slowly stops the production of the neurotransmitter called dopamine. Dopamine is an important chemical that carries messages between parts of the brain to control movement. The more dopamine producing cells are damaged by the disease, the more the motor symptoms of Parkinson's will appear.



While Parkinson's disease is not fatal, the symptoms do get progressively worse. Not everyone will experience all of the symptoms; however the disease tends to progress in stages where mild changes in posture, facial expression, tremors and walking progress to the stage where the person may not be able to perform any activities without assistance and may have little to no facial expressions. Other non-motor symptoms include depression; anxiety; irritability; cognitive decline; personality changes; difficulty with planning and decision making; hallucinations and psychosis; sleep disturbances; pain; fatigue; vision problems; and excessive sweating. The progressive cognitive deterioration, sleep disturbances and hallucinations that occur in Parkinson's disease are thought to be caused by the presence of the Lewy bodies in the neurons.

## Frontotemporal dementia (FTD)

Frontotemporal dementia (FTD), also referred to as frontotemporal lobar degeneration, was first described in 1892 by Arnold Pick (1851–1924) and was previously referred to as Pick's disease.

FTD is a form of dementia that occurs due to progressive damage to the frontal and/or temporal lobes of the brain. While similar to Alzheimer's disease, the initial signs of FTD are often in emotional and social functioning, rather than in memory. FTD makes up about five per cent of cases of dementia diagnosed.

People with FTD often display abnormal responses such as euphoria, disinhibition (an inability to control impulses) and a deterioration in their social skills. A person with FTD may be rude, impatient, and aggressive and have sexually inappropriate behaviours. They may also eat excessively or have a tendency to put inappropriate objects in their mouths.

Knowing about the causes, effects and symptoms of FTD can help you plan how you provide support to those with the disease.

## Younger onset dementia

Dementia is not necessarily an ‘older’ person’s illness. Dementia can occur in people as young as 30, but is much less common in people younger than 65, so is often more difficult to diagnose in these age groups. Younger onset (or early onset) dementia describes any form of dementia diagnosed in a person under the age of 65 years.

There is also a syndrome, Korsakoff syndrome (a form of alcohol-related dementia), where a younger person may experience short-term memory loss and cognitive deterioration due to insufficient thiamine in the body, usually caused by excessive alcohol consumption.

Also, people who are from Aboriginal and Torres Strait Islander backgrounds are more likely than other people to develop younger onset dementia.

Here are some examples of when dementia may occur at a younger age.

Conditions that may result in younger onset dementia	
Down syndrome, a genetic condition that people have from birth; dementia may occur in the early 50s	Multiple sclerosis (MS)
Head injury	Acquired immune deficiency syndrome (AIDS)
Alcohol abuse over many years	Chronic schizophrenia

## Pathological features

Some of the pathological features seen in people with dementia are amyloid plaques, neurofibrillary tangles, loss of connection between cells and cell death. Here is an overview of amyloid plaques and neurofibrillary tangles.

### Amyloid plaques

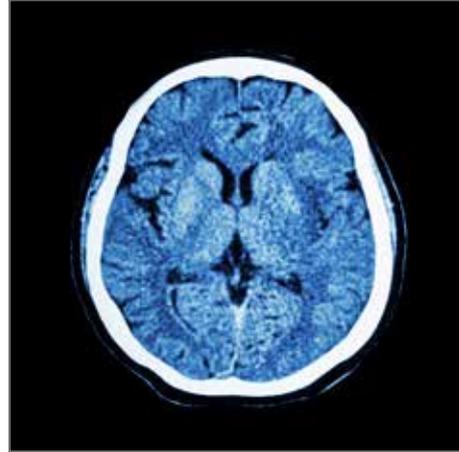
- ▶ Amyloid plaques are a build-up in the brain of proteins called aluminium silicate and amyloid peptides, and are believed to cause a loss of neurons and damage to blood vessels. (Neurons are cells that transmit nerve impulses and are the basic functional units of the body’s nervous system.)
- ▶ In a normal brain, these proteins are broken down and cause no problem. In the brain of a person with Alzheimer’s disease, the fragments of the broken-down protein stick together and form an amyloid plaque. The plaques can break the membrane of the nerve cells, letting other substances leak into the cell. This causes the neuron to malfunction or die

### Neurofibrillary tangles

- ▶ Neurofibrillary tangles are also made up of proteins and are caused by Tau proteins. These are important in forming the structure of neurons. In people with Alzheimer’s disease, Tau proteins cause the overproduction of enzymes resulting in the creation of neurofibrillary tangles. These tangles result in the death of the neuron cells.

## Effects of amyloid plaques and neurofibrillary tangles

Both amyloid plaques and neurofibrillary tangles cause neurons to malfunction or die. In the body, neurons transmit messages from one place to another. In the brain, neurons are important in forming and retrieving memories, generating appropriate emotions, and in understanding and communication. When neurons are not working correctly or have died, all of these functions can be affected. When parts of the brain are unable to transmit messages or communicate with each other, the symptoms of dementia begin to arise.



The actual role and effect of amyloid plaques and neurofibrillary tangles is not yet fully understood. Most people with Alzheimer's disease have some plaques and tangles, but some have only plaques; others only tangles. In some people, there is evidence at autopsy of plaques and tangles, but the person never showed any evidence or symptoms of Alzheimer's disease or dementia in their lifetime.

## Stages of dementia

Dementia has three stages: mild, moderate and severe. Here are the common symptoms and effects of each stage of dementia.

### The symptoms and effects of the stages of dementia

#### Mild

- ▶ Problems with memory
- ▶ Forgetful of details of recent events
- ▶ Problems finding the right word/s for people and objects
- ▶ Taking longer to do routine jobs
- ▶ Repeated speech; for example, asking the same question over and over
- ▶ Trouble understanding complex ideas
- ▶ Poor judgment and decision-making
- ▶ Problems making choices
- ▶ Trouble with cluttered or busy environments
- ▶ Becoming lost in unknown environments
- ▶ A change in mood or personality including losing interest in hobbies
- ▶ Difficulty handling money

### Moderate

- ▶ Greater trouble with memory
- ▶ Increased difficulty learning new tasks
- ▶ Repeated speech or speech that is jumbled and confused
- ▶ Problems thinking clearly
- ▶ Trouble recognising and/or naming known objects, friends and family
- ▶ Inappropriate behaviour
- ▶ Restlessness (finding it hard to settle)
- ▶ Becoming lost in known, as well as unknown, places
- ▶ Tendency to wander or become lost
- ▶ Limited skills in activities of daily living
- ▶ Confusion about time and place
- ▶ Neglectful of hygiene and eating
- ▶ Becoming angry or upset through frustration

### Severe

- ▶ Little or no speech
- ▶ Little or no memory
- ▶ Trouble understanding what has been said to them
- ▶ Acting on impulse
- ▶ Very little recognition of known objects, people or places
- ▶ Seeing or hearing things that are not there or not real
- ▶ Aggression
- ▶ No understanding of time
- ▶ Need for full support with all activities of daily living
- ▶ Incontinence
- ▶ Limited movement skills

## How dementia affects people

As dementia affects memory, communication, movement and thinking skills, a person with dementia can find their world quite confusing. They may have trouble working out which part/s of their environment they should pay attention to; or they may think of the past as the present.

Here are the different ways dementia can affect people.

### Perceptual skills

- ▶ Think about being in a crowded, noisy room where there are many things going on around you. There is lots of information entering your senses and it can be hard to work out which pieces of information are important. You use your perceptual skills to help work this out. Your brain filters out the information you do not need and lets you concentrate on the information you do need. For someone with dementia, this becomes hard to do, and can result in a person becoming agitated, worried, upset and restless. They may not be able to concentrate on a task for long; their attention may be caught by other things going on around them; or they may just forget what task they were doing. They may also be at risk of wandering into an unsafe area.

### Behaviours of concern

- ▶ People with dementia may have forgotten how to act appropriately around others, or in public. The people they meet may laugh at them, or be shocked or offended by their behaviour – they may even try to tell them off or call the police if their behaviour is offensive. Some examples of behaviours of concern include chatting in a familiar way with a complete stranger; talking to, hugging or patting children they don't know or yelling at or abusing strangers or objects.

### Anxiety

- ▶ Many people with dementia become anxious when they are away from their familiar environment. They may cry, yell, ask repetitive questions or ask for help from strangers. This can be upsetting and difficult for those trying to help the person, and those approached by them, especially when they don't know who the person is, what is wrong with them, where they live and so on. It can be frightening for children to see a person with dementia who is anxious and distressed.

## Effects of dementia

Dementia may have distressing psychological effects that impact both the person with dementia and the other people involved in their life and care. Psychological effects may include confusion, aggression, anxiety, delusion and hallucinations. The person with dementia may think of the past as the present. Some often require support 24 hours a day and may become disorientated and lost when they are away from their familiar environment.

A person with dementia may also experience grief and loss upon diagnosis of the condition and throughout the progressive stages of the dementia.

Here are more ways dementia can affect people.

### Dependence

Many people with dementia rely heavily on an informal carer to support them. They may wander at night or they may follow their carer around all day. They may call out as soon as the carer is out of sight. This can be exhausting and frustrating for the person caring for them.

People with dementia may also form dependence on strangers when they see a helpful or friendly face. They may assume the person knows them and ask them for help. This can be very difficult for the person approached; they may not know who they are, what is wrong with them or where they live. A person with dementia may also become too trusting of strangers, and come across people who are unhelpful or harmful. They may take their money, or other valuables, or take advantage of them in other ways.

### Disorientation

People with dementia can become lost when they are disorientated. Many family members are surprised at first, when a person with dementia becomes lost driving or walking a very familiar route. People with dementia can get lost in shopping centres or other buildings, even when with their carer or a support worker. They may wander away and be unable to find their way back to a familiar landmark or face. This can be very dangerous, as the person with dementia will not know how to get help to find their way back. They may enter dangerous areas, cross busy roads or fall, and become distressed, anxious or display aggressive behaviour.

### Grief and loss

In the early stages of dementia a person may feel grief and loss at their diagnosis and the loss of their abilities and independence associated with their symptoms. As the dementia progresses they may not be able to express their feelings of grief and loss and instead respond with frustration, anger and aggression. You may be able to reassure and comfort a person by talking about their fears, emotions and preferences for the future. As the dementia progresses, enabling the person to participate in activities of daily living and things they enjoy may ease their sense of loss. Towards the end stage of dementia it is important to identify strategies that allow you to connect with the person, acknowledge their story and show your support.

## Impact on the community

Dementia may also have an impact on the wider community. Many people with early to moderate dementia may still live at home, alone or with family. They may still participate in activities in the community, go to the shops, drive a car or use public transport. The people they encounter in the community may not be aware that they have dementia. They may not understand why they are behaving the way they are. They may be surprised, frightened or offended by them. Some may even try to take advantage of them. Some of the impacts of dementia on the wider community may include inappropriate behaviour, anxiety, dependence on others and disorientation.



## Support the individual needs of people with dementia

When providing care and support to people with dementia it is important to ensure that your approach matches the needs of the person. You cannot use the same approach for providing care to every person. Remember that you should look at the person first and the dementia second. Each individual you provide care to has a unique combination of history, life experience, knowledge, family, culture and religion. They will have different likes and dislikes; different things that make them happy or distress them. They may display different behaviours in response to the same set of circumstances.

### Identify individual needs

The needs of an individual with dementia may include their need for: support with activities of daily living, social activity or their need to be alone; fulfilment of their religious responsibilities; observance of their cultural traditions; physical contact; reassurance; and encouragement. The needs of an individual with dementia may in turn change as their dementia progresses. This is related to the changes in their memory, skills and abilities. Here is some more information about individual needs.

#### Individual needs



#### Memory

A person may experience more distress in the mild to moderate stages of dementia when they are more aware of the difficulty they are having remembering names, faces and recent events. They may need additional support, reassurance and understanding during this period. As their dementia progresses their awareness of this may decrease, making this less distressing for them.



#### Personal hygiene

A person's ability to maintain their personal hygiene will decrease as their dementia progresses and they will require more support as they become less able to care for themselves.



#### Social activities

A person's need for supported social activities may increase as their dementia progresses and they are less able to participate in social networks.



#### Language

A person who speaks English as a second language may begin to forget how to speak and understand English, and return to their native language as their dementia progresses.

## Plan your support

When planning how support will be delivered to an individual with dementia, consider a range of factors that will inform the best way to provide care to meet their individual needs. These factors must be discussed with the person, if they are able, or their family or carer so their needs can be met.

Factors to be considered include:

- ▶ the stage of dementia and the effect on the person
- ▶ family background and circumstances
- ▶ social history and support network
- ▶ employment history or career
- ▶ current and past language skills
- ▶ cultural and religious background
- ▶ level of education
- ▶ personal likes and dislikes.

## Develop a plan to meet needs

Each person you provide care to will have been assessed by a range of different professionals. The service you work for will have completed an assessment of the person's needs and developed a plan for meeting these needs. This plan will be documented as a care plan or service plan and will provide information about the person's needs, the ways they are to be supported, and information about their skills and preferences.

### Example

#### Interpret the individualised plan

Here are three examples of how to interpret an individualised plan for a person with dementia.

##### Parkinson's disease

Molly is a 70-year-old lady with Parkinson's disease who lives in a care facility. She has difficulty with movement, severe tremors and dementia. Molly can become very confused and aggressive when she is upset. The facility has a person-centred support plan to meet Molly's individual needs that include playing the music she enjoys to sooth her when performing daily care; hanging up pictures of her dog, family and carers in her room to create familiarity; and by calling her 'Mol', the name used by her close friends and family. The plan also directs carers to give Molly extra time to follow instructions and to only use single-step cues to prevent confusion and distress.

##### Alzheimer's disease

Len is a 67-year-old man with quite progressed Alzheimer's disease who lives in a care facility. Len can no longer express himself with words or actions and relies heavily on care support to perform all his activities of daily living. The staff at the care facility worked closely with Len's family to develop an individual plan to meet his needs. Len was always been an early riser who follows a regimented routine since his service in the army. He is distressed by sudden movements and loud noises. Together with details from the family, the carers are able to re-create Len's routine by getting him up first in the morning and following the order of his usual grooming and self-care. The workers also know to speak slowly and softly around Len and not to make sudden movements.

### Frontotemporal dementia (FTD)

Jack is an 80-year-old man with FTD who lives in a care facility. Jack has always been a very outgoing and sociable man who was always heavily involved in club activities. Unfortunately the FTD has affected the way Jack behaves in social settings, often causing him to make inappropriate sexual comments towards female residents and staff. The workers at the facility have had several training sessions about appropriate communication and responses to Jack's behaviour. Where possible, Jack is cared for by male staff members for showering and dressing. The facility also provides opportunities to participate in many activities with the activities staff who know how to interact with Jack. They have also restructured one of the games afternoons to have a male chess club like the one Jack use to attend, while the females play each other in another section of the activities room.

## Practice task 2

1. What are the neurological diseases that are commonly associated with dementia?

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2. List at least two common symptoms of dementia.

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3. What are the effects of amyloid plaques and neurofibrillary tangles in people with Alzheimer's disease?

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**Click to complete Practice task 2**

# 1C Identify and address the person's needs for a stable and familiar environment

The physical and social environment of your workplace can work together to meet the needs and abilities of people living with dementia. A dementia-friendly environment is one where the social and physical design eliminates unnecessary dependence and promotes self-sufficiency and choice, wherever possible. For those living with dementia, their physical surroundings and social interactions are strongly related and both very important.

Social and physical design should address a person's need to feel:

- ▶ comfortable and empowered
- ▶ attached and like they belong
- ▶ included and part of a group
- ▶ engaged and that they contribute socially
- ▶ individual and valued for their unique life story.

## The environment

Every aspect of the environment will generally affect a person with a form of dementia. It will affect how they feel, how they act, their skills and their communication. Having dementia can be likened in some ways to having 20 people talking to you at once, some of them in different languages. People with dementia often cannot filter out the sounds and happenings that they do not need to pay attention to; every stimulus (for example, sound, movement, thought, action) is given the same attention, meaning that the person cannot focus on a single thing, such as a conversation or task.



It is important that each aspect of the person's environment is monitored and managed as much as possible to give them the best opportunity to respond to those stimuli that are important and to cause them the least amount of confusion and distress.

## The physical environment

Support may be provided to a person with dementia in a range of environments. The person may be living in their own home; have moved in with other family members; live in an aged care facility; be supported in a day centre; or taken out into the community. Understanding the way in which environmental factors may be distressing or confusing to each individual with dementia will assist you in managing and monitoring their physical environment so they can be as safe, relaxed and comfortable as possible.

Here are some ways to manage different physical environments to provide for a person with dementia.

## Aged care home

Managing the environment in an aged care home:

- ▶ Use subtle security to prevent people with dementia wandering from the facility, such as keypad locks on doors, security fences and door alarms.
- ▶ Have walls and furnishings in soothing colours and textures, uncluttered spaces to prevent tripping and confusion, and control noise levels.
- ▶ Ensure each resident's name is on their door so people with dementia can find their own room easily.
- ▶ Restrict entry to areas such as kitchens and laundries where a person with dementia may injure themselves.
- ▶ Restrict access to chemicals and medications.
- ▶ Have circular hallways so people with dementia can walk around without feeling 'locked in'.
- ▶ Include domestic or homelike settings with furnishings that suit the clients' generation, and encourage people to have familiar items such as photos and ornaments in their rooms.

## Home environment

Managing the environment in a person's home:

- ▶ Declutter the home to prevent tripping and confusion.
- ▶ Reduce unnecessary or preventable noise.
- ▶ Use signage to prompt or direct the client.
- ▶ Ensure familiar or comforting objects, such as photographs, are prominent.
- ▶ Remove or disable items of danger to prevent the person with dementia using them; for example, irons, microwaves, ovens/hotplates.
- ▶ Install subtle security features.
- ▶ Create safe outdoor access.
- ▶ Keep dangerous chemicals and medications locked away and out of sight.

## The community

Managing the environment in the community:

- ▶ Avoid crowded, busy or noisy venues.
- ▶ Watch for trip hazards such as cracked paths, steps and loose stones.
- ▶ Take the client to familiar places.
- ▶ Ensure you can see the client and they can see you at all times.

## The social environment

The social environment of the person with memory support needs can also significantly affect their wellbeing and the provision of their care.

People with dementia become less able to independently maintain their social environment and social connections. Social connectedness is closely related to health and wellbeing, so it is important to help people with dementia stay socially connected as much as possible.

By designing daily life around a person's hobbies or pastimes you can often create opportunities for social engagement, pleasure and use of skills that are meaningful to them.

## The emotional environment

The emotional environment where support is being provided also needs close consideration when supporting people with dementia.

Here is some information about how a person with dementia may express their emotions.

### Unable to express emotions

People with dementia are often unable to control or express their emotions in the usual way. They may not be able to explain why they are feeling sad, angry or happy. It may be difficult for those around them to work out what has triggered a particular emotion the person with dementia is showing. Sometimes, a person with dementia may display an emotion that is inappropriate, such as laughing at a funeral. This can be difficult and embarrassing or upsetting for the person's family members and others around them.

### Excessive emotions

People with dementia may show inappropriate or excessive levels of emotion such as sadness, happiness, excitement, fear, anxiety and anger. They may also show appropriate types and levels of emotion in particular circumstances, such as laughing at a good joke, or crying about sad news. It is important to observe the situation to determine whether the level and type of emotion being displayed is appropriate for the event or situation.

## Manage emotional triggers

There are a number of ways workers can find out about the situations or events that may cause a person with dementia to become emotional. Assessments by health professionals and other workers may include information about the 'trigger'. Close family members and friends may also be able to provide information about triggers. Your own observations will also help you identify the types of stimuli or events that are likely to trigger an emotional response, and may best be avoided or at least planned for.

Be aware of these triggers and to try to manage the emotional environment of the person. Remember that even though the expression of emotion may appear inappropriate or excessive, the person with dementia is still feeling this level of emotion; it is very real to them, and they need to be supported and reassured accordingly.

To manage the emotional environment of a person with dementia you may:

- ▶ reduce conflicting or excessive emotional stimuli, such as music, television or other people who are emotional
- ▶ be aware of emotional triggers for individuals and minimise or avoid these situations
- ▶ provide continual reassurance in situations where the person becomes emotional
- ▶ take the person away if necessary, from the situation that is upsetting or over-stimulating them.

## Identify and address the person's needs

Here are three examples of how to identify and address a person's individual environmental needs.

### Aged care home

- ▶ Betty, an 85-year-old lady with dementia, lives in a care facility. She has always been a very active lady and now likes to wander around the facility. When Betty first came to live in the care home the staff had many complaints from other residents that Betty was coming into their rooms uninvited. Betty enjoys the company of others but becomes very distressed when there is too much noise around her.
- ▶ The care facility has adapted the environment to Betty's needs by:
  - having her name clearly labelled on her door
  - using the subtle security of a wanders tracking bracelet
  - shutting the doors of the residents nearby her room
  - taking Betty for walks outdoors with the activity staff whenever possible
  - making sure her hearing aids are turned down or off when she attends social activities, so she is not overwhelmed by the noise.

### Home environment

- ▶ Tony is a 65-year-old man with mild dementia who lives at home with the support of community services. Tony had a fall last year because he forgot to take his medication and became disorientated and confused and tripped over a mat in his hallway. After that event, Tony and his family decided that he was still capable of living at home if some support strategies were put in place. These strategies included:
  - decluttering the home to prevent tripping and confusion
  - placing signs around the home to remind Tony to take medicine and use his walking stick
  - arranging for the pharmacy to put his medications in a blister pack
  - disabling the oven and hotplates and instead arranging meals to be delivered or provided at the local day centre outing.
- ▶ Tony was a carpenter before he retired and has always enjoyed using his hands. Although he is no longer safe to use some workshop tools, there are simple woodwork tasks and finishing touches he can still perform. Therefore, his son has arranged for him to attend the Men's Shed where they keep a discreet eye on Tony and include him in activities that are safe and meaningful to him.

**The community**

- ▶ Joyce is 50 years old and has younger onset dementia. Joyce is living at home with some community support services and still enjoys doing her own grocery shopping with her granddaughter Rose. Rose has recently noticed that Joyce seems to experience anxiety, confusion and excessive emotions when attending loud crowded places. Joyce also often gets lost and disorientated and can become aggressive. To enable Joyce to continue to do her shopping Rose has structured their shopping trips to take place at a very quiet time of day, always at the same shop and always following the same routine and order as Joyce has always done. Rose has also noticed that by getting Joyce to push the trolley and walking besides her, Joyce is less likely to wander and feels more secure and calm.

## Practice task 3

Read the case study, then answer the questions that follow.

### Case study

Alexandra is a 68-year-old lady who has dementia. Alexandra lives in an independent living unit and last week started a small fire in her kitchen when she placed a cake in the oven and forgot it was there. Alexandra has had short-term memory loss issues for a few years now and becomes quite aggressive and verbally abusive when her family try to discuss management strategies with her. The family would like to enable Alexandra to stay in the unit as long as possible, but also recognise the need to address some of the environmental factors to make it safe for her.

1. What are some things Alexandra's family can do to make her unit safer for her?

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2. What are some ways that Alexandra's family can provide support to manage her emotional triggers?

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**Click to complete Practice task 3**

# 1D Recognise signs consistent with financial, physical or emotional abuse or neglect

People with dementia are particularly vulnerable to neglect and financial, physical and emotional abuse. Sadly, when faced with neglect or abuse, people with dementia are often unable to report it, or become too distressed and withdrawn to express their concerns and needs.

It is important that you understand the types of neglect and abuse that can occur to a person with dementia so you can prevent and report it.

Although often unable to express it, a person with dementia experiencing neglect or abuse may display the behaviours listed below. It is important to note that some of these behaviours are commonly associated with dementia and it is therefore important to pay attention to changes in usual behaviour patterns.

Behavioural signs of abuse may include:

- ▶ depression, withdrawal or lacking interest in things
- ▶ fear of one or many people
- ▶ shaking, trembling and crying
- ▶ worry, anxiety and avoidance of eye contact
- ▶ extreme changes in behaviour
- ▶ changes in sleeping and eating habits
- ▶ defensive postures and actions towards voice and touch.

## Neglect

If a person with support needs is neglected, either through intentional or unintentional acts, this means they are not being provided with basic necessities or the care and support they require. Here is further information about neglect.

### Neglect

Neglect includes:

- ▶ not providing enough food or drinks
- ▶ not providing an adequate level of care
- ▶ not spending time with the person – leaving them alone for prolonged periods
- ▶ inadequate provision of clothing or personal items
- ▶ unwillingness to allow for adequate medical, dental or personal care
- ▶ inappropriate use of medication; for example, overdosing a person so they sleep for longer periods of the day.
- ▶ leaving the person in the same continence aid for the whole day.

### Indicators of neglect

- ▶ Weight loss, dehydration, poor skin quality
- ▶ Person appears unkempt – same clothing worn every day of the week, loose or baggy clothing, clothing in poor state, hair unwashed, untrimmed nails, poor hygiene
- ▶ No dentures, hearing aids, mobility aids or glasses
- ▶ Skin burns from urine being in contact with the skin for prolonged hours

## Abuse

Abuse can be intentional or unintentional. Intentional abuse is when a person deliberately causes harm to the other person by depriving and/or hurting the other person. Unintentional abuse can occur when another person doesn't realise, through ignorance or other reasons, that their behaviour towards the person with support needs is abusive. An example would be when a primary carer hasn't had a break and is caring for someone with very high needs. If there is no one else the carer can call on, they can become very tired and resentful and not provide appropriate care as a result. They may not realise the impact their behaviour is having. This is still abuse and needs to be reported.

Here are some other causes of abuse.

### Causes of abuse

The primary carer may be stressed at home or at work

A person may be in debt and may steal from the older person

There is conflict, arguments and fights within the family

The older person is isolated and alone and the abuser thinks no-one will find out if they treat them badly

A carer may be using drugs or drinking too much alcohol and cannot care for the person properly

## Indicators of abuse

The importance of observation and getting to know the person you are supporting can assist in identifying indicators of abuse. When you know someone, you are more likely to pick up on changes in their behaviour. These changes may be a result of other things, as well as being an indicator of abuse, so it is important to check your assumptions before coming to the conclusion that a person is being abused.

Here are some indicators of abuse.

### Behaviour changes of a person with support needs

- ▶ A person may become withdrawn, depressed and anxious or display signs of being scared. They become quite ambivalent or non-responsive.
- ▶ You may find the person is becoming disorientated or making contradictory statements. (This of course can be a sign of a range of illnesses, so should be thoroughly assessed before making an assumption that the person is being abused.)

### Behavioural signs from the carer

- ▶ You may encounter situations where the carer makes lots of excuses so you cannot gain access to the person with care needs.
- ▶ The carer may be overly affectionate and flirtatious with the person, which may indicate an inappropriate sexual relationship.
- ▶ You may find the carer is giving conflicting accounts of incidents or is hostile towards the person with care needs.

### General indicators

- ▶ Changes in the person's health such as unexplained weight loss, bed sores, poor colouration, sunken eyes and cheeks
- ▶ Unexplained injuries or continual injuries
- ▶ Personal care needs are not being met, which can be indicated by dirty hair, dirty clothing, soiled bedding and unclean living conditions
- ▶ Medication is being used inappropriately, such as drugging the person so they sleep for longer periods of the day and night

## Physical abuse

Physical abuse is when a person is being physically assaulted. This can occur through physical acts of violence. Indicators may include physical pain or injuries. Physical acts of violence include, hitting, slapping, punching, pulling hair, spitting at the person, pinching, biting, twisting their arm or wrist, physical restraint such as being tied to a bed or chair, confining a person to a room or using objects to hurt the person (throwing rocks, using a strap). This abuse must be reported.

Indicators of physical abuse can include:

- ▶ bruises, cuts, scabs and scars
- ▶ abrasions, welts, rashes
- ▶ swelling, burn blisters
- ▶ agitation, cowering
- ▶ tenderness, pain, restricted movement
- ▶ broken or healing bones
- ▶ drowsiness
- ▶ unexplained weight loss
- ▶ unexplained hair loss.

## Financial abuse

This form of abuse is not always easy to spot. It can include a person's money, property or assets being mishandled or taken and used without their consent. It can be restricting a person's access to their own money, or requiring them to account for

how their own money was spent in minute detail. It can also include situations where a person with impaired cognitive abilities has given consent without truly understanding what their consent means. This abuse needs to be reported.

Financial abuse includes:

- ▶ embezzlement, fraud, forgery and stealing
- ▶ withholding money from the person or not paying accounts or debt
- ▶ forcing a person to change their will
- ▶ the enduring power of attorney refusing to provide enough money for the person to be able to live
- ▶ the enduring power of attorney refusing to provide money for the person to buy clothing or other required items
- ▶ forcing a person to hand over their money or assets.

## Psychological/emotional abuse

Psychological and emotional abuse is ongoing intimidating behaviour that is designed to disempower a person. Psychological and emotional abuse can be both verbal and nonverbal. It can include belittling, threats and withdrawal of affection. This abuse must be reported.

Here are some indicators of this form of abuse.

<b>Indicators of psychological/emotional abuse</b>
<p><b>Sense of hopelessness</b> Fearfulness, helplessness, withdrawal, reluctance to make decisions</p>
<p><b>Behaviour swings</b> Anxiety, anger, moodiness, agitation, depression, passivity, low self- esteem</p>
<p><b>Tiredness</b> Sleep deprivation, insomnia, confusion</p>
<p><b>Unexplained weight loss or gain</b> Change in appetite, increased alcohol consumption</p>

## Sexual abuse

Unwanted or uninvited sexual contact, language or exploitative behaviour by another person is sexual abuse. Sexual abuse includes sexual harassment, indecent assault and rape. This abuse must be reported.

Here are examples of indicators of sexual abuse.

<b>Sexual abuse indicators</b>
Withdrawal, disturbed sleep patterns, nightmares, agitation, fear
Unexplained difficulty sitting or walking
Bruising of genital areas or thighs
Unexplained sexually transmitted diseases
Unexplained bleeding from the genital areas

## Report abuse and neglect

You have an ethical and often a legal responsibility to report suspected cases of abuse and neglect. While mandatory reporting requirements in aged care are uniform throughout Australia, the requirements in other community services settings vary between states and territories.

According to the *Aged Care Act 1997 (Cth)*, ‘... if the approved provider receives an allegation of, or starts to suspect on reasonable grounds; a reportable assault, the approved provider is responsible for reporting the allegation or suspicion as soon as reasonably practicable, and in any case within 24 hours to ...’ (Section 63–1AA).

Aged and community services organisations will have procedures for workers to follow in situations where they find out or suspect that someone is being abused. This may include reporting to a supervisor, or to a state or territory department or to the police. Most organisations will also have documentation that must be completed, including case notes. Children, young people, frail older people and people with disabilities are particularly vulnerable to abuse.

Abuse in aged care services is referred to elder abuse. All adult victims of abuse have the right to report abuse issues or not.

### Example

#### Abuse and neglect

Jennifer works in an aged care facility as a support worker. Last week Jennifer noted that a resident named Jeff appeared frighten and withdrawn.

Jeff has quite advanced dementia and cannot respond to questions or requests. It is quite usual for Jeff to become confused and frightened, especially in unfamiliar and crowded places. However, Jeff is usually calm, engaged and easy to sooth in his own room.

When Jennifer goes into Jeff’s room to make him his usual cup of tea she notices that he won’t not make eye contact with her, is trembling, will not drink the tea and appears overly tired. Jenifer thinks Jeff may have just had a bad night sleep and is a little bit off because of that. However, when she notices that Jeff behaves like this all week, she suspects that he may be being abused.

Jennifer checked Jeff’s file and discovers that a distant relative had visited Jeff three times that week and that staff had noticed Jeff appear unsettled and distressed on those days. They had also found that Jeff’s lunch was untouched on those days and that his meal table had been moved out of his reach. There were also unusual bruises on Jeff’s shins and shoulders that staff had assumed were from an unwitnessed fall, but now appeared consistent with physical abuse.

Jennifer reports the abuse to management and directly to the police who advise that the relative has a criminal record for violence and recommends that the staff discuss with Jeff’s immediate family denying visitation rights to that person.

## Practice task 4

1. List at least two signs of physical abuse.

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2. List at least three signs of emotional or psychological abuse.

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3. List at least two types of financial abuse.

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**Click to complete Practice task 4**

## Summary

1. Your understanding of dementia will help you find the best ways to communicate and care for a person who has dementia, as well as those connected to the person such as their family, carer and friends.
2. Health professionals now use a social model of health that works from the expectation that, as far as possible, we should adapt the environment to enable people with dementia to participate in and access the community, rather than assume that their dementia is what is preventing them from doing so.
3. The cause of the dementia, the stage of dementia, how the dementia is affecting the person and their individual support needs should be taken into account when developing and interpreting a person-centred support plan for people with dementia.
4. The physical and social environment of your workplace can work together to meet the needs and abilities of people living with dementia.
5. There are a number of ways workers can find out about the types of situations or events that may cause a person with dementia to become emotional. Be aware of these triggers and try to manage the emotional environment of the person.
6. The expression of emotion in people with dementia may appear inappropriate or excessive; however, it is important to remember the person with dementia is still feeling this level of emotion; it is very real to them, and they need to be supported and reassured accordingly.
7. People with dementia are particularly vulnerable to neglect and financial, physical and emotional abuse. Sadly, when faced with neglect or abuse, people with dementia are often unable to report it, or become too distressed and withdrawn to express their concerns and needs.
8. It is important that you understand the types of neglect and abuse that can occur with a person with dementia so you can prevent it or report it, if necessary.

## Learning checkpoint 1

# Prepare to provide support to those affected by dementia

This learning checkpoint allows you to review your skills and knowledge in providing support to those dementia affected by dementia.

### Part A

1. What is dementia?

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2. What are some symptoms of dementia?

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3. What are amyloid plaques and how do they affect the brain of someone with Alzheimer's disease?

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4. What are neurofibrillary tangles and how do they affect the brain of someone with Alzheimer's disease?

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5. What are some symptoms of Alzheimer's disease?

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6. What is meant by the term vascular dementia?

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7. What is Huntington's disease and how does it affect a person living with the disease?

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8. What is Frontotemporal dementia (FTD) and how does it affect a person living with it?

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9. List two conditions that may lead to someone developing younger onset dementia.

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## Part B

Read the case study, then answer the questions that follow.

### Case study

Rhonda works in the community as part of a team that assists with showering people in their own homes. Thomas is an 88-year-old man with Parkinson's disease and moderate dementia. Thomas lives at home with support from Rhonda and some other home services. He has a son who comes over every evening to provide him with a hot meal and help him change for bed. Thomas has significant memory loss, becomes agitated by background noise, cannot express his emotions and is at high risk of falls. Thomas previously played violin in an orchestra, so he loves the sound of the violin.

1. How will establishing relationships with Thomas and his family help Rhonda to provide a person-centred approach to care?

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2. What are some ways that Thomas's family can tailor the environment to his needs?

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3. What are some ways that Rhonda can tailor her care approach to meet Thomas's needs and abilities?

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4. What are some things that Thomas's family and carers should consider when interpreting his individual care plan?

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5. What are five signs of moderate dementia that Thomas may display?

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6. What useful information could Rhonda share with Thomas's family about the motor and non-motor symptoms of Parkinson's disease?

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7. How can the physical and social design of Thomas's environment address his individual needs?

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8. How can Thomas's family increase his safety when they take him out into the community?

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9. What are some ways that Thomas's dementia may impact upon his ability to express his emotions?

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10. What signs and behaviours could make Rhonda suspect that Thomas was being neglected by his carers or family?

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11. What should Rhonda know and do about elder abuse?

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## Topic 2

In this topic you will learn how to:

- 2A Use verbal and nonverbal communication to maximise engagement**
- 2B Gain cooperation and provide reassurance by using reality orientation**
- 2C Use a range of validation strategies to relieve distress and agitation**

## Use appropriate communication strategies

Every person with dementia will have individual difficulties with communication as their symptoms progress. They may have trouble finding a word, make sounds and words that do not make sense, not understand what you are saying, lose the ability to read and write, or drop out of a conversation halfway into it. They may not be able to express the thoughts and feelings they are experiencing.

The body language, words, tone, gestures and communication strategies you use with a person with dementia will significantly impact on their level of distress and their quality of life.

When caring for people with memory loss you may need to repeatedly introduce yourself and orientate them to reality. For others, you may need to join them in their reality. There is no one strategy that suits everyone; instead, you will need to find out what each person's individual needs are and tailor your communication strategies to meet those needs.

## 2A Use verbal and nonverbal communication to maximise engagement

As a person's dementia and memory loss progresses, their communication and intellectual skills will deteriorate. The changes may start off small in the early stage of the dementia and progressively worsen as time goes on, until in the advanced stage of dementia a person may lose all ability to participate in and comprehend verbal communication.

The way that you communicate both verbally and nonverbally with a person with dementia has a big impact on their wellbeing and quality of life. Trial a range of communication strategies to identify what works best for each person.

Here are some things you should consider when using verbal and nonverbal communication with people who have memory loss.

### Verbal communication

When using verbal communication always talk quietly, use simple language and try to use short, clear sentences and single-step questions and requests. You may be required to raise the volume of your voice but never shout and always try to keep the tone of your voice both gentle and friendly. Be prepared to take your time with the person, rephrase things they do not understand and watch their facial expressions and body language for signs that they have or haven't understood you.

### Nonverbal communication

When using nonverbal communication make sure to use appropriate body language and touch. Smile at the person and think about how your position may influence the message you wish to get across; for example, standing over someone and looking down at them may be quite a frightening experience when you can't understand who they are and what they want from you. Always avoid sudden movements; use slow deliberate gestures. Appropriate non-sexual touch may be an effective cue, but you should always keep in mind a person's history and cultural background to avoid unnecessary distress. You may also find that using pictures and signs can be helpful; for example, hang a sign with the person's name and photo on their bedroom door.

## Communication strategies

Here are some communication strategies to maximise engagement when working with people who have memory loss.



### Manage the environment

To a person with dementia, a lot of background noise can feel the same as many people shouting at you all at once. It is easy for the person to become over-stimulated and distressed by the noise. Before communicating with them try to minimise other noise by muting the television, turning off the radio, closing the door to block out corridor conversations or the windows if noise from traffic, passers-by or lawn mowers can be heard.



### Check, maintain and use aids

A person with dementia may not be able to tell you if their aids such as dentures or hearing aids are not in or working properly. It is important to always check the care plan for any communication aids, ensure they are in correctly, regularly test hearing aids and check they are on before you try to communicate with them.



### Acknowledge their story

Get to know a person's life story so you can individualise the way you communicate with them. Always use their preferred name and avoid pet names like 'Darling' and 'Dear'. Use meaningful photos on memory charts and signs. Acknowledge their feelings and behaviours and allow them to express them. While you should try to minimise a person's distress, you must also allow them to express their distress. Be empathetic in your response to these feelings and avoid condescending comments, tones and gestures.



### Reassure them

Remember that although you may have provided care to someone many times before, to them it may seem like the first time. It is important that you use reassuring body language to put them at ease. Make sure you smile, give them your full attention, use eye contact, are mindful of how you are standing and ensure that you are not invading their personal space. You may find that you need to reassure them with appropriate touch, such as a hand on their shoulder or verbal soothing sounds and words such as 'You're ok' if they become confused or distracted.

## Example

### Verbal and nonverbal communication

Jacinta cares for her Grandma Lois who lives in an independent living unit. Lois has memory loss and can be hard to communicate with at times.

Last week Lois seemed more distracted and combative when Jacinta was trying to care for her. Jacinta couldn't understand why Lois was behaving so differently when she was doing exactly the same care routine they had always done together. It was almost as if Lois was not listening to anything she was saying to her.

Jacinta realised that perhaps she was not listening as her hearing aid batteries hadn't been checked in a while. When Jacinta tested them she realised that she was correct and the batteries were flat. Jacinta changed the batteries and also booked Lois in for her annual hearing test.

The hearing aid situation made Jacinta realise how important it was to have quiet to allow Lois to engage with her own care. Jacinta decided that before attempting to communicate with Lois, she would try to minimise other noise by muting the television, turning off the radio and closing the door to block out corridor conversations.

Jacinta also noticed that a gentle hand on Lois's shoulder and slow deliberate gestures also help to keep Lois focused on the care task at hand.

## Practice task 5

1. What are some important considerations when using verbal communication with someone with dementia?

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2. What acknowledgment and reassurance strategies could you use to maximise engagement when working with a person with dementia?

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[Click to complete Practice task 5](#)

## 2B Gain cooperation and provide reassurance by using reality orientation

Imagine you are sitting in your lounge room and a minute later a complete stranger is in your room, acting like they know you and pushing you into a bathroom, a room that you have never seen before, taking off your clothes, speaking in a language you don't understand and making gestures and requests that you can't follow. This situation would be very distressing. For many people living with dementia they may have this experience with everyday care routines and therefore find them very distressing to undertake. Their inability to remember things may mean they experience a moment like this many times over during a single episode of care as they repeatedly become disorientated to people, places, time and tasks.

You can help minimise the distress of people with memory loss by using reality orientation and other strategies to remind them of the day, time, place, occasions and important relationships.

The following strategies can be used to provide reassurance and gain cooperation when providing care to someone with memory loss.

### Orientate to relationships

- ▶ When communicating with a person with dementia you may need to repeatedly introduce yourself or someone else who is taking part in the conversation. Tapping name badges or gesturing to your uniform may help remind them of your role as their support worker. If a family member or friend is visiting, then showing old photographs of them with that person or retelling stories from their past that involve the visitor may help to remind them of the relationship.

### Orientate to day

- ▶ A person with dementia may need you to repeatedly remind them what day it is and of important events that will take place that day. Showing them a calendar, diary, memory chart or pictorials of important days, such as a cake or party hat to represent a birthday, can help to remind them of what day it is and the importance of that day.

### Orientate to time

- ▶ A person with dementia may need you to repeatedly remind them of the time and important appointments that will take place at certain times. Tapping your wrist to indicate time and showing them a clock or picture of the time, a calendar, diary, or memory chart with a time and appointment written on it, can help to remind them of what time it is and the important appointments they need to attend.

## Orientate to occasion and reality

- ▶ When providing care to a person with dementia you may need to repeatedly remind them of what activity or occasion is taking place and where they are. You may need to explain the activity and reinforce the purpose; for example, sometimes the use of signs and pictorials such as 'Today is shower day' and a picture of a shower can be useful in assisting the person to adjust to the idea of the activity. Related actions and gestures such as feeling the water temperature in the shower or patting a chair to indicate sitting may also be useful. Use of objects and tactile cues such as holding a face washer or a fork may also help to orientate them to the activity and encourage them to participate.

### Example

#### Provide reassurance

Here are two examples of using orientation strategies to provide reassurance and gain cooperation when providing care to someone with dementia.

##### Verbal communication

Sibella is an 80-year-old lady with moderate dementia who attends an activity at the local day centre once a week. On good days Sibella enjoys herself and chats with the other ladies at her lunch table. On not-so-good days she becomes disorientated and distressed. The support workers at the day centre find that by talking in a calm gentle tone and in short reassuring phrases such as, 'It's OK Sibella. You are at the day centre. Lunch will be here soon. Everything is fine', they are able to reorientate her to where she is and calm her down.

##### Nonverbal communication

Terry is a 90-year-old man who has Parkinson's disease and severe dementia. He lives in a care facility and requires assistance from support workers to get in and out of his chair, and to walk. Terry cannot follow verbal instructions to help him to stand. Sometimes he becomes distressed when workers try to help him get out of his chair. By putting his walker in front of him and purposely patting it, the workers can remind Terry what he is trying to do. Once standing, Terry becomes confused if the workers stand facing him and say anything, so instead they hold him and the frame and start walking a step in front so he can see the action and follow along.

# Practice task 6

Read the case study, then answer the questions that follow.

## Case study

Kathryn is a support worker and as part of her role she assists Mr Smith with showering and dressing three mornings per week. Mr Smith has advanced dementia and never recognises or remembers Kathryn.

Each time Kathryn provides care to Mr Smith she acts as if it is the very first time, taking time to introduced herself and ensure he feels comfortable around her.

Kathryn has a 'Today is shower day' sign and picture that she sits on Mr Smith's tray table before she goes to set up the bathroom ready for his shower. From the start of the task to the end Kathryn provides nonverbal cues to reorientate Mr Smith to his surroundings, such as a face washer in his hand or allowing him to see her test the water temperature and taping on her wrist to indicate it is time to finish.

Verbal communication tends to distress and confuse Mr Smith so Kathryn keeps it to a minimum and only uses his name, short reassuring phrases and soothing sounds throughout his care.

1. Why is it important for Kathryn to continue to repeatedly use reality orientation with Mr Smith?

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2. What are three reality orientation strategies that Kathryn uses to gain cooperation and provide reassurance to Mr Smith throughout care?

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**Click to complete Practice task 6**

# 2C Use a range of validation strategies to relieve distress and agitation

Sometimes it is more reassuring and appropriate to use validation strategies rather than trying to bring the person with dementia back to your reality. This method requires that you accept and acknowledge their reality and respond according to what they are seeing and experiencing. For example, a lady you are caring for is experiencing memories from the past and worrying about her husband driving home, even though he is long deceased. A validation approach would require that you acknowledge and empathise with the feelings that she is expressing and don't try to correct the belief that her husband is currently driving home.



Validating a person's current reality can develop empathy, acknowledge and allow their distress, build trust and their maintain dignity and self-esteem while creating a sense of safety.

## Example

### Validation strategies

Here are two examples of using validation strategies to relieve distress when providing care to someone with dementia.

#### Lost jewellery

Mrs Doncaster has moderate dementia and lives in a care facility. Mrs Doncaster often frets about missing jewellery and clothing that she has left in her room. She will repeatedly tell staff that someone is stealing from her and becomes agitated if they correct her. The support staff find that by taking a validation approach, Mrs Doncaster is comforted and feels cared for. They don't encourage talk of the theft but rather say 'How terrible! Well we'll make sure there is extra security for you then'.

#### Man outside my window

Mrs Claxton has early dementia and lives in her own home with support from her daughter Ruby. Sometimes Mrs Claxton is adamant that there was a man standing outside her window and looking in. Ruby does not try to correct her but reassures her by commenting, 'That must have been frightening. Don't worry, I will get your neighbour Bill to walk around and check the yard with me before I leave'. Ruby never needs to actually get Bill as her mother quickly forgets the event once the validation has relieved her distress.

## Practice task 7

1. What are two principles of validation strategies?

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2. What are some potential benefits of using a validation strategy with someone who has dementia?

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**Click to complete Practice task 7**

## Summary

1. As a person’s dementia progresses, their communication and intellectual skills will deteriorate.
2. The body language, words, tone, gestures and communication strategies you use with a person with dementia significantly impact on their level of distress and their quality of life.
3. When using verbal communication always keep your tone quiet, use simple language, and try to use short, clear sentences and single-step questions and requests.
4. When using nonverbal communication make sure to use appropriate body language and touch, smile at the person, think about how your body position may influence the message you wish to get across, avoid sudden movements and use slow deliberate gestures instead.
5. You can help minimise the distress of people with dementia by using reality orientation and other strategies to remind them of the day, time, place, occasions and important relationships.
6. Sometimes it is more reassuring and appropriate to use validation strategies rather than trying to bring the person with dementia back to your reality.
7. Validating a person’s current reality can develop empathy, acknowledge and allow their distress, build trust and their maintain dignity and self-esteem while creating a sense of safety.

## Learning checkpoint 2

# Use appropriate communication strategies

This learning checkpoint allows you to review your skills and knowledge in the use of various communication strategies to support people with dementia.

### Part A

1. What are some important considerations when using nonverbal communication with a person who has dementia?

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2. What are some reassuring communication strategies that can be used when caring for people with dementia to maximise their engagement?

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3. How can a support worker acknowledge the story of a person with dementia, to help maximise their engagement when providing care?

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## Part B

Read the case study, then answer the questions that follow.

### Case study

Aitor is a support worker who provides care to people with dementia. He currently provides care to two different men who both have moderate dementia.

Jim has limited ability to understand words and express himself. He often becomes disorientated and fearful of his environment and distressed by his confusion at his surroundings. Aitor can easily settle Jim by orientating him to people, place, time and task.

Ted communicates quite well with words and gestures but is frequently trapped in past memories and talks as though he still lives in a different place and time. Aitor finds it extremely hard to relieve Ted's distress as when he tries to orientate him to his own reality, Ted becomes aggressive, suspicious and even more distressed than he was to begin with.

1. What are some important things that Aitor should consider when using verbal communication with both Ted and Jim?

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2. What are five strategies Aitor could use to maximise Jim and Ted's engagement and cooperation in their care tasks?

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3. What reality orientation strategies could Aitor use with Jim to reassure him and gain his cooperation when providing care?

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4. What are some important considerations for Aitor to remember when using validation strategies with Ted?

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## Topic 3

In this topic you will learn how to:

- 3A Organise activities that aim to maintain independence**

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- 3B Organise activities that are appropriate to the individual**

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- 3C Ensure the safety and comfort of the person balanced with autonomy and risk-taking**

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- 3D Access information about the person's reminiscences and routines with family and carers**

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- 3E Provide support and guidance to family, carers and/or significant others**

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## Provide activities for maintenance of dignity, skills and health

Dementia is a progressive condition that gradually gets worse over time. The nature of the condition means people will lose skills and abilities, become more dependent on others for daily care and need more constant support and supervision. Support workers require a good understanding of dementia and the ability to be realistic about what to expect from someone with the condition. You need to match your expectations with the stage of dementia the person is in, as the way you work with people with dementia and the activities you provide can make a big difference.

# 3A Organise activities that aim to maintain independence

You can choose activities that will help people with dementia to maintain their skills and help them stay independent for as long as possible. You need to provide that suit the cultural needs of the person; find a balance between taking risks and safety; use activities to aid self-esteem and pleasure and lessen the impact of memory loss.

## Provide activities to maintain independence

It is part of best practice that you aim to maintain the independence of the people you support. It is important to remember you are working with people who have probably spent their whole adult lives being independent. It is often only in the latter part of their lives that they need extra support and help. This change can have a huge impact on the person, where they may feel they are no longer in control of their own lives and choices. For a person in the beginning stages of dementia, this can be very depressing.



Designing or planning activities that help a person with dementia stay as independent as possible, can help with how they feel about ageing and coping with dementia. It can also mean they feel more in control of their lives and choices.

## Types of activities

There are many types of activities that will help maintain a person's independence and exercise their physical and cognitive skills.

Here are some of the most common areas where activities can assist.



### Personal safety

Where possible, people with dementia should be involved in making choices about how to stay safe in the home, in the community or in an aged care facility. Activities may include understanding how to recognise dangers; learning what to do if danger is present; learning cooking safety; learning fire safety; understanding household security; reading evacuation plans; practising safe travel on public transport and understanding what to do if lost.



### Communication

People with dementia should be encouraged to communicate for themselves using spoken words, writing and body language. Activities may include learning to make reminder notes about important activities or dates; reading nametags of workers and using photos to help with choices about daily activities.

Attending activities run in their first language, if they have learnt English later in life, are also valuable.

If the person with dementia uses body language or signs to communicate, support workers should write about the possible meanings in the person's care notes.



### Mobility

When you are moving a person from one place to another, such as a bed to shower chair or a wheelchair to regular chair, they should be involved in the move. Activities may include using verbal and physical prompts to encourage the person to help with a transfer or movement and explaining what is happening using simple words and phrases.

Encourage physical strength and balance skills through exercise or physiotherapy programs and plan for a gradual loss of physical skills over time.



### Spiritual needs

The person with dementia can be encouraged to stay involved in religious or spiritual activities based on their individual likes and dislikes and background. Activities may include taking the person to a religious festival or regular religious events; reminding the person about religious activities that occur on particular days of the week; for example, church on Sunday.

People may not necessarily follow a religion but still need their spiritual needs met. You can find information about their spiritual needs in their care plans. For example, a person may wish to continue with their meditation practice every morning after breakfast.

## Activities for familiar routines

Many activities that help maintain independence centre upon the skills required to undertake activities of daily living.

Activities to help maintain skills that help people with familiar routines include those listed below.

### Eating and drinking

- ▶ People should be able to make choices about the food and drink they would like to have. Their likes and dislikes should be respected. Activities may include offering a limited number of choices based on your knowledge of their likes and dislikes; encouraging them to make choices; planning family-focused mealtimes or morning teas and involving them in setting the table, getting plates and cups ready, pouring drinks, making conversation at the table and clearing up after a meal.

### Undertaking personal hygiene tasks

- ▶ The person should be encouraged to maintain personal hygiene tasks such as bathing, toileting, brushing their teeth or caring for personal linen. Activities may include completing a task with the person; using visual prompts, such as a toothbrush, to remind a person about the task; doing the first part of the task for the person and then encouraging them to take over. Only provide the support that is required.

### Dressing and undressing

- ▶ Assist the person to make choices about the right clothing for the day according to weather, occasion, personal likes and dislikes and cultural background. Activities may include giving a choice of two items of clothing; doing the first part of the task for the person and encouraging them to do the rest; giving information about the weather through conversation, such as, 'It's a hot day today – we need summer clothes', and reminding the person about special occasions such as visitors, birthdays or outings.

### Grooming

- ▶ You can help the person make independent choices about hair care, shaving, make-up and nail care. Activities may include organising a hairdresser to visit, and making sure people with dementia are always well groomed according to personal likes and dislikes.

### Expressing sexuality

- ▶ Being able to express sexual needs and feelings in a socially acceptable way is an important part of being an independent adult. Options may include providing private places for couples; including photos of a person's partner, whether living or dead, in an album or book; and respecting privacy when needed.

## Choose familiar activities

Familiar means something you know very well or something you do often. You may find that people with memory support needs manage familiar tasks better than they do new ones. You can ask family members which tasks the person enjoyed doing in the past.

Using familiar tasks and items can help a person be more successful in their activities of daily living. They may also find these tasks more enjoyable. Often they will no longer have the language to tell you they are enjoying an activity, so you need to rely on other hints. Look at

whether they seem calmer or more relaxed; notice what has changed about their body language; and see whether they return to an activity by choice.



## Activities to enhance self-esteem

The activities chosen to assist people with dementia must be appropriate to the individual and help them to maintain independence for as long as possible in a safe environment. They must also have a meaning and purpose to them. In this way they will help the person's self-esteem and enjoyment of life.

Remember that dementia will often limit a person's ability to gain new skills and try new things. Activities should be focused upon the skills and interests the person has had in the past to optimise their confidence and sense of fulfilment.

## Activities that minimise boredom

Boredom in people living with dementia has been linked to an increase in other concerning behaviours such as anxiety, depression, wandering and aggression. Like any other type of care, one size does not fit all and you should individualise your approach to provide activities that minimise boredom in people with dementia.

Consider the following information.

When planning activities that eliminate boredom, consider:

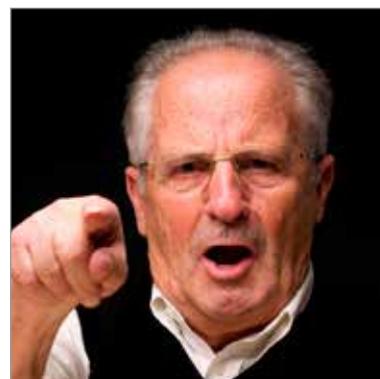
- ▶ the mood of the person
- ▶ meaningful activities that were of interest before the dementia
- ▶ appropriate relationships and connections
- ▶ behavioural responses to stimuli such as groups, loud noises and certain environments
- ▶ the use of music, dance and movement that doesn't require structured or sequenced responses.

## Activities to distract or eliminate behaviours of concern

Activities can be useful for distracting a person with dementia from any behaviours of concern and/or the psychological symptoms of memory loss they may have.

When planning distractions for people living with dementia it is important that you take into account the stage of the dementia.

In the early stages of dementia people can experience anger, frustration and grief from the awareness of their memory loss. Art, music and gardening can often be a good emotional outlet for these feelings and a way for a person with dementia to maintain a sense of identity and meaning.



In the mild to moderate stages of dementia, distractions that require cognitive skills can be used to keep the mind working and delay further decline. For these people crosswords, puzzles and problem-solving tasks can provide a great sense of pleasure, accomplishment and control.

Towards the advanced stage of dementia, distraction through sensory stimulation, such as the strokes of a hairbrush or patting a dog, can be a safe way to provide a sense of connection and pleasure.

## Plan for success

Before you plan the activity, think about how it will help the person's self-esteem and sense of accomplishment, as it is important that the person feels they are successful at doing a task. This in turn may reduce the person's frustration and confusion. Success means doing something and feeling good about doing it and about ourselves. It encourages us to try again.

We know we have succeeded at an activity by:

- ▶ the reaction of others
- ▶ what we did
- ▶ the result
- ▶ whether we feel we have completed all the steps
- ▶ whether we can remember how an activity felt the last time we did it.

## Successful activities

We can tell if someone else has felt success at an activity by looking at their body language, listening for comments they make and watching their facial expressions.

Planning for success means knowing what you have to do so the person with dementia will feel success when they do the activity. Always be aware of not setting the person up to fail in any activity. That is, make sure the activity is achievable.

Here are ways you can plan for success in activities.

### Plan for success in activities

You first need to understand the person's skills and work out how much of an activity they are likely to be able to do alone.

Work out how long they can concentrate for (this may only be a few minutes).

Think about which steps you will get the person to do. Have the person do the last few steps in an activity, as this is usually more satisfying for them.

Avoid activities with many steps, or ones that take too long to do.

Take into account the person's age. It is not acceptable to provide activities to do that are childlike for adults.

## Use purposeful and meaningful activities

There are many activities that are suitable for people with dementia. In aged care homes and some supported accommodation organisations, activities are coordinated by a worker whose sole role is to develop activities that are meaningful to people.

Meaningful activities are listed below.

The activities you choose will depend on:

- ▶ the specific stage of dementia
- ▶ goals listed in the care plan
- ▶ likes and dislikes of the person
- ▶ information given by family members or friends

- ▶ the degree of memory loss
- ▶ physical skills
- ▶ concentration span
- ▶ where the person is living (home or aged care setting)
- ▶ what sort of program you are working in.

## Activities in the home

Activities in the home include cleaning, shopping, preparing meals, doing minor repairs and washing, hanging out and folding clothes. Support workers may encourage the person with dementia to help prepare simple meals or set the table for dinner.

Showing by example works very well for home activities. Workers can start on a task and then encourage the person to join in. This often works better than giving verbal instructions, which can be confusing.



Joining in these activities can help avoid sundown syndrome, where people with memory support needs become agitated and restless in the late afternoon or early evening, or at sundown. People with a form of dementia may feel the need to be busy at this time. They cannot tell you what they are meant to be doing, but know they are meant to be doing something. Giving them something to do can avoid this distress.

## Personal management activities

Personal management activities include managing money, paying bills, answering letters or emails, organising activities in advance, attending to personal records and travelling from one place to another by a certain time.

Many people with dementia find personal management activities hard to do as they have lost many of the vital skills for managing their own lives. This may be an area where families have provided support from early on, and this loss of skills can be one of the first signs that someone has a form of dementia.

In many cases, it will not be your role to help with personal management activities. If you do, it is likely to be in simple areas such as opening and reading a letter to a person, or suggesting to a family member that new clothing is needed. Ensure you understand the policies of your workplace about handling money or opening mail.

## Social and recreational activities

Social and recreational activities include activities run in an aged care setting, as part of a community program, or to meet the individual needs for someone still living at home. Activities should be designed to suit the needs and skills of the person and should focus on activities the person has enjoyed in the past. They should be done in familiar places and take into account the person's cultural background.

Social and recreational activities include:

- ▶ doing craft and art activities
- ▶ going on social outings
- ▶ sharing a meal
- ▶ joining in a dance
- ▶ catching a bus to the shops or for morning tea
- ▶ sporting activities.

**Example**

**Activities to maintain independence**

Cheryl is a 55-year-old lady who lives at home and has recently been diagnosed with younger onset dementia. Cheryl's daughter Anna has noticed that since her mother's diagnosis she is expressing feelings of loss and helplessness.

Anna asked her mother's general practitioner Dr Scott what type of things she can do to help. Dr Scott explains that providing safe ways for Cheryl to continue to have choices and participate in activities was very important.

He suggests that at this early stage of dementia, Cheryl should be heavily involved in her care plan and could help Anna develop strategies regarding safety, establishing routines, memory prompts and social outings.

Anna discusses this with her mother and together they develop routines based on Cheryl's choices. These routines enabled her to participate and have some independence in eating and drinking, personal hygiene, dressing, grooming and attending social activities.

Anna subsequently notices that these activities help to give her mother back a sense of identity and control.

## Practice task 8

1. Why is it important to provide activities that eliminate boredom when caring for someone with dementia?

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2. What are some considerations when planning activities to increase self-esteem in people living with dementia?

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3. What are some examples of activities to distract from, or eliminate, behavioural symptoms of dementia?

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**Click to complete Practice task 8**

# 3B Organise activities that are appropriate to the individual

Part of your support role is to ensure that the activities undertaken with a person with dementia are appropriate to their particular needs, including reflecting their cultural likes and dislikes in order to support pleasurable memories.

When organising activities for a person, acknowledge their story and see them as individuals and not as the illness or symptoms. As you plan activities with and for them, keep in mind how culture, past interests and their capabilities may be used to address their needs and help them achieve a sense of self and self-worth.



## Activities for people from different cultural backgrounds

For people of some cultures, it may not be acceptable for men and women to socialise together. It may also be unacceptable for women to be out in public alone or to socialise with a male.

Here are some of activities you can plan for people from different cultural backgrounds.

### Singing or listening to music from a certain culture

- ▶ Music is especially useful for communicating with people who have dementia. Music from a person's cultural background can bring back happy memories of when they were younger. It can make them think about and remember their native country.

### Playing games that are traditional in some cultures

- ▶ People with dementia often feel more comfortable doing something they are familiar with and it can help with their self-esteem. Examples of games from particular cultures include bocce for people of Italian heritage; mah-jong for people of Chinese heritage; and bingo for those of English heritage.

### Celebrating special days, events or festivals

- ▶ Sharing other people's cultural customs is a positive and enjoyable experience. It is also a good idea to share these activities with people not from the same culture. Examples of such events are Chinese New Year, the German Oktoberfest and St David's Day (the Welsh national day). Activities may include decorating the activity area, organising carol singing or playing appropriate music.

### Sharing news from a particular country or region

- ▶ Reading about their native country in their first language may be soothing to a person with dementia. You may be able to obtain newspapers or magazines from family members.

### Sharing food or drinks that are traditional parts of a certain culture

- ▶ Eating food from your own culture is extremely pleasurable and can bring back many memories. Arrange for traditional food to be available on a regular basis or for special occasions. As with special days, it is a good idea for people to share different foods, but don't encourage this if you can see the person is not happy.

## Provide activities to suit the person's needs

Care plans provide you with the information about the specific needs of each person you support. They keep you up to date with information about their skills levels, as often the needs of people with dementia will change over time.

Here is some further information about providing activities according to need.

### Care plans and policies

- ▶ Care plans may need to be changed often so workers have the current information they need. The plans provide an individual approach to support for people with dementia. Make sure you check care plans regularly. Your workplace will have policies about how you care for people with dementia and there may be rules about getting people out of their rooms, or encouraging them to join in activities.

### Individual needs

- ▶ Although some activities may be offered as part of a group, it is still important that the activities have been planned to meet the needs of individuals. Much of the information you have about the person will have been put together by family members. They can explain who was important in the person's life and fill in details about places they have lived and things they have done.

### Cultural background

- ▶ Also think about the background of each person you support. They may have been born in another country. Understanding cultural background will help you plan for activities. Never assume that all people from one culture will like and dislike the same things. There may be things you should know about their background that will tell you what activities may suit them.

### Language

- ▶ Some people may have spoken another language before they learnt English. This is important to know because as people lose their language skills, they may be able to express their needs better in their first language. Language skills tend to be lost backwards, with the most recently learnt skills lost before earlier skills. Use an interpreter when needed.

### Likes and dislikes

- ▶ Plan activities to cater for the things the person enjoys and try to avoid activities that you know they do not like. Check the person's reaction to activities and never force people to participate if it is clear that it is causing them distress.

## Social devaluation

Social devaluation is a term used to describe the way those who are seen by others as 'different' can be grouped together and considered of less value than others.

Social devaluation can lead to people with dementia being badly treated by people and communities.

Here is some information about the effects of social devaluation for people who have dementia.

The effects of social devaluation include:

- ▶ feeling rejection by family, friends and society
- ▶ experiencing a loss of control over one's own life
- ▶ losing social connections and relationships
- ▶ losing natural or freely given relationships
- ▶ substituting artificial or 'paid for' relationships rather than developed ones
- ▶ feeling like a stranger in their own environment
- ▶ feeling a sense of worthlessness, self-dislike or despair
- ▶ feeling insecure
- ▶ being aware of being a burden or source of distress to their loved ones
- ▶ withdrawing from human contact
- ▶ becoming angry.

## Minimise social devaluation

Try to prevent or minimise the social devaluation of people with dementia, by facilitating their participation in socially valued roles. This can be done by focusing on the person's abilities and competencies and finding ways for them to use these to remain socially involved and connected.

Knowing about the effect of the social environment on the person with dementia can help you plan how you will provide support and care for them. Focusing on the person, their skills and their social history will help you plan ways for them to maintain their social networks and connections and participate in socially valued roles.

Here are some examples of strategies to address social devaluation.



### Cooking

Encouraging a person with dementia, who has always cooked the family meal, but can no longer do so safely, to participate in those aspects they can safely do, such as meal planning, peeling vegetables and setting tables helps them to remain socially involved.



## Volunteering

Assisting a person who has volunteered in a community setting to maintain this role by finding tasks they can do, partnering them with someone who can monitor and support them, and facilitating understanding among those they volunteer with in focusing on their abilities, rather than their dementia, helps them to remain socially involved.

## Activities to enhance image

You may need to address the social devaluation of people with dementia, through competency and image enhancement. Image is concerned with a person's sense of self and self-worth. Often the loss of independence and ability to communicate will erode a person's sense of self.

Enhancement of competency and image is achieved through validating a person's sense of self, enabling them to present themselves the way they want to and focusing on positive attributes to reduce shame and embarrassment.

Activities that enhance image should take into consideration:

- ▶ that everyday life activities can strengthen identity
- ▶ the importance of how an environment makes a person feel
- ▶ that appearance can increase self-esteem and feelings of wellbeing
- ▶ the importance of appropriate language and communication
- ▶ the role of discrete supervision and assistance
- ▶ that self-care activities can create a great sense of meaning, comfort and purpose
- ▶ ways that a task or environment can provide opportunity for participation.

### Example

#### Individualised activities

Here are three examples of individualising activities to meet a person's needs.

##### Care plans and policies

Jill works at a care facility as a support worker. Her workplace has policies and care plans to support the needs of people with dementia who live at the care facility. The policy and plans address the importance of identifying and providing for the person's individual needs, taking into account special consideration of the environment, communication and provision of activities to allow the person to participate and have a sense of identity, value and social connection.

##### Cultural background

Arnold likes to individualise activities to a person by acknowledging their cultural background and celebrating special holidays, events and festivals. One of the ladies he provides support to is from Irish heritage. On St Patrick's day Arnold wears all green and hangs up a banner with four-leaf clovers on it that says, 'Happy St Patrick's Day' in her room.

**Likes and dislikes**

Emily runs activity programs for people with dementia. She is aware that one size does not fit all and what one person may enjoy another will be distressed by or just not interested in. For this reason Emily carefully watches the reactions of the people attending her activities. She never forces anyone to participate, but she does subtly adjust activities to meet individual needs within the group.

## Practice task 9

Read the case study, then answer the questions that follow.

### Case study

Po-Shun is an 80-year-old Taiwanese migrant who lives in a care facility. Po-Shun has been called Pete ever since he moved to Australia 40 years ago. On arrival to Australia he quickly learnt how to speak in English and was fluent in the language for most of his life. Po-Shun has vascular dementia and as part of the condition is losing his memory.

Sonia is a support worker who has worked with Po-Shun for the past three years. In the last two months Sonia has noticed that he will no longer respond to being called Pete and can become upset and agitated when referred to by that name. His understanding of English has also rapidly deteriorated and he has reverted to speaking his native language.

Sonia is concerned that Po-Shun's current care plan no longer meets his needs and that he is at risk of social devaluation unless appropriate cultural considerations are made.

1. What are some ways that the care staff can use Po-Shun's culture to acknowledge his life story and make him more comfortable?

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2. What are five potential effects of social devaluation if Po-Shun's needs are not met?

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3. What should Sonia take into consideration when planning activities to enhance Po-Shun's image and competency?

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**Click to complete Practice task 9**

# 3C Ensure the safety and comfort of the person balanced with autonomy and risk-taking

When providing care for a person with dementia you will constantly be challenged by the balance between respecting the person's rights and managing the risk associated with the activities they wish to participate in.

On one hand, the person has a right to autonomy and you need to respect their choices and wishes; but on the other hand as a carer you also have a duty of care to keep them safe. The relationship between autonomy and managing risk will also change throughout the dementia progresses and as the person's ability to make decisions diminishes.



There is no concrete rule that sets out how to achieve a balance; you will need to find this balance individually with every person you work with, and to take a person-centred approach to the individual's care. By talking to the individual and their family you can develop a care plan that optimises participation and quality of life while keeping the person safe throughout the progress of their dementia.

## Your duty of care

As a support worker, you have a duty of care to the people requiring support, which means you are responsible for their care and safety. Duty of care is a legal term that covers what you do, what you report and the decisions that you make. Your decisions about how you provide care must be the same as the decisions any reasonable adult with your level of training and skill would make in the same situation.

## Negligence

Duty of care also relates to negligence, where if breach your duty of care to a person, you may be found negligent. This means you have not provided reasonable care to the correct standard and as a result a person may have been hurt in some way.

To prove you have been negligent, it must be found that:

- ▶ you owed a duty of care to the person at the time
- ▶ you breached (stopped or broke) your duty of care
- ▶ the injury or incident was a direct result of you not upholding your duty of care.

Your workplace will have a policy that explains your duty of care. Talk to your supervisor if you have any questions.

## Understand risks

Helping people to maintain independence is an important part of your job. But what happens when independence puts a person with support needs at risk? Do they still have the right to their independence, even though they may get hurt?

The rights of people to dignity and choice, upheld in legislation and service standards, requires that duty of care or safety is not used to limit a person's freedom or personal choice. A manager's adherence to duty of care and safety must be coupled with the concept of dignity of risk, which means that a person has the right to make their own choices and to take risks, as long as they are able to understand the risks.

All people requiring support have the right to self-determination, to make their own decisions, and to act independently, even if their actions involve an element of risk; however, this can be a grey area regarding people with dementia who are unable to fully understand any risks involved.

Understanding the risk and doing something independently can be difficult for someone who has a dementia as they are not always able to judge situations well. They may not notice all the things in their environment that could be a risk, or remember how a risk may adversely affect them. Therefore, people with dementia are not always able to make sound decisions related to their own safety. They may start a task and then move on to something else, forgetting about the first task. This could be very dangerous; for example, a person may leave and forget about a pot cooking on the stove top and it may catch fire.

Wherever possible, allow the people in your care to be independent. Consult their care plans and about what they are safely able to do, and always seek advice from your manager if you feel a person may be at risk of harm.

## Learn from risks

Risk taking is often a part of learning when we try out a new activity. We may have the risks explained to us or discover them along the way. We then remember what the risks are and can take steps to manage them. By managing the risks we reduce the chance of harm to ourselves and others.

People with dementia may not have the ability to learn or remember about risks. They may not always make good choices about risks they may wish to take – or even realise a risk is present at all. Each situation may seem new to them, so they may not know that there was a risk when they did an activity the last time. They will be facing a set of risks that are apparently new and unknown to them.



## Types of risks

There are many risks that may apply to someone with dementia. Some risks become more of a problem as dementia progresses, while others exist just because a person has lost some of their abilities. You need to make sure that all the planned activities balance the person's independence with their safety, as described below.

How you handle each situation of possible risk will depend on:

- ▶ your knowledge of the person, their skills and level of dementia
- ▶ your workplace policies and procedures
- ▶ past experiences (if any) of working with that person
- ▶ your judgment about the level of injury or harm that may occur as a result of the activity
- ▶ instructions from your supervisor
- ▶ information written in the care plan
- ▶ requests made by family members or advocates regarding the person's care.

## Reduce risks

There is a lot you can do to reduce the risks to the safety of a person with dementia. Often just being there is enough to reduce risks. There are also some strategies you can put in place to reduce or eliminate risks. Your ability to use your observation skills and judgment can also help to greatly reduce the risks to people with support needs.

To reduce risks you can:

- ▶ act straightaway if there is a problem
- ▶ offer tips about what to do next in a task
- ▶ remind a person about what they were doing
- ▶ finish off tasks that have not been completed
- ▶ make sure an area is safe before you leave
- ▶ remind them about the risk in doing the task.

## Common risks and dangers

A person with dementia will increasingly encounter risks as their dementia progresses. Here are some common risks the person may encounter in the community.

### Finding their own way

- ▶ In the early stages of dementia, the person may have trouble finding their way in unfamiliar places. As the condition progresses, they may become lost in known environments. The person may wander away, or go looking for a person or place that is familiar to them. People who are likely to wander from home need to have personal information and emergency contact numbers in their pockets, on bracelets or in their wallets/purses.

### Staying safe in traffic

- ▶ The person may become confused by lots of noise and fast-moving objects. They may not be able to judge speed and direction. To manage this risk, ensure the person is not put in a situation where they have to negotiate traffic alone. This means ensuring they are supervised when near streets or roads.

### Wandering or roaming about

- ▶ People with support needs tend to wander, especially if they are agitated, confused or upset. This may happen at a certain time of day, such as the late afternoon, or when things are stressful. It can assist to have calm but focused activities at times when a person is likely to be most confused or wander. Activities can include reminiscence, music and other tasks that focus on the person's state of mind at these times.

### Recognising dangers

- ▶ Sometimes situations happen that require a quick response. Examples include house fires, car accidents, injuries or falls, or a sudden serious illness. People with dementia may not be able to judge a dangerous situation well, or they may realise there is a danger, but not know how to respond. They may know they have to call someone, but by the time they reach the phone they will have forgotten who. Have a list of emergency phone numbers by the phone, or pre-program numbers into their phone. Providing emergency call bells or personal alarms can also assist people to easily reach emergency assistance.

### Recognising the safety of others

- ▶ The behaviour of people with dementia may not only put them at risk, but may also present a risk to the safety of others. A person with dementia may cause a fire in a facility where others are present; they may leave items in the way of others; or they may behave in a manner that may injure or harm others. It is important to manage or minimise these behaviours to prevent harm to others.

## Risks and dangers

There are also a number of risks for the person with dementia in their own home, as described here.



### Food safety

People may forget how to safely store and prepare food and drinks. They may leave items out of the fridge for long periods, or keep items well beyond their use-by dates. They may eat food that is uncooked, or has been prepared in an unsafe manner. They may try to eat or drink things that are not food. They may forget to eat or drink enough for their own health.

Ensure food is regularly checked for freshness and safety, and that the person has access to regular healthy meals, such as through a delivered meals program.



### Water temperature

People may not be able to judge water temperature, or they may forget that they need to check it. They may enter the shower or bath when it is too hot, and get burnt. They may enter when the water is very cold, and become sick.

These risks can be minimised by ensuring that people are supervised when using hot water. It can also help to have temperature-limited hot water in homes and facilities to reduce scalding.



### Personal and home security

Memory and judgment play an important part in personal and home security. People may struggle to judge who is a 'safe' person and who is not.

Using signs to remind people about locking doors and windows, having self-locking doors and those that are always able to be opened from the inside, can assist in ensuring that people with dementia and their homes are kept safe.



### Appliance safety

There are many household appliances that can pose a danger. Examples include toasters, ovens, hotplates, kettles, blenders, air-conditioners, fans, fridges and microwaves. Used in the right way, these appliances make our lives easier. Used in the wrong way, they can cause electrocution, burns, cuts, food poisoning or fires.

People can be assisted to use appliances safely by having appliances with a cut-off switch or alarm if left on too long, and placing signage around to remind the person about the proper use of the equipment.

## Financial risks

People with dementia will become less and less able to manage their own finances as their condition progresses. This may begin with forgetting to pay bills, or whether they have withdrawn or spent money. Encourage the person and their family members to prepare for such events early, by setting up a financial power of attorney or other financial arrangements.

When providing support to people with dementia it is important to ensure they do not have significant amounts of money with them, and that they are monitored to ensure that they spend their money appropriately and are given correct change for purchases. Also be alert to the fact that other people may take advantage of their condition and try to steal from them or have their possessions signed over into their name.

### Example

#### Autonomy and risk-taking

Paul is a 67-year-old man with early dementia. He is still driving his car, and keeps telling people he knows he is having trouble with his memory, but as he only drives around his local area it is still safe. His wife knows that Paul has had a few minor accidents, but doesn't want to be the one who takes away his independence by telling him to stop driving.



A support worker meets with Paul and his wife and discusses the dangers of Paul driving and the risks he poses to others if he becomes confused or lost while driving. She talks to Paul about where he drives and what he would miss out on if he couldn't drive. Mostly, he says, he goes to the local shops and to his lodge.

The worker talks with him about the local community transport service that has a regular route that goes to the shops and past his lodge. The bus picks people up at their own homes.

Paul and his wife agree that if he is able to access these venues independently, by taking the bus, he would not feel such a great sense of loss in being unable to drive.

# Practice task 10

1. What are some risk considerations you should take into account when planning activities for someone with dementia?

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2. What are five common risks or dangers to people living with dementia?

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3. How can you uphold your duty of care by minimising risk to the people with dementia you care for?

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**Click to complete Practice task 10**

# 3D Access information about the person's reminiscences and routines with family and carers

People with dementia often enjoy thinking or talking about the past. They may also spend some time believing they are living in a different time or place and not fully understand where they are or recognise who the people around them are. People and places they have known earlier in their life become important to them. By helping and allowing people with dementia to reminisce you can improve their mood, sense of wellbeing and connection, and help them feel secure.



## Communication strategies

Reminiscence involves thinking about and reflecting upon past activities and experiences. At times, the person with dementia may actually believe they are still living in that period of their life.

To help people in your care to reminisce you may find using nonverbal communication strategies such as photographs, films, journal entries and tactile objects such as a seashell, can be useful in retrieving memories.

You may find verbal communication strategies such as asking someone to talk through their life events in the correct order, or describing a particular event in detail, are useful for memory retrieval in those with mild to moderate dementia.

Strategies or things to use in reminiscence are listed below.

Nonverbal strategies	Verbal strategies
▶ Holiday photos	▶ Describe a feeling
▶ Favourite films	▶ Describe an event
▶ Familiar music	▶ Talk about a relationship
▶ Family videos	▶ Describe a significant other
▶ Touching sand or grass	▶ List life events
▶ Significant smells	▶ Describe the impact of an event

## Frequent reminiscence

People living with dementia often feel overwhelmed by the environment and activities going on around them. New environments, people and experiences can confuse and distress them. As their memory loss increases, the people, places and things that were once familiar to them can be forgotten, become distressing and cause them to withdraw. Because of this it is often difficult for people to experience connection and meaningful social interactions.

As a support worker you can use your verbal and nonverbal communication strategies to frequently connect with people over meaningful events of their past. As memory loss tends to happen in reverse with the most recent experiences forgotten first, it is useful to draw on details from early in their life that family and friends can provide.

There are also activities such as developing a life journey book that can help increase the recall of memories and a sense of meaning and connection for those with dementia.

## Reminiscence activities

Support workers can help people with various forms of dementia by facilitating activities that focus on the past. These activities benefit the person's cognitive abilities. As long-term memories are the last to be forgotten by a person with dementia, reminiscence is a vital activity to help the person maintain their long-term memories for as long as possible. Here are examples of these activities.

Reminiscence activities include:

- ▶ singing songs or playing music from earlier times
- ▶ asking questions or using simple quizzes about the past
- ▶ making photo albums that use pictures from earlier in a person's life
- ▶ learning who the important people in the person's life were.

### Example

#### Reminiscences and routines

Gary is a 78-year-old man who lives in a care facility. Gary has Alzheimer's disease and can no longer remember the people, places and things around him. If he leaves his room he cannot find his way back. He becomes distressed and disorientated when people try to have conversations with him and constantly calls out for Edna, his wife who passed away 20 years ago.

Gary is often overwhelmed by the environment and activities going on around him. He cannot attend structured activities as he becomes agitated and wanders. Because of this it is difficult for Gary to experience connection and meaningful social interactions.

Darren, a support worker, has been trying to engage with Gary using nonverbal communication to try to connect with him over meaningful events of his past. Darren has pieced together details from early on in Gary's life and made a journey book of photos and information provided by Gary's family and close friends.

Gary has had many family holidays by the seaside and Darren has discovered that holding up seashells to Gary's ear and letting him hold them makes him smile and talk about his memories with Edna. Gary's mood seems to improve on the days that Darren sits by him and helps him to reflect upon his past.



# Practice task 11

1. What are some potential benefits of reminiscence for someone with dementia?

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2. What are some nonverbal communication strategies you could use to help someone with dementia reminisce?

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3. What are some activities that can help people with dementia to focus on the past?

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**Click to complete Practice task 11**

# 3E Provide support and guidance to family, carers and/or significant others

If a family member, spouse or close friend has dementia, it can have a very significant impact on your life. Being the carer for the person with dementia can be a 24-hour-a-day job. As a support worker part of your role may also be providing support to the family and friends of the person with dementia.

The term 'significant other' refers to a family member, spouse or friend who is close to the person, and who is involved in their care and wellbeing.

The term 'carer' refers to a family member or friend who provides unpaid care and support to the person with dementia. This may be a son, daughter, husband, wife, mother, father or a friend.

It is important that support workers are aware of the impact that dementia has on significant others, carers in particular, and that they try to help them in understanding the condition as much as possible.



## The effects on significant others

Here are some ways that dementia can affect significant others, how the significant other may behave, and what a support worker can do to help.

### Depression

A significant other may be withdrawn, quiet, not see friends and unable to provide proper care to the person with dementia.

Ask significant others how they are feeling. Suggest they take a break. Ensure they get a referral for respite and/or counselling.

### Loss and grief

As the person's dementia progresses, they may begin to seem less and less like the person their significant other has known, and may be unable to recognise their family and friends. Significant others may feel a sense of loss and grief. Carers may also feel a sense of loss and grief for their own lifestyle, which changes significantly with the progressive caring role.

Be available to listen to significant others, include them in family/carer support events and ensure they are referred for appropriate counselling and support.

### Anger

Caring for someone with dementia can be frustrating, especially when the person is repetitive or behaves in a dangerous way. Significant others can display anger or frustration by yelling, and sometimes in physical ways, such as hitting.

Ensure that the caring situation is safe for both the person with dementia and their significant others. Recommend the significant others take regular breaks from caring, through use of respite. If you are concerned about a situation, you can refer the person for counselling and support.

### Despair

Significant others can become overwhelmed with caring for the person with dementia and can feel despair at ever having their own life back, or at being able to provide proper care. They may display this despair verbally, through tears, or by being withdrawn.

Be available to talk and listen. Ask significant others how they are managing. Include significant others in carer support events where they can talk with other carers in similar situations. You may also refer them for counselling and support.

### Social embarrassment

Taking the person with dementia out in public and to social events can be embarrassing for significant others, if the person behaves inappropriately. Family members may become reluctant to take the person out, and may stop going to social events or public places themselves if they are unable to leave the person alone.

Ensure the family are aware of support services for the person with dementia and respite services that can give them a break. Talk with them about ways they could manage the person's behaviour, or explain simply to others why the person is behaving inappropriately.

## Effects of memory loss on significant others

Here are some more issues for you to consider, when providing support to significant others, regarding the effects of memory loss on them.

### Isolation

Caring for a person with dementia is a 24-hour job. This can prevent carers or significant others from participating in their own employment, social or family activities, and they can become isolated.

Ask significant others about activities they did in the past, and those they are currently doing. Explain to them the importance of maintaining their other roles, employment, social and other family responsibilities. Ensure they are aware of supports and services that can help them find time to participate in other activities.

### Financial difficulties

Caring for a person with dementia can be costly. Medical expenses, equipment, and loss of income due to decreased employment, can all affect the finances of significant others.

Family members may feel a sense of despair, anger or failure at being unable to cope with this financial burden.

Talk with and listen to significant others about the financial pressures their caring role may have. Ensure they are aware of financial supports that can assist them in their caring role.

## Example

**Family and carer support**

Providing support to significant others will assist them to maintain their caring role for longer. Here is a situation, the impact on the carer and how the support worker assisted her.

**Provide information and support to a carer****What is the situation?**

Kate, a support worker, regularly attends the home of Mrs Randwick to assist her with personal care. Mrs Randwick has dementia and lives with her daughter Judy. Lately, Kate has noticed that Judy doesn't mention having been out to work, with friends or with other family members. When she arrives some mornings, Kate also notices that Judy looks like she has been crying.

**What is the impact on the carer?**

Kate asks Judy about the job that she had. Judy tells her that she has had to take extended leave without pay from her job. She says this has meant that she can no longer afford to go out with her friends or take a break. She says her friends don't visit her much anymore as they are uncomfortable around her mother. Judy tells Kate that she is becoming depressed and angry about the caring role she can see no end to.

**What does the support worker do?**

Kate talks to Judy about these feelings and tells her about respite services that provide carers with regular breaks from caring and that there are also carer support groups, where she can meet with others in similar caring roles. She tells Judy she may be eligible for government payments to support her financially in her caring role. She provides Judy with the phone number for a local support service that can give her more information.

## Practice task 12

Read the case study, then answer the questions that follow.

### Case study

Jason is a carer for his granddad Walter, who has moderate dementia. Jason loves his granddad very much but taking care of him is getting increasingly challenging.

Last week when they went shopping together, Walter made loud and inappropriate comments about the weight of the lady in front of them in the grocery line. Jason apologised to the lady and felt very embarrassed by his granddad's behaviour.

Julia, Walter's daughter and Jason's mother, has noticed that Jason is struggling to cope with his granddad's progressive symptoms of dementia. He is starting to appear withdrawn and upset lately but won't talk about it because he feels guilty about his frustration with his granddad.

Julia is worried about Jason, so she speaks to Aaron, a support worker who assists with Walter's care needs, and asks him for help.

1. What are three ways that Aaron can support Jason and Walter’s significant others at this time?

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2. How can Aaron provide support to any of Walter’s significant others who are feeling isolated because of the round-the-clock care they are providing?

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**Click to complete Practice task 12**

## Summary

1. Help choose activities that will help people with dementia to maintain their skills and help them stay independent for as long as possible.
2. When providing activities to maintain independence you should offer ones that suit the cultural needs of the person; find a balance between safety and taking risks; use activities to aid self-esteem and pleasure and lessen the impact of memory loss.
3. The activities chosen to assist people with dementia must have a meaning and purpose to them. In this way they will help the person’s self-esteem and enjoyment of life.
4. Activities can be useful for distracting a person with dementia from any behaviours of concern and/or the psychological symptoms of memory loss they may have.
5. It is important to prevent or minimise the social devaluation of people with dementia by facilitating their participation in socially valued roles.
6. When providing care for a person with dementia you will constantly be challenged by the balance between respecting the rights of the individual and managing the risk associated with the activities they wish to participate in.
7. People with dementia often like to remember and think about past events. To help people in your care to reminisce you may find both verbal and nonverbal communication strategies can be useful in helping them to remember things from the past.
8. It is important that support workers are aware of the impact that dementia has on significant others, carers in particular, and that they try to help them in understanding the condition as much as possible.

## Learning checkpoint 3

# Provide activities for maintenance of dignity, skills and health

This learning checkpoint allows you to review your skills and knowledge in providing activities for maintenance of dignity, skills and health.

### Part A

1. What are some important factors that need to be considered when planning activities for someone with dementia?

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2. What are some examples of social and recreational activities that someone with dementia may find enjoyment in?

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3. What is social devaluation and how might it apply to people with dementia?

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4. What are three reasons that activities that enhance image and competency are important for someone with dementia?

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5. What is meant by 'the balance between autonomy and risk' when supporting someone with dementia?

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6. What is meant by 'duty of care' when working with people who have dementia?

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7. What are people who have dementia at higher risk of harm than people who don't have memory loss?

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8. Why might a family member caring for someone with dementia experience a financial burden?

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## Part B

Read the case study, then answer the questions that follow.

### Case study

Elizabeth is a carer for her close friend George, who has Frontotemporal dementia (FTD).

Elizabeth and George met through the bowls club 15 years ago and have had an ongoing friendship ever since. George lives just around the corner from Elizabeth so she is able to pop in and do things to help George out. Initially it started out with just a meal here or there, or helping with the banking or a little cleaning, but lately George has needed more and more help to the point where Elizabeth feels like she has no time for anything else.

George really wants to stay at home and can be quite abusive towards Elizabeth whenever she tries to talk about his future care needs. Sometimes she can still have a short conversation with him but at other times he doesn't remember who she is anymore.

George has recently started to need more physical help with showering and dressing. Elizabeth is able to discuss the need for increased support with George and he agrees to let her arrange for some help. Now Niles, a support worker, comes and helps George shower three days a week. Niles is also eager to support Elizabeth and helps set up activities to allow George to remain independent and socially engaged.

1. What are some ways that Niles can give George choices and independence through routine activities of daily living?

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2. What are some things that Niles should consider when planning activities to enhance George's self-esteem?

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3. What are some activities that Elizabeth could use to distract George from the behavioural symptoms of his dementia?

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4. What are some ways that Niles could individualise George's activities to meet his specific needs?

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5. What are five potential risks or dangers to George, due to his dementia, when he participates in activities?

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6. What are some verbal communication strategies that Niles could use to help George reminisce about events from his past?

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7. What are some reminiscent activities that Elizabeth and Niles could do to create frequent meaningful connection?

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8. What are some ways that George's dementia may be affecting Elizabeth?

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9. What are five ways that Niles can support Elizabeth in her role as a carer?

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## Topic 4

In this topic you will learn how to:

- 4A Identify behaviours of concern and potential triggers**

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- 4B Contribute to team discussions on support planning and review**

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- 4C Take action to minimise the likelihood and impact of behaviours on the person and others**

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- 4D Evaluate the implemented strategies to ensure effectiveness in minimising behaviours**

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## Implement strategies that minimise the impact of behaviours of concern

Managing the behaviour of people with dementia is a vital part of your work in community services. You may work with just a few people with dementia or you may work in a facility that specifically caters to people with dementia. People with memory support needs often display behaviours that cause concern to others. These are behaviours that present a 'challenge' to the people who may be affected by them, such as family, friends, carers, visitors or the person with dementia themselves. Support workers need to understand the cause/s of such behaviour, the effect behaviour can have on the person with dementia and others, and strategies or tips that can be used to manage the behaviour.

# 4A Identify behaviours of concern and potential triggers

Damage to the parts of the brain that affect mood, self-control and inhibition, as well as mood disturbances and psychiatric disorders, can cause people with dementia to act in socially unacceptable and frightening ways. This can include yelling and screaming for no apparent reason, being physically aggressive and repeating themselves. Behaviours of concern can be a source of distress for the person, their loved ones and others observing the person's actions. Prevention is the preferred response. When prevention is unsuccessful, workers and others need to implement strategies to minimise the impact of the person's behaviour.

## Needs-driven behaviour model

In the past, the treatment of dementia symptoms was based on a medical model where more and more psychoactive or sedating drugs were given to people with dementia who exhibited frightening or inappropriate behaviours.

Today's social model of health now incorporates working with the need-driven behaviour model, which looks at disruptive or problematic behaviours as messages, not symptoms, from the person with dementia. Each concerning behaviour indicates an unmet need and identifying and meeting that need should stop the disruptive behaviour and increase the person's quality of life.



The first step to understanding a person's unmet needs is to understand what is triggering their disruptive or problematic behaviour.

## Observe and document behaviours to identify triggers

Most people make choices with a full understanding of society's expectations and the consequences of their actions. This is not the case for people with moderate to severe memory loss and dementia who may not understand where they are, who they are talking to and the affect their behaviour has on others. If you keep this in mind, you will find it easier to cope when people exhibit common behaviours of concern.

Here is a description of some behaviours of concern.

### Physical aggression

- ▶ Physical aggression can be directed at people or property and can include hitting, pushing, shoving, biting, scratching, throwing things, and other violent attacks.

### Social withdrawal

- ▶ Some people with dementia become non-responsive. They do not interact with others. Social withdrawal can be a coping mechanism; however, ongoing social withdrawal can compound mental health problems.

### Verbal disruption and repetition

- ▶ Examples of verbal disruption are screaming, yelling, laughing, grunting and making other sounds that are loud and inappropriate. People may ask the same question several times. This is not because they didn't listen to your response. It is because they have forgotten that they have asked the question. Verbal repetition is known as echolalia.

### Resistance to personal care

- ▶ Lack of judgment and absence of insight are two key features of dementia. People may not be aware that they need personal care, such as a bath, and may react physically.

### Sexually inappropriate behaviour

- ▶ Examples of sexually inappropriate behaviour include masturbating in public, touching others inappropriately and exposing sexual organs.

### Refusal of services

- ▶ People may believe they have all the required skills to live independently and refuse to accept services in an attempt to maintain autonomy.

### Eating

- ▶ People may forget to eat, eat continuously, eat foods and other items that are toxic, and in severe cases, lose the ability to chew and swallow.

## Behaviours of concern

Common behaviours of concern refer to changed behaviour and behavioural and psychological symptoms of dementia.

Example of behaviours of concern can include those listed here.



### Socially inappropriate behaviour

As people move through the developmental stages of childhood, adolescence and adulthood they learn what socially acceptable behaviour is. They learn to modify and censor their responses to prevent causing offence. People with dementia lose sight of how their behaviour will affect others. As a result they may say things that are hurtful.



### Wandering or intrusiveness

People with dementia may not know where they are. They may try to escape from their home, an aged care home, wander into other people's rooms, search through other people's things or wander at night.



## Sleep disturbances

People's need for sleep decreases throughout the life cycle. Babies, for example, spend more time asleep than awake. The reverse is true for older people who spend less time asleep than awake. The quantity and quality of sleep in older people is reduced. Sleep issues are compounded for people with dementia may keep other people awake and may cause family members and others stress.

## Triggers for the behaviours

As dementia is a progressive disease, medical intervention cannot be applied to 'cure' the person. Instead, you can help by recognising any triggers (sometimes referred to as antecedents) and then treating their underlying cause.

Here are some triggers or antecedents for you to consider.

### Triggers or antecedents

1

#### Physical health issues

The person may have an infection, illness or other condition that is causing them pain and discomfort. If they can't communicate their discomfort, they may act out in attempt to signal their pain.

2

#### Emotional health issues

The person may be stressed and worried; they may have too little or too much stimulation; or they may have a mental illness such as depression.

3

#### Environmental stimuli

Particular stimuli such as light, sound, smell and temperature can impact on behaviour, as can the presence of other people, or the physical setting.

4

#### Task-related issues

The person may be attempting a task that is too difficult or they do not like.

5

#### Communication-related issues

The person may be unable to make themselves understood or may not be able to understand others. This can cause stress and frustration. People with dementia also have people they like as well as people they dislike. They may react badly in the presence of the people they dislike.

6

#### Personal history

Something unpleasant may have happened in their past that causes them to react violently when something happens to awaken the memory, such as a movie, music or a visit from a friend from the past.

## Document behaviours

There are so many possible triggers it can be difficult identifying the specific trigger that results in behaviours of concern. Documentation can be used to identify patterns of behaviour. Workers should record ongoing details in the person's progress notes as their condition and circumstances can change. Triggers should be detailed in the person's care plan as outlined below.

### Detailing triggers in the care plan

Describe the behaviour. Provide objective detailed information.

Be clear. 'Mavis threw a tantrum' is open to interpretation. 'Mavis raised both hands above her head while screaming' provides a clear description of what happened.

Describe when it happens. Establish if it happens after meals, early in the day, etc. to help you determine what the trigger/s are.

Describe where it happens. Does it happen in a crowded room, large open space or smaller space?

Describe what else is occurring at the same time. For example, does the behaviour always occur at the same time as another event?

## Impact of behaviours

The impact of behaviours of concern on the person can be physical, emotional and/or social. Other people may also be physically or emotionally hurt by the person's behaviour. They may find the behaviour disruptive and distressing.

Here is a list of the impact of the behaviour on the person and behaviours that impact on others.

Impact on the person	Impact on others
<b>Physical:</b> the person may harm themselves through skin rubbing, or may not eat and drink sufficient food and beverages to meet their nutritional needs.	<b>Physical:</b> other people may be physically hurt, or put in dangerous situations if they have to chase or find a person with dementia who wanders.
<b>Emotional:</b> insufficient food, vitamin deficiencies, lack of sleep and prolonged crying can cause and amplify mental health issues and mood disturbances.	<b>Emotional:</b> other people may become upset, angry and exhausted by the behaviours displayed.
<b>Social:</b> other clients may avoid the person. Family and friends may stop visiting to avoid being hurt.	<b>Social:</b> other people may change their routines or alter their lives to avoid certain situations, or the person with dementia themselves.

**Example**

**Identify behaviours of concern**

Beverley (Bev) is a 70-old-lady who lives with her husband Tim. Bev has dementia and sometimes her behaviour is socially inappropriate and frightening for those around her.



Last week at the grocery store Bev wandered off when Tim was doing their shopping. He was only distracted for a few seconds and when he looked up, Bev was gone. In a panic, Tim left his trolley and went off to find her. He had not gone far when he heard the shout of an upset woman. As he approached the source of the noise he found Bev and another lady fighting over the other ladies handbag.

He ran over and apologised to the lady explaining that Bev was not having a good day and did not know what she was doing. He tried to calm Bev down but she burst into tears and began loudly accusing him of stealing everything she had and hiding all the money from her. Tim was so embarrassed and assured the bystanders that it was not true and that she was not herself today.

When Tim discussed the event with Carol, a support worker, she explained that there could be many possible triggers for the behaviour. She suggested that Bev may have become frightened by the environment; that the lady reminded her of someone she disliked; or that she was distressed that she didn't have her own handbag like she did when she was shopping when she was younger.

Bev may also be expressing frustration at her loss of control over finances and her lack of a role in shopping, which was once her job in the home. Carol says that it could have been many things and that the best way for Tim to identify the cause is to write down a clear description of these incidents and look for a pattern in the behaviours.

## Practice task 13

Read the case study, then answer the questions that follow.

### Case study

Bill is a 90-year-old man who lives in a care facility. He has dementia and his behaviour can be a challenge for the support workers who assist him. Jodie sometimes takes care of Bill and has noticed that at times he yells, pushes people away and waves his hands in the air.

Bill can also be quite disruptive in group activities and at lunchtimes. From time to time he also upsets the other residents. Shirley, another resident with dementia, cries and rocks whenever Bill approaches her.

1. What are some possible triggers for Bill and Shirley's behaviours?

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2. What are some impacts that Bill and Shirley’s behaviours may have on others in the home?

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3. How should Jodie detail triggers in each of their care plans?

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**Click to complete Practice task 13**

# 4B Contribute to team discussions on support planning and review

As a support worker you will often know and see things about a person with dementia that are valuable for the whole team to know. When you have spent enough time with a person you will instinctively know things they like or dislike, things that distress or calm them and the most successful ways to manage their behaviours.

Sometimes it will be a well-known fact that a person likes a certain support worker more than others. There can be many reasons for this, but your insights into a person and how you treat them are a big contributing factor.

Sharing your insights on and experiences with a person with dementia can benefit the whole team. As each team member contributes new information, you can all piece together a bigger picture of who the person is and what their individual needs are.

Having a team discussion can be a very useful strategy for reviewing and updating behaviour plans in your workplace.

## Ways to contribute

- ▶ Share information on what the person likes and dislikes
- ▶ Share observations on what foods they do and don't eat
- ▶ Share information on what makes the person smile or calm
- ▶ Share how they respond to different kinds of music
- ▶ Share verbal and physical cues that help when assisting the person
- ▶ Share important details of their life that family members have told you
- ▶ Share experiences of them being distressed
- ▶ Share strategies that work and don't work to manage behaviours

## Example

### Contribute to team discussions

Ed has dementia and manages to live at home with some help from support services. He receives domestic assistance with cleaning and showering three times a week.

Jeremy is one of the memory support workers who provide care to Ed. All of the workers on Jeremy's team like to joke that he is the favourite 'golden boy' who can do no wrong when it comes to Ed. This has upset other workers, who feel Ed is unnecessarily mean and aggressive towards them, so they have written incident reports about his behaviour.

Jeremy's manager organises a team discussion as part of the Ed's behaviour plan review. During the discussion the workers learn that Ed had an abusive childhood and that the people he loved most and felt safe around had always called him 'Eddy'.

Jeremy tells the team what words, tone and body language he finds work best for Ed. He also says that soft background music has a great soothing effect on him and that when he puts on one of his favourite songs he rarely refuses or resists showering.

Ed's behaviour plan is updated with these strategies and the number of behaviour-related incidents significantly reduce.



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# Practice task 14

1. Why is it important for support workers to contribute to team discussions about a person's behaviour plan?

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2. What are four ways that a support worker can contribute to a team discussion about a person's behaviour plan?

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**Click to complete Practice task 14**

# 4C Take action to minimise the likelihood and impact of behaviours on the person and others

In the past, extreme actions were taken to manage behaviour. Physical, psychological or chemical restraint were used to control and subdue people exhibiting behaviours of concern. These strategies neither took into account the wellbeing of the person, nor did they fit in with current best practice. Today, there are a number of strategies you can employ to minimise the impact of the behavioural and psychological symptoms of dementia.



## Best practice behaviour management

Current best practice in behaviour management is based on the least restrictive approach. In particular, people with dementia should be free to move around; free to choose what they do; not be restrained or held; and not be locked in against their will. You have three choices for dealing with behaviours of concern, as described below.

### Do nothing

- ▶ If you do nothing, this may mean the behaviour will continue and probably get worse. Remember you have a duty of care to the person with dementia and others who may be affected by your actions or by your lack of action. In this situation, no action at all may be a breach of your duty of care.

### Observe then act

- ▶ When you observe then act, this allows you to consider possible options before taking action. This is only appropriate when the behaviour is not impacting on others.

### Act straightaway

- ▶ If a person is about to harm themselves or others you need to act. Examples of behaviours that require an immediate response include physical aggression; screaming in public or in group settings and wandering onto or near the road.

## De-escalation procedures

Strategies you choose depend on the person's behaviour and the impact the behaviour may have on themselves and on others. You need to manage a person's behaviour in a manner that promotes their independence, dignity and overall wellbeing, as described below.

### Tips for selecting strategies

- ▶ Use the least restrictive approach by using the minimal amount of interference to effectively modify or avoid the behaviour.
- ▶ Behaviour is a form of communication. Try to establish the message conveyed by the behaviour. Is it fear, discomfort, boredom, stress or pain?
- ▶ Allow the person to express themselves however they can, as they may not be able to express themselves through words.
- ▶ Take action to prevent and deal with distress.
- ▶ Do not hurt a person when attempting to manage their behaviour; this can include physical and psychological harm.
- ▶ Document all behaviours.
- ▶ Help paid and unpaid carers to develop appropriate responses to manage the person's behaviour.

## Best-practice strategies for de-escalation

Ideas about best practice evolve. What is best practice today may be considered poor practice in later years. You should therefore maintain your knowledge about best practice by participating in networks, attending professional development workshops, completing formal studies and by reading relevant legislation and standards. Here are some examples of current best practice.

### Distraction

Help the person by focusing on another task. Talk to them, show them something in the garden to look at, play some music or lead them to another area.

### Reassurance

Tell the person they are okay. They may not understand your words, but may gain comfort from a calming soft tone of voice and gentle touch. Use appropriate eye contact; their name; short, simple sentences; limited questions and a calm, quiet approach.

### Reminiscences

People with dementia may have vivid memories of the past. This is a strength you can draw on to help people manage their behaviour. Talk to them about their family, their schooling and their early career.

### Orientation therapy

People with dementia who are still verbal (use words) often express feelings of loss and being lost. Orientation therapy can help people understand where they are now. You can use visual cues such as picture boards with the time and date. Simple information can help orientate people with mild to moderate dementia. Tell the person who you are, what is happening and the time of day.

### Physical and mental activities

Sometimes older people behave inappropriately because they are bored and need an outlet for expression and their energy. Dancing, walking and listening to music are pleasant activities that can help prevent behaviours of concern.

### Behaviour modification

Typically behaviour modification therapy is based on encouraging positive behaviours through using rewards and discouraging negative behaviour by withholding rewards. This is rarely appropriate as its success relies on people remembering the learning and remembering the consequences of behaviour. Short-term memory issues can make this an ineffective approach for people with dementia.

## Other strategies

Other strategies that are very useful include strategies for addressing behavioural triggers and alternative therapies.

### Address physical triggers

- ▶ Physical aspects that can trigger a specific behaviour include underlying medical conditions, pain, tiredness, hunger, thirst or overheating. You can remove some of these triggers by using routines and documenting these routines.
- ▶ Consistent sleeping patterns and providing food and beverages at set intervals can ensure that a person's physical needs are met.
- ▶ You should always make sure that a person is adequately dressed for the weather. If they are moving around they may need less clothing than a person who is sedentary.
- ▶ Regular medical attention can help healthcare professionals detect and treat underlying medical conditions. Pain can be treated through physiotherapy and use of medication.

### Alternative therapies

- ▶ Examples of complementary (those that can be practised alongside traditional medicine) and alternative (those that are practised instead of traditional medicine) medicine and health services include massage, yoga, meditation, hypnosis, supplements, herbal treatments and homeopathic medicines.
- ▶ While these treatments and homeopathic medicines are natural, they can still lead to adverse effects. They may interact with a person's condition or other medication they are taking and should only be used with a doctor's approval.

## Consider a range of options

The best option for dealing with behaviours of concern may vary. A strategy that works today may not work tomorrow and no one strategy will work with all the people you support.

You should involve all stakeholders in selecting options, usually during a formal meeting, where you should record all the information discussed in a behavioural management plan. A coordinator will be involved in the development of the plan in most services; however, the implementation of the plan occurs initially at the support worker level.



All people involved in supporting the person need to communicate the requirements of the plan as well as the strategies to other workers and family members. The best approach is usually when everyone who helps support the person use the same strategy.

### Example

#### Minimise the impact of behaviours

Here are three examples of how to minimise the impact of disruptive or problematic behaviours of people with dementia.

##### Distraction

Athalie is an 85-year-old lady with dementia. She often cries and rocks back and forth when under-stimulated. Sarah, Athalie's support worker, has found that when Athalie is upset, the best way to calm her down is through distraction. Sarah and the other staff will take her for a walk in the garden or put on a nature documentary for her to watch.

##### Reassurance

Donald is a 73-year-old man with severe dementia. When Donald is frightened he screams and throws things. The support workers who provide care to Donald have found that he cannot be reasoned with or distracted when he is like this. However, he responds well to a firm hand on his shoulder and a calm soothing voice repeating 'You're okay Don. You're okay'.

##### Reminiscences

Elaine, a 60-year-old lady with moderate dementia, can become very quiet and withdrawn at times and refuse to eat. Support workers have found that using photos, videos and by asking questions about the past, Elaine is able to remember important people and places from her life and that the reminiscing helps to improve her mood and appetite.



# 4D Evaluate the implemented strategies to ensure effectiveness in minimising behaviours

As part of the philosophy of continuous improvement, you should always look for opportunities to do things better. This is true of all activities including behaviour management. Regularly reviewing strategies with stakeholders, including the person with dementia, their legal guardian and significant others, carers and healthcare professionals, can help coordinators and support workers evaluate what is and is not working, as well as develop better ways to manage a person's behaviour.



## Review methods

When reviewing a behaviour plan for someone with dementia it is important to remember that as the memory loss progresses the person's needs change and the plan needs to be updated to meet those needs. This means that strategies that were once effective may no longer work, or worse, trigger the very behaviours that you are trying to address.

Your workplace should have policies and procedures for when and how to review a behaviour plan. There are many ways to review whether or not a plan is working. Be aware of the methods used in your own workplace.

Example review methods:

- ▶ Completing formal assessments forms
- ▶ Observing behaviours
- ▶ Looking over documented behaviours
- ▶ Talking to carers and significant others
- ▶ Documenting sleep patterns
- ▶ Noting weight loss and changes in appetite
- ▶ Counting the number of documented incidents

## Review behaviour management strategies

All behaviour plans should be reviewed at least every six months to evaluate their effectiveness in minimising behaviours. If a person's condition changes more often or activities aren't meeting needs, their behaviour may escalate, requiring more reviews. The plan should also be reviewed if carers or others express concern about the appropriateness of the plan or in response to incident reports involving the person. Involve all stakeholders, as each of these people can offer their unique insight and help you gain a comprehensive picture of the success of the current strategies.

When reviewing care plans:

- ▶ make sure that all stakeholders are involved
- ▶ focus on whether the person’s behaviour has improved, worsened or stayed the same
- ▶ look at the consequences of the person’s behaviour for themselves and others
- ▶ assess the strategies that have been trialled along with their outcomes
- ▶ determine the strategies that should be retained, modified or replaced
- ▶ document changes according to policy and procedure.

**Example**

**Evaluate strategies**

Dolly has memory loss and lives at home. In the past she had displayed manic behaviour by spending excessive money on clothing. The coordinator, Vic, helps her husband Ben manage Dolly’s behaviour by dealing with the main trigger – boredom. Ben uses reminiscences to distract Dolly.

Recently Ben called Vic and said, ‘I’m exhausted. Talking is no longer working. My wife becomes very angry at me when I try to distract her. She hits out at me. To be frank, I’m scared’. Vic immediately arranges an assessment and a care plan review.

In this situation a once-successful strategy now no longer works. It now acts as a trigger for behaviour of concern: physical aggression.

## Practice task 16

Read the case study, then answer the questions that follow.

### Case study

Mr Singh has dementia and lives in a care facility. He sometimes tries to leave the facility or wanders into other people’s rooms when bored or distressed. Fergus is a support worker who enjoys caring for Mr Singh.

Yesterday another resident reported that Mr Singh was going into other people’s rooms and rummaging through their things. Fergus checks Mr Singh’s behaviour plan and notes that he responds best to a reassuring hand on his shoulder and soothing words.

Fergus finds Mr Singh in another resident’s room and places his hand on his shoulder and says, ‘You’re okay Mr Singh, come on now’, and attempts to lead him out of the room.

Mr Singh responds violently to the cue, slapping Fergus’s hand away, screaming and then rushing out of the room.

Fergus documents the incident and requests that the team review the Mr Singh’s behaviour plan as the strategies in it are no longer effective.

1. What are three methods that Fergus could use to review Mr Singh’s behaviour plan?

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2. What are some important things to consider when reviewing Mr Singh's behaviour plan?

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**Click to complete Practice task 16**

## Summary

1. People with moderate to advanced dementia may not understand where they are, who they are talking to and the effect their behaviour may have on others.
2. People with dementia may display behaviours of concern ranging from physical aggression to withdrawal.
3. Triggers, such as the person's physical and emotional health, the environment, tasks, communication issues or the person's history can act as antecedents to these behaviours.
4. Behaviours of concern can impact negatively on the person and others.
5. Best practice in relation to dementia is based on the least restrictive principles.
6. Where possible treat the underlying causes of the behaviour.
7. Treatment options should be documented in the person's care plan.
8. The care plan should be reviewed on a regular basis.

## Learning checkpoint 4

# Implement strategies that minimise the impact of behaviours of concern

This learning checkpoint allows you to review your skills and knowledge in implementing strategies that minimise the impact of behaviours of concern.

### Part A

1. What are two principles of a needs-driven behaviour model of care when working with people who have dementia?

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2. What are some examples of communication-related triggers for people with dementia that may result in problematic or disruptive behaviours?

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3. Why is it important to document triggers of behaviours when working with people who have dementia?

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4. How might a person's behaviour of concern impact on other people?

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5. How do de-escalation procedures help when managing behaviour in people with dementia?

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## Part B

Read the case study, then answer the questions that follow.

### Case study

Josephine has advanced dementia and lives in a care facility. She cannot communicate using words and requires a lot of physical assistance with showering and dressing.

When Josephine is bored, distressed, angry or upset she throws her head back into the chair repeatedly and pulls out her hair. It is not always obvious to the support workers what the triggers are for these behaviours or how they can best minimise her disruptive and problematic behaviours.

Isaac works at the care facility and seems to be able to minimise Josephine's problematic behaviours more so than other workers.

The rest of the workers don't understand why her behaviour varies so much as they are all following the same information in the behaviour plan.

1. What are some common behaviours of concern of people with dementia that the workers at the care facility should look out for?

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2. What are four possible triggers that could be causing Josephine's behaviour?

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3. What type of information should Isaac and the other support workers document about Josephine's behaviours?

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4. Why is it important for Isaac and the support workers to contribute to discussions about Josephine's behaviour plan?

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5. What four important things should Isaac consider when choosing a strategy to de-escalate Josephine's behaviours?

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6. What are some best-practice strategies that Isaac could use to minimise the impact of Josephine's disruptive or problematic behaviours?

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7. What are four methods that the support workers could use to review Josephine's behaviour plan?

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8. What important stakeholders should be involved when reviewing behaviour management activities at this care facility?

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## Topic 5

In this topic you will learn how to:

**5A Comply with reporting requirements**

**5B Complete, maintain and store documentation**

## Complete documentation

There are documentation and record-keeping requirements in all community services environments. Accurate and up-to-date record-keeping underpins quality service provision that meets the individual needs of people with dementia.

Actions are documented in a way that increases accountability, duty of care, and record-keeping needs to adhere to legislative and policy requirements, and any organisational protocols. Completing, maintaining and storing documentation is an important part of support a worker and coordinator's role as it facilitates the sharing of people's current care information.

# 5A Comply with reporting requirements

Reporting and documentation requirements in aged care, disability and community care settings are extensive. Maintaining accurate information enables workers to respond to people's needs and to provide effective and quality services. Information lacking accuracy or currency regarding a person's status or the issues affecting them may mean incorrect care or disjointed services are provided.

Documents also provide evidence of the actions compliant with industry standards in the event of an incident or other adverse effect. Another compelling reason for complying with organisational reporting and recording requirements is to demonstrate accountability to and compliance with the requirements of service users, funding bodies, government and other stakeholders.



## Collect information

All workplaces will have policies that dictate how information is gathered, who receives information about a person's progress, how the information is stored and who may access it. These policies are designed to help organisations meet their requirements under different legislation, regulations or industry standards, including privacy laws, freedom of information legislation, regulations and codes of practice.

## Information

Workplace reports and documentation that collect information relevant to aged care, disability or community care services include those related to the person's care, health and safety needs.

Here are some examples of information that workers may be required to collect.



### Personal information

A personal information form is completed the first time a person uses a service. The basic information about the person may include their first, middle and last name; address; telephone number; date of birth; Medicare number; emergency contact details, as well as details of medical conditions, allergies and medication they take.

### Health assessments

Initial health assessments are used to identify physical, psychological, emotional and cultural needs. Support workers may not be directly responsible for completing these forms with a client, but this information can be used to develop an understanding of the progress of the person's general condition or provide an insight into changes in their health condition. Health assessments can include questionnaires; cognitive function questionnaires and intake interviews.

## Care plans

Care plans outline roles and responsibilities for those involved in providing care and support. Care plans always include the person's goals; actions; the personnel responsible; resources required; and measurable outcomes.

## Case documentation

Case documentation can include medical records and test results; progress notes; completed questionnaires; completed assessment tools; service delivery plans; and records of feedback.

Medical reports help assess a person's needs, as they provide a wide range of information about a person's current physical and mental health, and future prognoses. This information may also be used to assess a person's eligibility for other support services.

# Documentation

Documents that deal with other agency-specific information regarding the support of people with dementia are described below.

## Documents held by organisations



### WHS reports

All support workers have workplace health and safety responsibilities. Communicating with others about risks is part of these responsibilities. If you witness a workplace accident involving a person, you may be required to fill out an accident report form. Recording near misses or incidents also assists in making improvements to workplace safety to minimise hazards or risks.



### Service data

Service data includes hours spent on each activity, with each person, in each program area, and are usually entered directly into an electronic database, as required by the funding body/government department/organisation's board. The data is often collected daily and submitted quarterly.



### Organisational reports

Organisational reports include annual reports, strategic plans and business plans. These are generally produced on an annual basis.

Project and program reports require regular progress reports at intervals throughout project or program delivery. Evaluation reports are provided following the completion of a project.

## Report observations

You will be required to report observations when working in aged care, disability services or community care services. The types of observations you will report on include the behaviour and actions of the care recipient and any conversations and circumstances that influence your delivery of care.

Reported observations can be used to show that you have been compliant with your legislative requirements and have followed the policies, procedures and care plans in your workplace.

Reported observations are a useful source of information when reviewing policies, procedures and care plans, and for identifying the need to make changes to them. You may be required to report observations in care plans, progress notes and formal assessments, or as your workplace practices require.

When reporting observations you should document:

- ▶ when the observation took place (time/date)
- ▶ what you observed (include specific details)
- ▶ where did the observation occur (include details on the location and the environment)
- ▶ who was present (include details of what they were doing at the time)
- ▶ why the observed event took place (include any relevant behavioural triggers)
- ▶ any outcomes or consequences that occurred as a result of the observed event.

### Example

#### Comply with reporting requirements

Donna is a care provider in a community services environment. This morning Donna was providing care to Irene, a 70-year-old lady with mild dementia.

Irene's daughter was present at the time, and Donna noticed that Irene seemed frightened and that there were notable changes in her behaviour.

No incident took place during the care but Donna felt that she really should report on Irene's behaviour. She was feeling nervous as she did not want to make any false accusation or assumptions.

Donna spoke to her supervisor about the situation, and together they looked through the workplace policies and procedures and found that Donna had a duty of care to report what she had observed, and to do so objectively and within a twenty four hour period.

Donna's manager told her that she did not need to worry about making accusations if she kept the information objective and accurately documented when the observation took place, what she observed, where she was, who was present and any other relevant circumstances and outcomes.



# Practice task 17

1. What are some important reasons that you need to comply with the documentation requirements of your current or future workplace?

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2. What are some types of information that you may be required to collect as a worker in a community services environment?

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3. What type of information should you document when reporting observations from your workplace?

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**Click to complete Practice task 17**

# 5B Complete, maintain and store documentation

Many of the documents, reports and records completed by workers are considered a legal record of the support provided to people and how the organisation manages work health and safety and infection control. Most government-funded organisations undergo regular audit evaluations, where records are examined to ensure work is carried out to the appropriate standard. Different types of information may need to be documented at different times, and several people may enter information on a single record. The protocols for recording information should be detailed in organisational policies and procedures, and confidentiality and record management must meet legislative requirements. Seek advice from your manager if you have questions about protocols surrounding recording information.



## Complete documentation

Professional standards require that reports and documents use objective language based on fact and observation. Objective language describes what has been observed or heard, while subjective language may be based on feelings, emotions or opinions. Objectivity is important for accuracy and accountability, and ensures individuals are described in ways unaffected by judgments, stereotypes, assumptions or opinion.

You also need to ensure the language suits the audience. Each part of the community sector often has its own language and jargon. To ensure clarity and accuracy, use complete words rather than abbreviations or acronyms and plain English instead of jargon. Here are some examples of objective or factual information compared with subjective information.

### Objective versus subjective language

Objective: Mrs Smith stated, 'I am feeling depressed'.

Subjective: Mrs Smith seemed depressed.

Objective: Alex rose quickly, slammed the door and raised his voice.

Subjective: Alex acted aggressively.

Objective: When Tam was asked about her parents, she avoided the question.

Subjective: Tam didn't want to answer when I asked about her parents.

Objective: Mark uses heroin regularly.

Subjective: Mark is a drug addict.

Objective: Mr Thompson requires full physical assistance with meal preparation.

Subjective: Mr Thompson is unable to cook for himself at home.

# Meet further record-keeping requirements

When completing workplace documentation, there are other points to consider.

## Record-keeping requirements



### Meet timing requirements

The nature of a report or document, along with the expectations of the organisation, determines the time lines and protocols for their completion. Reports such as funding submissions or statistical reports to government have externally set time frames. Internal documentation is dictated by urgency, organisational policy and the end use of the information. Your organisation will have standard operating procedures for completing documents on intake; developing care plans; providing care; and consultation and reporting incidents and accidents.



### Maintain confidentiality

Often case notes, programming and incident reports include interactions that involve events with other clients and people. Confidentiality of clients and others must be maintained when writing notes or reports recorded in another client's file or records.



### Correct spelling and accuracy of information

Spelling is another critical aspect of recording information. Spelling a person's name incorrectly may have a number of unintended consequences. Their data may be confused with another person's data, leading to serious privacy breaches, confusion or duplication of records. Incorrect spelling of medical terms can cause confusion; for example, the treatments for and effects of hyperthyroidism and hypothyroidism are quite different.



### Use forms and control alterations

Use the appropriate form or report template, as this helps other workers identify the required information and follow protocols about using organisational stationery. Make sure you have completed all sections and entries make sense, and that writing is legible and comprehensible. Completed documents generally must not be changed. Errors or alterations should be identified in an additional note or new record, clearly explaining the reason for the change. Do not use correcting fluid to change a written note or record. Computer-based records may not allow changes to saved information.



### Authorise records and obtain authorisation

Records should be signed and dated by the person completing them. Computer-based records may require a log-in to access records that identify the author. For reports, show drafts to another authorised person for feedback; some organisations have a requirement that any outgoing reports are signed off by a manager.

## Record true and accurate information

Aged care and community care organisations must keep client or resident records about the clients they provide services for. As a care worker it may be your responsibility to collect, write down and store information about clients.

The information you collect must contain only true and accurate information. You must not guess about what you write down; you must stick to the facts and only write down what you know and what you saw.

Organisations will have specific policies and procedures that you need to know when you complete documents. Documents and forms will vary between workplaces. Make sure you're familiar with the documents used in your workplace.



## Maintain documentation

Recording and documenting work is an ongoing task. Documentation should not be allowed to become out of date; it must be completed as the work is done to prevent errors or omissions. This information could be required at any time by other workers, by your supervisor, government agencies or for legal proceedings. Personal details can change as people move or change contact details. People's conditions can improve or worsen, or their circumstances or preferences may change. Unless records are updated, decisions may be made based on out-of-date data.



The general rule is that records of past work are stored and maintained, even if they no longer appear relevant or have been superseded by more recent information. Your workplace will have procedures and guidelines about how and when documentation is to be maintained.

## Ensure documentation is updated

There are many records that need to be kept current and accurate. If you forget to complete paperwork, there may be significant consequences in terms of accountability and reliability, particularly if financial documents are involved or there are external reporting requirements to be met.

### Individual's information

Your organisation will have standard operating procedures that must be followed on intake, when developing care plans, when providing care, when consulting with others and when reporting incidents and accidents.

Regardless of whether your organisation uses paper-based or electronic forms, use the most current version. Using superseded forms or information may result in a failure to collect and record the information required for the person's support.

### **Policies and procedures**

A policies and procedures manual, or wiki/intranet, is a living document that guides the daily activities of staff members. Policies and procedures manuals must be up to date and reflect current practices within the organisation. They are a critical reference for all employees of a service provider.

### **Operational documents**

Operational documents may include funding reports, reports regarding supplies and equipment, annual reports, business plans, complaints and financial forms. If you forget to complete paperwork, there may be significant consequences later on in terms of accountability and reliability, particularly if financial documents are involved or there are external reporting requirements to be met.

### **Funding and grant submissions**

Submissions for new or ongoing funding need to accurately reflect actual activities. They must include accurate information about the specific objectives of the project or program together with an explanation of how the funding will assist to meet these objectives. The objectives detailed on the funding submission may be referred to later as part of an evaluation or report on the success of the program.

### **Work health and safety**

Work health and safety checklists record when safety inspections have been carried out and any actions required to improve or maintain safety. Documentation may be used to record safety checks on a workplace, vehicles or persons' homes. It may relate to physical safety, infection control, safety with chemicals, food safety or equipment. You may be required to complete and document safety checks as part of your role.

## **Human resource documents**

Other documents that are a legal requirement include a range of human resource information. Documents specific to your role as a support worker includes time sheets and performance appraisals. Ensure you keep a copy of these documents.

Legal documents specific to your role might include the following.

### **Time sheets**

A time sheet records the hours you have worked and, in some cases, the people you have seen and details such as kilometres driven. An accurate time sheet determines your pay and may also be used for invoicing people or funding bodies for hours of service provided.

### **Performance appraisals**

When staff performance is assessed, a record of the outcomes and plans for development or improvement are completed. Some organisations may ask you to complete a self-appraisal to say how you think you are performing and how you could develop and improve in your role.

## Store documentation

Records must be stored in the correct place so they can be easily located and referred to when required. Within people's files, each type of record or document will be stored in the same place. For example, in a person's file you might find that personal information is always at the front, progress notes next, assessments behind that and payment records at the back. For electronic files, particular information is recorded in a specific form or field. Many community agencies use electronic systems that allow users to input all people's details, referrals, assessments and case notes directly to a database.

Other types of documents such as incident reports, safety checklists and time sheets may also be stored electronically. These systems may be password-protected, which limits access to authorised staff only.



## Access to documentation

Privacy laws demand that an agency has valid reasons for collecting, storing and disseminating information about people they provide services to. There are also various guidelines on file retention times. There may also be times when additional information is required to meet new standards. For example, when privacy legislation was introduced, community service providers had to get both existing and new service recipients to sign 'consent to disclose information' forms. If they did not do this, it would be illegal for them to share this information with other agencies. Here are examples of different types of information and storage protocols.

### Information about legislation and standards

- ▶ Information about legislation and standards is stored to ensure currency and accessibility, and as a reference for obligations of the organisation and workers.
- ▶ In some organisations this information is stored within policy documents. It may also be displayed visually (for example, summary posters) to increase accessibility.

### Information about other agencies

- ▶ Information about other agencies is stored as a reference for the organisation and workers, and to ensure currency and accessibility of information about other services, so it can be disseminated or accessed as required.
- ▶ This information may be filed or stored electronically. It is not confidential, so does not have to be locked or password protected.

### Organisational policies and procedures

- ▶ Organisational policies and procedures are stored as a reference for obligations of the organisation and workers, and to ensure information about policies and procedures is accessible and up to date.
- ▶ This information may be in hard copy and provided to staff. In some organisations policies and procedures are only available electronically to ensure the most recent records are used

### Individual's files and information

- ▶ People's files and information are stored so a plan can be developed and implemented to meet individual needs, and to meet duty-of-care and other legal requirements.
- ▶ This information may be stored in a locked filing cabinet or password-protected database or electronic files with limited access.

### Staff information

- ▶ Staff information is stored so human-resource functions (recruitment, induction, professional development, performance appraisal) can be implemented, and to meet duty-of-care and WHS obligations.
- ▶ This information may be stored in a locked filing cabinet or password-protected database or electronic files with limited access.

## Store information

You must always follow organisational procedures for updating and storing information to ensure it is current and can be readily retrieved by authorised personnel. Information should always be kept in safe and secure areas. It is common to store hard copy files in a lockable cabinet with files stored alphabetically by surname. Personal information should not be kept in an area accessible to clients and other members of the public.

Electronic filing systems are common. In most cases software allows information to be retrieved using one or many fields such as a person's last name or file number. Electronic filing systems use a password, instead of a key, and a lock to protect the information. You should avoid logging on for another staff member and always logoff when leaving the computer.



**Example**

**Complete, maintain and store documentation**

Here are some examples of how to complete, maintain and store information.

**Complete documentation**

Trey, a support worker, is required to complete documentation in progress notes, care plans and other assessment forms. Trey always makes sure that he documents things in a timely and appropriate manner. He always uses objective language and tries to avoid the use of jargon wherever possible.

**Maintain documentation**

Fatima works in an aged care facility and plays an active role in maintaining the workplace work health and safety checklists and records. She ensures that when safety inspections have been carried out that the required actions and follow up activities are recorded. As safety checks are routinely completed in her workplace, she is constantly updating the records.

**Store documentation**

Jacinta works in a community service environment that collects information on the individuals that access the community services. Each person's file and information must be stored so a plan can be developed and implemented to meet individual needs, and to meet duty of care and other legal requirements of her workplace. To meet privacy and confidentiality requirements the files are stored in a locked filing cabinet and access is limited to care providers only.

## Practice task 18

1. What are some essential record-keeping requirements when completing workplace documentation?

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2. What are some types of records in the community services environment that should be maintained and updated?

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3. What are some important considerations when storing information records?

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**Click to complete Practice task 18**

## Summary

1. Documentation can be used to identify and keep a record of people’s needs and the steps taken to meet these needs.
2. The integrity of a person’s information is critical to their care and support.
3. Laws affecting information collection, use, access and storage include privacy and freedom of information legislation.
4. Protocols require that people’s information contained in reports is objective and factual.
5. When completing documentation, support workers must check the content, accuracy and currency of the information.
6. People’s information must be complete. Your workplace will have policies and procedures to ensure all required information is collected.
7. Information must be stored according to organisational procedures.

# Learning checkpoint 5

## Complete documentation

This learning checkpoint allows you to review your skills and knowledge in completing documentation according to the organisations policies and procedures.

### Part A

1. What are some types of information that might be collected in a community service environment?

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2. What is the purpose of documentation policies and procedures in a community services environment?

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3. Why is it important to use objective language when completing documentation in the community service environment?

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- 4. What information should be considered when setting up systems to store documents in the community service environment?

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## Part B

Read the case study below and answer the questions based on the information provided within the case study.

**Case study**

Jonathon works for a community services organisation that provides domestic assistance and care to people in their own home. There are many documentation requirements that Jonathon must complete every time he goes to work.

This morning he did a home visit to shower and dress Maisy, an 81-year-old lady with Alzheimer’s disease and mild dementia. As this was his first visit to Maisy’s house he had to call Maisy beforehand and go through a home safety checklist that would ensure that he would not be put at unnecessary risk by visiting her.

On the first visit to Maisy’s house he also had to complete a risk assessment to alert himself and his team of any hazards that are present in the environment. It might be a lot of documenting but the checklist and risk assessment makes sure that everyone is aware of things like dogs, uneven steps, syringes and aggressive family members that the team need to know about of when going into someone else’s home.

Jonathon’s work place also has documentation policies and procedures to help him to provide best practice care, while complying with relevant work health and safety and privacy legislation.

- 1. What are three important reasons that Jonathon should comply with the documentation policies and procedures in his workplace?

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2. What type of personal information might Jonathon need to collect from Maisy?

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3. Why might the documentation policy require Jonathon to report observations while he is at work?

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4. What important record-keeping requirements might Jonathon find in the documentation policies and procedures for his workplace?

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5. Why is it important for Jonathon and his team to maintain and keep up-to-date records in their workplace?

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## Topic 6

In this topic you will learn how to:

**6A Monitor own stress level**

**6B Use appropriate self-care strategies**

## Implement self-care strategies

Working with people with dementia can be stressful. Workers can be faced with people who are distressed, agitated, restless, aggressive or withdrawn. The people you support may not remember you from one day to the next, and may show little gratitude for the support you provide. It can be difficult at times to see whether the support you provide or the strategies you implement are having significant success. It is easy to become stressed, frustrated and disillusioned if you do not also take time to care for yourself.

# 6A Monitor own stress level

Working with people with dementia can be challenging. In many of the settings where people receive support, there are a number of people with dementia all in the same place. Their demands can be constant. You need to monitor the people you are supporting to ensure they are safe and are benefiting from the activities they are being provided. You may need to do the same tasks repeatedly, or answer the same questions multiple times.



Working with people who have a form of dementia can be sad as you watch their dementia progress and the person become less able to remember things, complete tasks and look after themselves. It can be upsetting to see people with dementia who are distressed or angry. It can be frightening to be with someone who is angry or aggressive, even violent. It can be frustrating when people with a form of dementia fail to understand or cooperate with an instruction or request. It can be exhausting work.

## Be aware of how you feel

It is important to monitor your own reactions to the work you do. You need to be aware of how you feel and the impact it is having on the work you do, and your life outside your job. It is important to identify and act when your job is causing you significant stress.



Some people are calm, cool-headed and do not react to stressful situations in a visible way. However they may store up their stress and display it in different ways or at a later time. Others may have difficulty managing their reactions to a stressful situation and feel angry, upset or frustrated. They may exhibit this behaviour by becoming impatient with the people they are supporting, being abrupt or rude to the person and co-workers, or becoming upset. The way you react to a situation will be different to the way others react. It is important to be aware of the reactions and feelings you are experiencing.

## Types of stress

In its simplest form, stress is the pressure or tension exerted on a person. Some stress is useful and makes us feel motivated and alive. This type of stress can help us by providing a drive to succeed at the work we do and the support we provide. Other stress can worry us and undermine our ability to cope both physically and mentally. It can drain us, cause illness, absenteeism, accidents, industrial disputes and staff turnover. What may be a good stress for one person may be a threatening stimuli to another.



What one person finds stressful another may not. Whether or not you react with a stress response and whether the reaction to stress is useful or draining will depend upon your awareness of how stress is impacting your life and your ability to identify strategies to cope with the stress.

It is important to remember that all stress, even the useful type is only meant to be a short, time-limited response. Experiencing stress for a sustained duration of time can have serious health consequences.

It is important that you regularly review how you are dealing with stress in your workplace and seek help if you feel that you are not coping.

## Stressors

A 'stressor' is the event, activity or situation that is causing stress. In your work supporting people with dementia, you will encounter many different potential stressors. Here are some examples of stressors.

### Time stress

In your work you will probably have a set number of tasks you need to achieve in a certain amount of time. If you work in people's homes, you may only have an hour to complete your work, before you need to move on to the next person. If you work in a residential facility, you may have a list of support tasks that must be completed for a number of residents before a certain time of day.

As discussed earlier, people with dementia become slower at completing everyday tasks. They also have difficulty understanding simple instructions or concepts. They may be argumentative or refuse your support. All these things can slow you down and may cause stress, especially if your supervisor expects you to complete work to a fixed timetable.

### Stress from behaviour

People with dementia may behave in ways that are challenging or worrying. Part of the dementia support worker's role is to monitor and manage the environment, and to use particular strategies to minimise or manage challenging behaviour when it occurs. This means being constantly aware of what is going on around the person or people with dementia that you are supporting. It means thinking about how each change in the environment may affect a person with dementia. It can mean dealing with people who are angry, upset or violent, or who may wander off.

Worrying about what might happen, and dealing with these things when they do happen, can cause stress.

### Frustration

People with dementia often cannot remember things from one day to the next, and even sometimes from one moment to the next. This means you may have to repeat instructions or information to them repeatedly. It means they may tell you the same thing or ask the same question multiple times. They may not be able to understand what it is you want them to do, or may forget halfway through doing it.

All this can lead to a level of frustration or impatience in dementia support workers and may lead to stress.

## Distress

People with dementia and their family members and significant others may display their distress to a support worker. They may need to talk about how they are feeling. They may cry or express sadness or feelings of being overwhelmed or scared. Support workers need to be supportive in these situations, be good listeners, and provide reassurance and comfort. Inevitably people with dementia die. This can be upsetting for workers who have come to know the person and have provided support over a significant period of time. All these factors can cause stress for a dementia support worker.

## Monitor stress

Support workers need to recognise when they are feeling stressed and to take steps to manage this stress. Not dealing with stress when it occurs can affect your work performance, your health and your relationships both at work and in your personal life.

Monitoring your own stress levels can be done by learning to recognise your own physical, emotional and behavioural responses to stress. These will alert you to the presence of a stressor.

Some considerations when monitoring stress are outlined below.

### Considerations when monitoring stress

- ▶ Think about how you are feeling, and how you are interacting with others. Are you less open with people? Do you feel you don't have the time or 'headspace' to deal with people?
- ▶ Look at the way you are interacting with the person with dementia. Do you find yourself wanting to tell them to 'Hurry up' or 'Stop asking that question'?
- ▶ Consider your health. Are you unusually unwell or tired? Are you getting headaches?

## Example

**Monitor own stress level**

Here are some examples of monitoring stress in the community services environment.

**Stress from behaviour**

Sadiq works with clients who have memory loss, and is currently caring for three people who have very challenging behaviours. Lately, he has been feeling tired all of the time and like he does not have the headspace to deal with people, not even his close friends. Sadiq stopped to reflect on how he was feeling, and his behaviour, and realised he was not coping with the stress of the challenging behaviours of the people he was caring for. He sought help to implement some strategies to help him to manage and cope with those challenging behaviours.

**Stress from frustration**

Elina works in a dementia care facility and is currently caring for many people with severe memory loss issues. She recently noticed herself wishing people would hurry up, and feeling sick and tired of answering the same questions over and over again. Elina realised that what she was experiencing was caused by the frustrations of her role. By recognising the stressor, she was able to implement more resilient coping strategies.

**Stress from distress**

Daryl works with people who have moderate to severe dementia. He works with the same clients consistently and gets to know them and their significant others well. Daryl acts as a constant support to families as they grieve the loss of their loved ones with the progression of dementia. Lately Daryl has been feeling exhausted and developed a sense of hopelessness that he can't do anything to stop the dementia and make it better for the people he is supporting. Daryl recognised that he was having a negative response to the stress of distress and has decided that he too might need to debrief with someone about how he is feeling.

## Practice task 19

Read the case study, then answer the questions that follow.

### Case study

Ariella is a support worker for people who have dementia but still live at home.

Sometimes she works with people with moderate dementia that do not even recognise her or what she does for them. Sometimes she goes all the way out to their homes and they refuse to let her provide care and say hurtful things to her.

Last week Ariella went to Juan's house to assist him with his shopping, but he ignored her and then spat on her when she calmly asked him if he wanted to come to the shops. Ariella raised her voice towards Juan and told him that he was very rude and should be ashamed of his behaviour. Later she felt ashamed of her outburst, as she knows that because of the dementia Juan no longer knows how to behave in a socially acceptable way.

Ariella's reaction to Juan made her realise that she needs to be more aware of stressors in her workplace and how to cope with stress.

1. Why is it important for Ariella to be aware of and monitor her stressful feelings at work?

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2. What are some potential stressors in Ariella's workplace?

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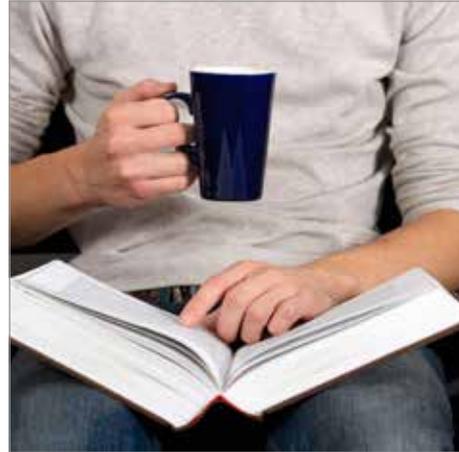
**Click to complete Practice task 19**

# 6B Use appropriate self-care strategies

Once you have identified that you are experiencing stress, it is important to manage your stress. Unmanaged, prolonged stress can cause serious health issues, both physically and mentally. It can affect your job and your personal life. There are many ways to manage stress, and everyone manages stress in different ways.

Self-care strategies aim to teach you how to cope with stress, reduce the effects of stress and help you to regain control of how you respond to certain situations.

As a general rule, self-care focuses on having a well-balanced lifestyle, being mindful of how you are feeling and responding to different stimuli and being able to identify when you should seek help. There are many types of self-care strategies and no single type will meet everyone's needs. It is important you take the time to work out what works best for you.



## Self-care strategies

Not every care strategy will suit every person. You will need to find the strategies that work for you. Here are some descriptions of techniques or activities you can use to manage stress.



### Get plenty of rest

You cannot function properly at work, or deal with issues that are causing you stress, if you are tired. It is important to make sure you get enough sleep and take your allocated breaks when at work. A rested mind and body will cope better with stressful situations.



### Eat well

Eating a well-balanced diet keeps you healthy. Eating well provides you with energy. Being well and having energy will help you deal with stress. Make sure you take your meal and tea breaks when working. Have a healthy snack or meal at these times to maintain your energy levels.



### Ask for a mentor

Having an experienced person to talk to about the way you handle your work and deal with stressful situations can be very helpful. You can talk through situations that have caused you stress, and discuss ways in which you can handle situations better. This will help to address future stressors. Role playing or practising the ways in which you will talk to people with dementia, who are causing stress through their behaviour, will help you to think of ways you can communicate with them calmly and effectively. If you feel you need this kind of support, ask your supervisor to help you connect with a mentor.



### Seek support

You may find that even though you know that certain parts of your role supporting people with dementia are causing you stress, it can be hard to look at the situation objectively and decide on strategies to manage your stress. Sometimes you may not be able to control the situations that are causing you stress. It is important to ask for help when you are unable to control stressors or manage your stress alone. You can ask your supervisor for help to manage stress and stressful situations. Your workplace will have an employee assistance program where workers have access to independent and confidential counselling and support to work through issues that are causing them stress at work.

## Care strategies

Other strategies can include undertaking professional development so that you have more information about the situation. Here are more care strategies for you to consider.

### Learn more about dementia

- ▶ Sometimes the best way to get control over a situation that is causing you stress is to learn more about the reasons it is happening. Knowing about the causes and effects of dementia will help you understand more about the way in which people with dementia may behave. It can help you take things less personally; for example, if a person with dementia does not recognise or trust you, says something hurtful or behaves in an aggressive or angry way towards you. Understanding more about dementia will help you manage your own reactions to such situations and help manage your stress.

### Reduce negative effects of stress

- ▶ In some cases, the situation that is causing you stress cannot be changed. It may be necessary for you to remain in a stressful situation in order to fulfil your work role. If you are unable to reduce stressors or decrease the stress you are experiencing, it is important to find some way to reduce the negative effect that the stress has on you. Some techniques for this include: meditation, yoga, exercise, self-talk and relaxation training.

**Example**

**Use appropriate self-care strategies**

Eric works in a community services environment and is a hardworking and supportive member of his team. Lately there have been a lot of people on Eric’s team who have been off sick. Some days, Eric finds himself feeling like he is the only one still working and as though he is doing the job of three people all at once.



Yesterday Eric had so much work to do that he did not even know how he could possibly get it all done. To make it worse he had to provide care to a lady with memory loss who took forever to do even the simplest things.

By lunch time he was so far behind that he felt overwhelmed. Unfortunately, right about the same time, a fellow support worker named Carla asked Eric if he could show her how to do something. It felt like the last straw for Eric and he yelled ‘Am I the only person on this team with a brain? Can’t anyone else do anything for themselves around here?’

Carla burst out crying and said not to worry and that she would work it out herself.

Later that afternoon Eric felt terrible about his behaviour and spoke to his supervisor Elliot about what had happened, and how he was feeling. Eric told Elliot that he had not been sleeping very well and noticed that he was always worrying about work and no longer had the energy to spend time on the things he enjoyed. Elliot arranged for Eric to have a mentor at work to help him to find ways to cope with stress. He also recommended that Eric spend more time on things he enjoyed doing, as well as getting enough rest and eating a well-balanced diet.

Eric has noticed that since implementing these self-care strategies that he feels calm and in control at work even though the work environment has not changed.



## Practice task 20

1. Why is it important to use appropriate self-care strategies when working in the community service environment?

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2. What are some types of self-care strategies that can be used to manage stress?

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**Click to complete Practice task 20**

## Summary

1. Working with people with dementia can be stressful. People with dementia can, at times, be affected by their grief, display behaviours of concern and can be very repetitive. Different workers will have different reactions to their work.
2. There are useful and draining responses to stress. Draining responses to stress can affect your health, your job and your personal life.
3. It is important to monitor your stress and your own reactions to stressful situations.
4. Stress must be managed to reduce its impact on workers.
5. There are many ways of managing stress.
6. Different people will benefit from different stress management techniques.

# Learning checkpoint 6

## Implement self-care strategies

This learning checkpoint allows you to review your skills and knowledge in monitoring your stress levels and caring for yourself.

### Part A

1. What is stress and why do people respond to it in different ways?

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2. What are four examples of circumstances that a person may find stressful when caring for someone who has dementia?

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3. What are two different ways that a person may respond to stressful stimuli?

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4. How can having a mentor help a memory support worker to reduce workplace stress?

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## Part B

Read the case study below, then answer the questions based on the information provided within the case study.

### Case study

Sally works in a busy aged care facility as a memory support worker. As part of her role Sally provides care to many people with memory loss. On any given day Sally's daily work plan will go out the window due to unpredictable interruptions, problematic behaviours and competing demands.

Recently several of the people Sally regularly works with have had significant progressions of their dementia and related symptoms. Previously Sally used to be able to focus on what she knew about dementia to help her to deal with the disruptions and interruptions caused by the behaviour of the people she was caring for. Lately she has realised that the particular self-care strategies she was using are no longer helping her to cope with the situations she is facing at work.

1. What are some potential causes of stress in Sally's workplace?

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2. What are some questions Sally could ask herself to help monitor her stress levels?

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3. Why is it important for Sally to use appropriate self-care strategies to manage her stress?

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4. What are some self-care strategies that Sally could use to help her to cope with stress while she is at work?

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