Learning Guide

Dementia: Person-centred support

23921 Provide person-centred support to people living with dementia in a health or wellbeing setting

<table>
<thead>
<tr>
<th>Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workplace:</td>
</tr>
</tbody>
</table>

Issue 3.0
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>What is dementia?</td>
<td>2</td>
</tr>
<tr>
<td>Supporting a person living with dementia</td>
<td>4</td>
</tr>
<tr>
<td>Person-centred care – a holistic approach</td>
<td>4</td>
</tr>
<tr>
<td>Personal plan</td>
<td>7</td>
</tr>
<tr>
<td>What is in the personal plan</td>
<td>7</td>
</tr>
<tr>
<td>Using a personal plan</td>
<td>8</td>
</tr>
<tr>
<td>What is a life story?</td>
<td>9</td>
</tr>
<tr>
<td>Features of a life story</td>
<td>10</td>
</tr>
<tr>
<td>Supportive interactions</td>
<td>18</td>
</tr>
<tr>
<td>Supporting positive interactions</td>
<td>18</td>
</tr>
<tr>
<td>Assistance with daily living activities</td>
<td>22</td>
</tr>
<tr>
<td>Observing changes and carrying out clinical tasks</td>
<td>26</td>
</tr>
<tr>
<td>Strategies for responding to changes</td>
<td>30</td>
</tr>
<tr>
<td>Risk management</td>
<td>30</td>
</tr>
<tr>
<td>Information provision</td>
<td>30</td>
</tr>
<tr>
<td>Barriers to communication</td>
<td>31</td>
</tr>
<tr>
<td>Communication skills</td>
<td>35</td>
</tr>
<tr>
<td>Communication as a partnership</td>
<td>36</td>
</tr>
</tbody>
</table>
Introduction

In this learning guide you will learn how to provide person-centred support to people living with dementia in a health or wellbeing setting.

How to use your learning guide

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

This guide relates to the following unit standard:

- 23921 Provide person-centred support to people living with dementia in a health or wellbeing setting (level 4, 6 credits).

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

Follow the tips in the notes column.

You may use highlight pens to mark important information and ideas, and think about how they apply to your work. You may find it helpful to talk to colleagues or your supervisor.

Finish this learning guide before you start the assessment.

What you will learn

This topic will help you to:

- understand dementia and your role in supporting a person living with dementia.
- identify and follow personal care plans.
- understand life stories and how they can help you understand a person’s behaviour.
- support interaction and effective communication with people living with dementia.
- assist with personal daily living activities.
- carry out routine observations and clinical tasks.
- support personal choices and preferences for people affected by dementia.
- understand changes in conditions and symptoms and how to observe, record and report these.
- understand strategies for responding to changes in a person’s condition.
- describe possible barriers to communication.
- develop communication skills for interacting with a person living with dementia.
What is dementia?

Dementia is an umbrella term used to describe a chronic disorder of mental functioning caused by physical changes in the brain as a result of disease or injury. When these physical changes occur they can lead to a loss of the functions controlled by the part of the brain that is affected. These changes involve memory, thinking, behaviour, emotions and physical functioning.

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

Dementia can be described as reversible or non-reversible.

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

The irreversible dementias are known as degenerative dementias and include a group of different illnesses causing a progressive and irreversible loss of cognitive functioning that results in a decline in the person’s ability to think, reason and remember.

Alzheimer’s disease is the most common of these conditions, accounting for 50–60% of all diagnoses.

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

Although we do not clearly understand what causes dementia, it appears likely that there is a link between age, lifestyle, environmental factors and family history. Dementia can affect people of all ages, intellectual ability and ethnicity. It is known as a ‘progressive’ condition, as the symptoms appear to get worse over time.
Common symptoms include:

- gradual memory loss.
- repeating statements or questions.
- difficulty in performing familiar tasks.
- difficulty in handling money.
- loss of initiative.
- impaired judgement.
- disorientation in time and place.
- personality changes.
- changes in mood or behaviour.
- problems with language.
- deterioration in driving skills.
- misplacing things.

It is important to understand that dementia is not a normal part of the ageing process.
Supporting a person living with dementia

There are special challenges in supporting a person living with dementia. It is vital that you:

- understand your role and responsibilities.
- recognise your own limitations.
- ensure that you are able to treat all the people for whom you provide care with dignity and respect.

People living with dementia have a tendency to feel vulnerable and start to rely more heavily on personal care as their condition worsens. It is important that you reassure them and support and respect their choices, so that they can feel safe, can maintain their independence and can continue to feel that they are valued members of society.

Person-centred care – a holistic approach

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

Person-centred care is a holistic approach to the person’s wellbeing. A person-centred model recognises that everyone is unique and individual and must be cared for according to their needs, regardless of age, race, religion, social status or disability.

Your role is to provide quality individualised care that respects the wishes and needs of the person you support. It is important to understand from a person-centred approach how responding to holistic needs can promote a person’s health and wellbeing.
The concept of holistic health is that the physical, social, emotional, mental, cultural and spiritual dimensions of a person must be viewed as an integrated whole. This leads to a broader concept of care in which a person’s holistic needs must be met in order to maximise their health and wellbeing.

Holistic care is not about how much time you spend with a person you support, but rather about how that time is used. Being aware of the effect of holistic needs on wellbeing will influence the care and support you provide.

Overall, person-centred care means being more flexible about the way services are delivered. This requires a ‘needs-led’ service that is based on what the person’s needs are at a particular time so that these needs can be met in the most effective way possible.

Organisations that use a person-centred approach are more likely to retain and recruit suitable people who enjoy their role and work more effectively.

It is also beneficial to the person living with dementia as it helps the person to feel accepted, listened to, understood, informed, involved (especially in making decisions and choices) and empowered.

Individualised care and support, which is the foundation of person-centred care, builds on a person’s abilities and strengths rather than on any deficits or deadlines.
Individualised care and support means:

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

The quality and efficiency of the service provider also supports the person living with dementia. This includes the quality of the staff and team work, good communication with the person, their family and other members of the multidisciplinary team, and documentation that records and informs all members of the support team of the day-to-day changes experienced by the person.

Think about

Being consistent with the care you provide. Do tasks at the same time each day and keep the room the same if possible. Consistency helps reduce confusion.
Personal plan

A personal plan is a document created for each person who is supported by your organisation. It explains the services and support your organisation has agreed to provide. Each organisation has its own format for the personal plan, but there are many common features.

Different organisations may use different names for personal plans, such as:

- service plan.
- care plan.
- personal care plan.
- lifestyle plan.
- support plan.
- nursing care plan.
- individual development plan.
- personal delivery plan.

There may also be other plans that are used alongside the personal plan.

Every person’s personal plan will be different because of the individual needs of that person. As we have read, a person-centred approach focuses on a person’s individuality, relationships, needs, communication, feelings and abilities, and takes a holistic view of the person’s situation as the starting point for determining the type and level of support to be provided.

What is in the personal plan

The plan is a basic profile of important information about a person. It will list the person’s needs and may specify such things as the services to be provided to support the activities of daily living (ADL), equipment used, instructions on maintaining a safe environment and the person’s food preferences. The plan will also include reports about anything significant to do with a person’s health or daily progress.

The personal plan will usually include information about the person such as their preferences, what abilities they have retained, what they can do for themselves and how they communicate and interact with others.

Preferences may include the name the person prefers to be called and recognises, what they prefer to do throughout the day, where they prefer to sit or relax, how they would like to be dressed and which foods or drinks they prefer.
Information about how the person communicates may include what assistance they need to interact with others, the things that interest them, how they can be engaged in these interests and how they may express their sexuality.

The personal plan should also include information for staff on how they can best communicate with the person at different times of the day.

Alongside the personal plan (or sometimes included in it) will be background information where applicable, a risk assessment or personal risk plan, the person’s life story describing significant life events and health information.

**Using a personal plan**

The personal plan describes the tasks to be performed for the person.

You need to look through the service plan of each person you support and find the information that you need to know. In some cases, you may need to add your own observations about the person’s daily progress.

Your role is to:

- read and be familiar with the personal plan.
- provide the support described in the personal plan within the set boundaries.
- support the person to meet any stated goals.
- regularly check their progress towards those goals.
- report any changes in the health and wellbeing of the person you support.

Your responsibilities are to:

- report anything that has an impact on the delivery of the personal plan.
- check and report goal achievement and/or progress, where relevant.
- carry out designated tasks.
- report any risks.
- work within the Code of Rights.

The information in a personal plan is confidential. This means that the information is private. The personal plan must not be left lying around for other people to see. You must not discuss it with anyone other than the person you support or your supervisor, unless you are authorised to do so.
What is a life story?

A life story reflects the details of a person’s life before the person was diagnosed with dementia. It is part of the personal plan and helps a support worker to find ways to interact with a person in a way that has meaning to them. It provides further detailed information about the person’s history, behaviours, likes and dislikes, and information related to their past before they were diagnosed with dementia. When a person is unable to communicate, a family member may supply personal information for the life story.

The life story helps people to appreciate the roles a person has played in life and the contribution they have made. Understanding a person’s life story can provide a great foundation for supporting a person living with dementia to engage in daily activities.

A life story is made available to the people who work to support a person living with dementia so they understand the person’s unique history and why certain things are important to them. Each person places different values and importance on the activities and events recorded in their life story.

It’s not a legal document and it doesn’t include progress notes. Life stories are usually paper documents, often including photos that may help to stimulate feelings or memories for the person.

A life story can be used to:

• involve the support workers in the person’s care.
• remind support workers of the life experiences of the person living with dementia.
• explain patterns of behaviour.
• suggest why past experiences may affect the person in the present.
• encourage the person to interact with other people and their support workers.
• enable people associated with the person’s care to see beyond the disease.
Features of a life story

Life stories include information about a person’s family relationships, employment history and roles in life, spiritual preferences, leisure activities and community involvement, sporting interests, cultural values and traditions, people and places that are important to them and their daily routines.

Family relationships

Understanding family relationships and their importance to the person living with dementia will allow you to follow and assist in these relationships as the person’s condition progresses.

Information about family relationships may include where and when the person was born, who their parents were, how many children were in the family, where the person fitted into the family and what has happened to family members over recent years. It may include when the person met or married their wife/husband, information about their children and grandchildren, and any deaths of significant people in the person’s life.

Spiritual preferences

Understanding the person’s spiritual preferences can be particularly helpful, as this can be a strategic way to assist the person you are supporting to reduce stressful or anxious situations as their condition progresses. Identify any religious practices that are important to the person, as well as their value, and how they may want or require quiet times for reminiscence or personal or spiritual reflection.
Important places

The life story will capture information about places that are important to the person, often starting with where they were born, grew up and went to school. It will include details of places the person moved to over their lifetime, holidays or travel overseas, places that were important to the person’s work role, and places that had a special significance to the person and/or their family or whānau.

Knowing about places that are important to the person you are supporting may be a great way for you to develop a rapport with them. In addition, you could use this knowledge to develop nurturing exercise programmes (if available nearby) or to communicate with the person to guide them through any behavioural struggles related to environmental vulnerability.

Employment and roles

Understanding the roles a person living with dementia has had in employment, volunteer work, military service or other areas could help you relate to them, provide experiences or situations in which they are comfortable, and support their family/whanau.

How much information of this type is included in the life story will depend on how the person values the roles that they had during their working life. Usually the life story will describe some employment role, perhaps the most recent or the one that was most important to the person. It is important to remember that unpaid, voluntary work is very significant as well, as it helps to fill out the picture of what is important to the person.

Cultural values and traditions

The life story may include information about the cultural aspect of the person’s life: the values, celebrations and traditions that are important to them and their family. There may also be particular ways of doing things that are very important to the person and their culture.

These cultural comforts can be a great way for a support worker to provide stability and structure in daily activities and is crucial to supporting the person as a whole.
Leisure activities and community involvement

This section of the life story can be quite extensive and will give you some very useful information on the person you are supporting. You will also find information about what non-work activities the person was involved in.

These activities might include:

- hobbies the person has participated in.
- clubs or groups they belonged to.
- roles or responsibilities they had in the clubs or groups.
- routine tasks they did around the home, such as gardening. The person may have loved to grow roses or been a keen vegetable gardener, supplying their family and friends with fresh vegetables.
- DIY activities such as decorating and renovating their own home, or the person may have knitted and sewn for the family.
- the music they most like listening to, and whether they played an instrument or enjoyed singing.
- the radio station or TV programmes they prefer.
- their interests in the creative arts.

Staying engaged in daily activities related to leisure and community involvement is a great way for the person living with dementia to maintain independence, be stimulated mentally and continue to feel valued in the community. It is also a great opportunity for you as the support worker to develop activities and strategies that will benefit the person.

Sporting interests

Sports are great way for people to engage socially and take part in an activity that is often deeply rooted in their past and present. The life story may include what sports the person played as a child, or their involvement in sport as an adult, such as sports they coached or supported in other ways, the sports they follow or are interested in now and sports and teams that they enjoy watching on TV.
Harvey Reid’s life story

Harvey is 72 years old. He had been a widower for five years when he had a stroke. Since then Harvey has been in the dementia unit of Kiwi Residential Care.

After treatment for the stroke, Harvey was assessed as a safety risk and could not be discharged home. He cannot understand this and tells people he will be fine when he gets home.

Harvey and his wife married late in life and did not have any children. He lived in the same suburb since he was a young boy. Harvey had two brothers who have both died in the last ten years.

Harvey worked for a local engineering company all his working life. As well as working in the workshop as an engineer he was responsible for hiring staff and monitoring their performance. Since retirement he has continued to visit his former workplace on the last Friday of each month for morning tea to catch up with his mates.

He has a passion for classic cars and has participated in several car rallies. Harvey has always dreamed of restoring a car himself.

Most afternoons Harvey walks to the nearby tavern, the King’s Oak, where he is a member of the social club and the darts team. Since his wife died Harvey has an evening meal at the tavern and says “The kitchen staff are just great, they look after me really well and they make the best sausages and mash with onion gravy.”

His friends walk him home afterwards.
Service plan

Name: Harvey Red  
Date: 7/3/2013

Last address:  
263 Sunshine Rd Amberley

Next of kin:  
Adel Justice (Spouse)  
263 Sunshine Rd, Amberley  
Pk 03 123 4567.

Residential setting issues

Harvey often very quietly appears in the staff office and stands behind staff as they are writing the person’s care plans or reports. Staff often are startled when they discover Harvey behind them in the office. They are also concerned about what he may have heard or read over their shoulder while they were writing. This could be a breach of client/consumer confidentiality. Staff members have often found Harvey listening to the conversation of another consumer and their visitor. When asked to move on he seems puzzled about why there was a problem.

Coping strategies

The Nurse Manager has stated that staff must keep the office door closed. Staff must ensure work/consumer discussions are held in appropriate places. Staff who see Harvey listening (inappropriately) to consumers and their visitors’ conversations are to request Harvey to move on, or engage him in an activity away from the consumer and their visitors.
Medical history

Appendicectomy 1966
Dislocated shoulder 1982
High blood pressure/heart attack 1995

Medical information

2002 diagnosis of dementia information.
2010 Assessment information and transition into residential care.
Medications as per drug sheet.

Support tasks

Daily care ADL’s required.
Communication methods.
Consumer interactions.
Consumer preferences.
Interests and abilities.

Physical

Harvey’s CVA was mild but this was exacerbated by an underlying condition, Korsakoff syndrome (alcohol abuse related condition). Harvey was unable to be discharged home, he was assessed as a safety risk due to his poor memory, personal safety issues and being unable to complete his daily care needs. There was also the potential if he was at home he would gain access to alcohol.

He has reduced mobility, requires assistance to stand from armchair or bed and walks with a high gutter-frame walker.
Mildly obese, is on a weight reduction diet. Cadges lollies from other residents.

This information is usually in a separate section of the file. It may still be referred to by the GP.

This records the progress of the condition, what was done to assist, and what the outcome was.
Assessment information identifies the supports that were required. The transition into care assessment and plan records the type of support the person requires at this stage, and how and by whom the support can be provided (e.g., the Kiwi residential facility).
It will include medications required by the person. Support tasks will be fully detailed.

Physical factors

Records the physical activities the person needs support with; can do independently; when the person prefers to bathe, go to bed etc.
Cognitive (thinking and problem solving skills)

Harvey’s cognitive abilities have been reduced by both conditions: he has poor long- term and short- term memory. Requires simple instructions one step at a time, with verbal prompts to keep him focused on his task.

He has developed coping skills for his poor memory, to cover his inability to remember staff and residents’ names. He calls all females “Mrs” and all males “Mate”. His main topic of conversation is the weather.

Harvey has not attempted to leave the grounds however there is a real concern that if he had access to the street he would quickly become completely lost and unable to explain in clear detail where he now lives.

Social

Harvey enjoys the company of others, plays rest-home bowls and watches most resident activities.

Needs firm direction to keep out of the staff office, the kitchen and to respect the privacy of other residents who have visitors.

Sensory

Harvey has good hearing and vision.

Emotional

Harvey presents as accepting of his health changes. Grief and loss issues are blurred with his inability to understand the need for him to be placed in a care facility.

Spiritual

Harvey would like to visit the RSA every Sunday afternoon to spend time with his friends.

Environmental

Harvey prefers to sit close to the windows.

Environmental factors

Records the important aspects of the person’s living arrangements such as the person’s preferences in the environment. For example a favourite chair or possessions.

Cognitive factors

This outlines any foreseeable concerns about the safety of the person due to cognitive ability. It may also give tips or strategies about how best to support the person.

Social factors

Records the relationships and supports the person has and their social interaction. For example, the family/whānau supports or others that are significant in the person’s life.

Emotional factors

Records the emotional, mental and psychological wellbeing of the person including mood changes. For example, if the person experiences mood swings or is fable (up and down).

Spiritual factors

Records the religious or spiritual interests the person has. For example, if the person would like contact with a chaplain, priest or tohunga. This can also be about activities that provide satisfaction and meaning, and which acknowledge the person’s values.
**Progress notes**

A record of changes, documented by staff supporting the person.

**Multidisciplinary team meeting notes**

Documentation of the MDT meeting and consumer review.

**Family meeting notes**

Record of the outcome of the family meeting.
Supportive interactions

Supportive interactions are positive relationships and communications that we have with other people, including people we support.

These interactions include working together, helpfulness, kindness, care, positive relationships, compassion, being sympathetic, giving support and connecting with others.

When supporting a person living with dementia, it is essential to ensure that your interactions are supportive and positive. Supportive interactions are made up of social, physical and communicative interactions.

Social interactions

Social interactions are a sequence of actions and events that occur between people and/or groups of people. These include social contacts, relationships and social activities.

Physical interactions

Physical interactions are the actions and reactions a person has within their environment. These include behaviour and the ways a person responds to their physical abilities and their environment.

Communicative interactions

Communicative interactions are the opportunities and situations in which a person is able to express individual choices, wants, needs and preferences and can contribute to discussions and interact with others.

One-on-one time is essential for supportive emotional and social interactions. You should try to make time each day to talk to and be affirming with the person you support.

Supporting positive interactions

Positive interactions are ways in which you communicate with people living with dementia so that they feel valued, supported and respected.

Positive supportive interactions include:

- communicating with the person in a positive manner so they can maintain good self-esteem and independence.
- creating one-on-one moments: time for you and the person you are supporting to interact, making sure that the person feels included and can participate.
- listening to what the person has to share. This helps them to express their feelings, needs and emotions. By listening you also show respect for the person.

Think about

Increase assistance as needed. As a person’s dementia progresses, the person’s support needs will also increase.
• not passing judgement on the actions of the person. This will help that person to feel valued and safe.

• understanding that spiritual needs are lifelong. Helping the person participate in their spiritual support networks is an important aspect of your interaction with them.

• being aware of any personal likes and dislikes and cultural preferences the person has.

• helping the person feel valued and respected. This reduces stress because their holistic needs are met.

• ensuring that people who are significant in the person’s life are also encouraged to interact effectively, by role modelling respectful, dignified and personalised time together.

• checking in and checking out by saying “Hello” when you come to work and “Goodbye” when you leave. This also helps the person to orientate to time and place, and supports the cognitive abilities that the person retains.

It is important to remember that each person living with dementia is unique and needs to be treated as an individual, with their personal needs, preferences and choices respected. It is important to be empathetic and see things from the person’s point of view. Remember that promoting the person’s independence is important so that, whenever possible, they can have some control over their life.

Personal plans and life stories help provide you the information you need to be able to interact effectively with the people you support.

Take another look at Harvey’s life story and plan. The next page shows an example of how you could use them to enhance communication and interaction with him.
<table>
<thead>
<tr>
<th>Promotion of:</th>
<th>Environmental</th>
<th>Physical</th>
<th>Social</th>
<th>Spiritual</th>
<th>Emotional</th>
<th>Cultural</th>
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<tr>
<td>Supportive interaction with the person you support</td>
<td>Accompany/assist Harvey to the lounge, check he is comfortable and that he has someone to talk to.</td>
<td>While assisting Harvey with dressing or grooming allow extra time for him to respond to a request.</td>
<td>Ensure Harvey knows the activities that he can attend today at Kiwi Residential Care.</td>
<td>Sit and listen to Harvey’s story about the loss of his wife.</td>
<td>Check that Harvey has something to occupy him when other residents have visitors.</td>
<td>Make sure Harvey has the opportunity to socialise with other men in Kiwi Residential Care.</td>
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<td>Encourage Harvey away from staff areas of the facility. Accompany him to a residents’ area and sit with him until he has settled.</td>
<td>Verbal prompts or instructions are given one step at a time.</td>
<td>Reintroduce Harvey to other residents taking part in the facility’s activities.</td>
<td>Look at and talk about the photos of his wife and brothers that Harvey has in his room.</td>
<td>Sit and listen without correcting when Harvey talks about being fine if he could just go home.</td>
<td>Arrange for a member of his former darts team to visit him.</td>
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<tr>
<td>Communication skills used to interact with the person you support</td>
<td>Re introduce yourself each time you interact with Harvey.</td>
<td>Give verbal instructions simply and one step at a time.</td>
<td>Explain to Harvey what is happening. Show Harvey how he can take part.</td>
<td>Make sure Harvey has a “quiet time” when he can talk about the things that are important to him.</td>
<td>Be aware of Harvey’s body language and/or behaviour; respond by making time to talk with him.</td>
<td>Organise a volunteer to spend time with Harvey sharing his interest in engineering and darts.</td>
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<td>Explain clearly but firmly that the office is for staff only. Show Harvey the staff sign on the door.</td>
<td>Check that Harvey has understood the message/instruction. Use open questions.</td>
<td>Explain to Harvey who each person taking part in the social activity is. Name stickers may help.</td>
<td>Use active listening skills to assure Harvey you are interested in his story.</td>
<td>When Harvey is moved away from residents with visitors, explain carefully that they need to be alone. Take time to be with him and talk to him about his interests.</td>
<td>While sitting with Harvey show him books about engineering and encourage him to comment about the photos.</td>
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</tbody>
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Think about a person living with dementia who you support. What type of engagement do you have with the person that promotes the following three supportive interactions?

Social interactions

Physical interactions

Communicative interactions

What other interactions do you have that supports the person?

Culture?

Spirituality?

Emotional needs?

Cognitive functions?
Assistance with daily living activities

One of your top priorities in supporting a person living with dementia must be to keep them fit and healthy, both physically and mentally. Monitoring a person’s health, particularly as dementia progresses, is important as they may no longer be able to identify certain health risks. As you carry out your daily tasks you must look for signs of pain and discomfort and ensure that you work to make the person’s life more enjoyable.

You may be tasked with helping a person carry out routine daily activities with as much client autonomy as possible. The role of a personal care provider is an important one and the responsibility of supporting a person living with dementia is significant.

Providing support to carry out daily activities must be done with respect for the dignity of the person, be in accordance with their personal plan and include all members of the person’s healthcare team (that is, doctors, nurses, psychologists, nutritionists, family, whānau and other team members). You must stay within your roles and responsibilities and keep to your organisation’s policies and procedures.

The daily tasks for which you provide care may include:

• personal hygiene cares.
• urinary/bowel elimination.
• nutrition and fluid needs.
• mobility needs.
• comfort.
• rest/sleep.

Each person you support with personal care has their own life experiences, culture, needs, feelings, likes and dislikes. All people, regardless of illness or impairment, must be treated with respect and dignity.

When you provide personal care you need to think about why you are doing the task and how you are supporting the person. This may include ways you encourage independence and what the expected benefits are.

When supporting a person you need to ensure you treat them with dignity and respect, support and encourage their independence and protect their privacy as much as possible.

For more information about personal care refer to the learning guide for US 23386, Supporting personal care.
Personal hygiene care

Personal care aims to support the person to maintain a clean and healthy body.

This type of care can include:

- showering, including bathing or sponge bathing.
- going to the toilet and maintain cleanliness.
- mouth care, including brushing teeth and gum care.
- hair or skin care, including keeping skin healthy and nails clean.
- dressing, including the person choosing which clothes to wear.
- eating or drinking, including any equipment or special diet needed by the person.

Urinary and bowel elimination

Toileting personal care includes understanding the functions of the person’s bladder and the bowel, being aware of the frequency of elimination and observing hygiene practices.

There are a number of reasons why a person living with dementia might have difficulty going to the toilet. These could be related to difficulty in recognising the need to go to the toile, loss of control, difficulty in getting to the toilet due to physical problems such as mobility, co-existing illness or frailty and increased loss of memory or cognition.

Understanding incontinence

Incontinence describes a loss of bladder or bowel control that may result in involuntary leakage of urine and/or faeces.

Incontinence is not an inevitable part of dementia, but there are some situations that may cause a person living with dementia to become incontinent. These could include urinary tract infections, severe constipation, the side-effects of medication and prostate gland problems.

Many support workers find supporting a person who is incontinent to be one of the most difficult aspects of their role. Family carers can find it very difficult to cope with and manage incontinence.

There are products available to help manage incontinence and help you, as the support worker, carry out your task of keeping the person mentally and physically healthy.

Nutrition and fluids

Fluids and hydration care includes understanding how the body uses fluids, understanding the effects of dehydration and increasing and maintaining the person’s nutrition and fluid intake.
Most people living with dementia lose weight in the later stages of their condition. This in turn can have a negative impact on their immune system, making it harder for them to fight infection.

Frailer, older people, including those who live in aged care facilities and particularly those who have been diagnosed with dementia, are at higher risk of poor hydration. They not only feel less thirsty; they may forget to drink or eat, and rely heavily on others to provide the hydration and nutrition levels they need.

You need to encourage a proper intake of food and liquids. Nutritional specialists can advise on proper diets. Other problems associated with intake, including issues with chewing or swallowing, can be managed by the healthcare team.

Signs of inadequate fluid intake are: passing small amounts of concentrated urine; constipation; recurrent urinary tract infections; poor skin elasticity; and dry mouth, lips and tongue.

If you wish to know more about the fluids and hydration aspect of personal care, ask your supervisor or a Registered Nurse for more information.

**Mobility**

As the dementia process progresses over time it is likely that the person’s brain will be affected to the point where movement and balance are reduced. As the person becomes more frail they are likely to become uncoordinated and may lose their ability to move or walk. They may take shorter steps, their posture may become stooped, the space between their feet may narrow, and they may no longer be able to pivot when they turn. When they carry objects their movements may be slow and clumsy. They may bump into things or have a tendency to fall. These changes can happen quickly or may take years.

You need to look for early signs of deterioration in mobility and adjust your care according. The person may:

- only be able to walk for a short distance.
- require a cane or walker and eventually a wheelchair.
- start to need someone with them as they move or walk.
- feel more comfortable when there is someone standing nearby as they walk or move.
- need to be positioned in bed.
- have difficulty in getting up from chairs.
- have difficulty in walking outside or on uneven surfaces.
- hesitate when going through doorways.
- be afraid to use the stairs.
Regardless of the changes in mobility it is important to remember that maintaining the person’s dignity and independence is paramount. Even if they eventually become confined to a bed or chair, they should still receive care that supports mobility, such as care from a physiotherapist or a community nurse to help them move without injury. This care should be in accordance with the person’s personal plan and should be supported by the healthcare team.

**Comfort**

A person may feel discomfort for many reasons – they may be unable to move, their visual and hearing aids may not be functioning properly, their medication may not be appropriate, they may feel uncomfortable with too many people around or if they are in an unfamiliar area, they may feel bored or disconnected, they may feel that their wishes or needs are not being met, or they could simply be cold, hungry, thirsty, tired or need to use the toilet. The list is endless.

You must be vigilant for signs of discomfort and distress and help minimise them to the best of your ability. You must also recognise your own limitations in being able to minimise their discomfort and gain as much support and reassurance as you as the care provider need, through self-advocacy and advice from colleagues or a supervisor.

In the later stages of dementia a person may not be able to communicate their discomfort. It is important to watch for changes in behaviour or increased confusion. If you notice such changes you must record and report them immediately, as they may relate to a more severe problem that could have serious consequences.

**Rest and sleep**

As dementia progresses it can be increasing difficult for the person to get the rest they need. Many people living with dementia experience changes in their sleep patterns so that they are drowsy or require naps in the day but are unable to sleep at night. Sleep disturbances or difficulty in resting are common with people living with dementia, Alzheimer’s disease in particular. Research has shown that people living with dementia tend to experience increased confusion, anxiety and frustration as the day goes on – this is referred to as ‘sundowning’.

Factors that may contribute to this are mental and physical exhaustion by the end of the day, a disruption in the body’s internal clock and less need for sleep. The caregiver may miss non-verbal cues because they too are tired by the end of the day.

All of these factors can have a direct impact on the person’s ability to cope from day to day and can lead to behavioural problems.
Observing changes and carrying out clinical tasks

Observing, monitoring, reporting and recording are all part of your role. It is essential that you observe and respond to the changes in the person you support, report those changes to the appropriate people and record them in accordance with your organisation’s policies and procedures.

You will observe and monitor the person you support under the direction and delegation of a health professional and in accordance with the person’s personal plan and your organisation’s policies and procedures.

As you are supporting the person you are in a position to notice any change in the person’s state or their ability to cope with daily life. You must review the person’s personal plan and understand their condition. Check whether their condition is:

- permanent.
- terminal.
- unstable.
- stable.
- part of a healing process.
- part of a disease process.
- part of the aging process.

It is important to be aware of the information you gather through sight, touch, hearing and smell.

Other notable changes you observe might be:

- an increase in pain.
- bruising or bleeding.
- frequent falls or unsteadiness.
- different breathing sounds.
- slurred speech, clammy or dry skin.
- emotional changes.
- behavioural changes.
- physical changes.
The following are routine observations and/or clinical tasks that you may monitor on a daily basis.

**Observations may include:**
- systolic and diastolic blood pressure.
- blood glucose level.
- temperature.
- oxygen status.
- heart rate.
- weight management.
- other observations.

**Clinical tasks may include:**
- wound management.
- bowel management.
- administering medication.
- catheter care.
- nebuliser use.
- oxygen administration.
- other tasks.

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**Diagram:**
- Oxygen administration
- Blood glucose
- Systolic and diastolic blood pressure
- Nebulizer use
- Bowel management
- Administering medication
- Temperature
- Oxygen status
- Catheter care
- Heart rate
- Wound management
- Weight management
- Special observations
The diagram on the previous page lists several routine observations and/or clinical tasks that you might observe, report and record on a daily basis. Please select **four** observations or tasks, or identify and list your own, and provide your organisation’s process for:

- recording a change in condition.
- reporting a change in condition.

<table>
<thead>
<tr>
<th>Observation or task One:</th>
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<tbody>
<tr>
<td><strong>If the condition changes, how is it recorded?</strong></td>
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<tr>
<td><strong>If the condition changes, how is it reported?</strong></td>
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<table>
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<th>Observation or task Two:</th>
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<tr>
<td><strong>If the condition changes, how is it recorded?</strong></td>
</tr>
<tr>
<td><strong>If the condition changes, how is it reported?</strong></td>
</tr>
</tbody>
</table>
Observation or task Three:

- **If the condition changes, how is it recorded?**
- **If the condition changes, how is it reported?**

Observation or task Four:

- **If the condition changes, how is it recorded?**
- **If the condition changes, how is it reported?**
Strategies for responding to changes

In a single day there could be several situations where you need to use your skills and strategies to observe and respond to changes in a person’s mental and physical condition, personal needs, quality of life or behaviour. Such situations also give you the opportunity to assess risk, react to the change positively, communicate to the person and provide information to the other members of their healthcare team, including family and whānau.

Risk management

Risk management is a process by which we identify elements of a person and their environment that could be harmful to them and others in the area. It is important to identify these risks so that we can offer safe and efficient support.

Risk can occur in many different ways. How we provide support can be compromised when something is identified that may have the potential to cause harm to the support worker, the person living with dementia or others. Managing that risk involves identifying and reporting safety issues early to ensure that the controls can be put in place to reduce the likelihood of harm.

Steps to managing a risk may include:

- identifying the risk.
- taking action to manage the risk.
- isolating the risk.
- eliminating or minimising the risk.

Information provision

It is increasingly recognised that involving the person living with dementia and their families in the process of care is an important aspect of support. Communication and the relay of quality information is a crucial part of being a support provider.

The person and their family/whānau may be involved at all times. Language and literacy barriers may cause difficulties in supporting the person, their family/whānau or other people providing care and this may cause conflict to arise.

When you need to communicate important information, allocate sufficient time; don’t rush. Make sure that the information you give about the person’s status, medications, treatment plans and notable changes are clear.

Check that your listeners have understood the information you have given them and keep your information concise and relevant.
Barriers to communication

Communication involves giving and receiving messages in order to exchange information between two or more people. When one of them has failing abilities, communication becomes more difficult. This becomes frustrating for people living with dementia, and for those trying to communicate with them, as sometimes messages become misinterpreted.

A limited attention span can make longer conversations difficult. The person has limited ability to focus on more than one idea at a time and becomes confused with instructions that have several steps. Break an activity down and explain it step by step.

Short-term memory problems can lead the person to lose their train of thought or to repeat things again and again. The person may quickly forget something that they understood at the beginning of the conversation.

People living with dementia sometimes describe an object that they cannot name or create a new word to describe that object.

Background distractions (such as the TV or other nearby conversations or activities) can provide too much information for the person to process, making communication difficult.

People living with dementia may need more time than the average person needs to respond to a question. This requires extra patience and giving the person time to process the question and make a response.

It is common for people living with dementia to experience a gradual decrease in their ability to communicate as their dementia progresses. Communication can be affected in a number of ways, depending on what area of the brain is affected and the person’s underlying personality.

Verbal communication

Dementia commonly affects the verbal skills. There may be a progressive loss of the ability to speak. Verbal communication, the use of language and words, is the most obvious method of communicating. The person also interprets the words they hear into meaning – for example, to understand instructions.

People living with dementia may have difficulty expressing themselves clearly to others even though they may understand what is said. They may have difficulty in recalling the words they need, especially for objects and names. They may experience a complete loss of words or become stuck on an idea, word or part of a word in their efforts to get an idea across.
They may have a limited spoken vocabulary and have difficulty in putting a sentence together in a way that makes sense. These difficulties are to do with **expressive communication**.

People living with dementia may have difficulty organising their thoughts and difficulty with producing sounds and speech. This is called **receptive communication**. It may make it difficult for them to communicate verbally with others. If you speak to them you may need to repeat the communication several times in order for them to understand what you are saying.

Sometimes a person living with dementia reverts to a previous language that they learned as a child. This can be particularly difficult, especially when the person loses the language of their present world.

There are many ways other than verbal language in which a person communicates. As people lose their language skills, they seek other ways to communicate their message.

**Vocalisation**

Vocal communication is how you use your voice, to express thoughts, feelings and emotions. It includes the tone and pitch of the voice.

People living with dementia can have a noisy way of communicating called vocalisation. This can include sounds such as screaming, repetitive speech, moaning and sighing.

Some noise making has a negative effect on the person, the person’s family or those in a caring role and may cause them distress. This is called ‘inappropriate vocalisation’ and is very difficult to change.

Sometimes the behaviour is treated with medication, but more often it is modified by changing factors in the environment or by looking for the meaning behind the behaviour. Causes that are often overlooked may be pain, discomfort, depression or too much stimulation in the environment.

**Non-verbal communication**

Non-verbal communication includes body language such as eye contact, facial expressions, posture, gestures and touch. Good lighting is important, to make sure that the person’s face and body language can be clearly seen.

A person living with dementia may pick up non-verbal cues much more clearly than what is being said. Hand gestures and facial expressions are useful ways of improving understanding – pointing or demonstrating what is required can help. Touching and holding the person’s hand may bring a positive response, as it helps to keep their attention and shows them that you care.
Communication aids

A person living with dementia may have sensory losses such as impaired vision and/or hearing loss. Communication aids such as glasses and hearing aids need to be fitted correctly and work properly.

Poorly adjusted aids can mean that communication is further compromised for the person. It is important to check the person’s personal plan to find out if they usually wear glasses or a hearing aid to help with communication.

Hearing aids should have their batteries checked frequently, as the person may not recognise when they need to be changed. Even poorly fitting dentures can make speech more difficult to understand, as well as affecting the person’s ability to maintain a good nutritional intake.

Communication partner

A communication partner is someone who is significant in the person’s life and who the person prefers to communicate with – it may be a spouse, regular carer, friend or family member. This communication partner plays a crucial role in helping the person to make sense of the world and connect with their environment and memories.

Communication partners can promote social conversation because they know and understand the person’s previous experiences, routines and interests. A communication partner uses verbal and non-verbal language, cues and triggers in a way that provides opportunities for the person living with dementia to express their personal preferences, thoughts and emotions.

Culture and background

Traditions, customs, life experiences, how we do things, ways we talk, what we talk about, eye contact, and personal space are all part of who we are and aspects of our culture. People living with dementia may express themselves in ways that reflect their cultural background and preferences. The person may revert to a language that they learned as a child, or they may behave quite differently from the way they did previously. This can cause distress to the person and their family.

Understanding the person’s unique experiences and values can help overcome barriers to effective communication with them.

Age and gender

Age and gender are important things to consider. Respect for older people is no less important for someone who is affected by memory loss and confusion. The use of respectful and age-appropriate language helps the person feel valued and retain their self-esteem. It may be more comfortable for the person to communicate their needs and negotiate their care with a carer of the same gender.
**Health status**

The person’s state of health can reduce or enhance their ability to communicate. Medications, depression and underlying medical conditions can all influence how a person living with dementia responds at any particular time. Generally, poor health will reduce the person’s ability and desire to communicate.

Caregivers need to be very observant when they are supporting a person living with dementia. Knowing the person’s normal functioning and daily patterns is a useful way to recognise when changes occur. Inability to communicate a health problem can put the person living with dementia at high risk of health complications.

Medication and its side effects can make a person less responsive. It may make people drowsy, reducing their ability to process information.

Communication can be affected by pain and discomfort that the person may not be able to tell you about. Reading expressions and body language can be a helpful way to recognise when a person living with dementia is uncomfortable or in pain.

**Environmental factors**

A busy environment with activity, noise and distraction can make it difficult for the person living with dementia to make sense of the many messages at once. This sensory overload can lead to high levels of frustration and anxiety, with the person becoming increasingly restless and confused. Occasionally it will lead to verbal or physical aggression.

Improve communication by avoiding competing noises (such as the TV or radio) and activity around the person. Stay still when you are talking to them, as this makes it easier for them to follow what you say.

A consistent approach is much less confusing for the person living with dementia, so it is helpful if everyone uses the same style of communication with them. Repeating the message in exactly the same way is important if the person living with dementia is to function to their full potential.

Regular routines also help to minimise confusion and can assist communication.

**Life stories**

A life story, as we have already seen, includes personal details, important family members, friends and colleagues, major life events, abilities, likes and dislikes and routines the person followed.

Using additional information in a person’s life story and personal care plan, as well as photos, personal mementos and anecdotes, to learn about their background can be a way of improving communication with them.
Communication skills

Supporting a person living with dementia presents special challenges for effective communication. The way you communicate with a person includes verbal and non-verbal communication and has a direct effect on how they interpret the messages they receive from you. These messages can be positive or negative. Positive interactions will help reduce stress and anxiety, which can be very confusing and upsetting.

Don’t assume you know what the person living with dementia thinks or wants. Ask them. Avoid giving orders or telling the person what to do. Tell them what they can do rather than what they can’t. Avoid arguing with them or contradicting them. Don’t ‘talk down’ to a person living with dementia – they may pick up on your tone of voice, even if they don’t understand the words. Never talk about people in front of them as if they are not there.

Here are some tips for helping a person living with dementia to communicate:

• approach the person from the front. Get their attention and use their name.
• face the person, be at the same eye level and make eye contact, if that is culturally appropriate.
• be calm and gentle. Remember that your facial expressions, body language and tone of voice are extra important.
• use touch to help draw and keep the person’s attention, as well as to communicate feelings of affection.
• avoid talking when there is background noise (for example, from a TV or radio).
• remind the person about upcoming events and activities.
• use activities like music and singing to communicate.

Giving instructions

• use short, simple sentences and make one point at a time.
• use familiar ideas rather than new or complex ones.
• allow time for the person to understand the information and to respond.
• use simple questions with short answers. Do not ask questions that rely upon the person having a strong memory.
• if you repeat a question or any information, try to use the same words.
• If you have not been successful, try again later.
Communication as a partnership

Develop a partnership with the person you are supporting. Know the person’s specific needs and preferences. Work together to achieve a common goal by using the person’s retained abilities to involve the person and encourage the activities and tasks the person is able to do. For example, “If I help you with the top button of your shirt, can you do the other buttons?” Your helpful actions and encouragement will enable the person to participate.

Social conversations

- Introduce the person to other people nearby when you seat the person in the lounge or dining room.
- Know the person’s interest or hobbies and provide opportunities for the person to talk about these interests.
- Observe activities that people are engaged in. You might stop and ask about their activity, e.g., knitting.
- Comment on photos in the person’s room to encourage the person to talk about their family and friends.
- Use library books or pictures in magazines to encourage conversations about a person’s former work roles or interests.
- When you engage with a person make sure the person can see your facial expressions by ensuring you are both in a good light. Being seen properly helps reduce confusion about who you are and what you are saying.

Promoting good communication

Avoid coercing the person. Coercion is a form of bullying, sometimes involving threats or force. People living with dementia can feel bewildered and confused, and support workers can unwittingly force people to do what they want rather than accepting the person’s lead.

It is important to calmly and gently encourage the person to do what you want, rather than bully, frighten or threaten the person to achieve your goal. For example “I am making a cup of tea for you, shall I put it on the table for you” - rather than - “If you don’t come to the table now, you won’t get a cup of tea.”

Avoid patronising the person. When you patronise someone you tend to talk down to the person and assume that you know better than the person about their needs. When you act like this, it affects the person’s confidence and self-esteem and takes away choice and respect.
Minimising stress and anxiety

The way you communicate with a person with dementia includes verbal and non-verbal means, and has a direct effect on how the person interprets the messages they are receiving from you. These messages can be positive or negative. Positive interactions will help reduce stress and anxiety which can be very confusing and upsetting.

Choice and preference

Personal choices and preferences are an important part of everyday life and are part of what makes each person an individual. Think about all the things you did this morning to get ready for work. You will have made many choices: what time to get up; what to wear; what to eat; which radio station to tune into; what tasks to do before leaving home and what to leave until you return; whether to make your lunch or to buy it on the way; whether you will walk or drive to work.

Imagine what your life would be like if you could not express your preferences or make choices. How would it feel to have someone else choose what you wear and what you do for the day?

People who are denied the opportunity to express their preferences and choices quickly lose confidence, have low self-esteem and can become depressed.

You can play an important part in preventing loss of confidence and self-esteem by ensuring that the people you support are able to express their own preferences, make choices and have their choices respected.