Learning Guide

Dementia: Effects of providing support

23922 Manage the effects of providing support for people living with dementia in a health or well-being setting.

Name:

Workplace:
Contents

Introduction .................................................................................................................................................. 1
Dementia ......................................................................................................................................................... 2
Effects of providing support ..................................................................................................................... 3
Effects, causes and impacts of providing care .......................................................................................... 5
  Stress ......................................................................................................................................................... 5
  Burnout .................................................................................................................................................... 6
  Role change and loss ............................................................................................................................... 7
Increased knowledge, understanding and skills ....................................................................................... 9
  Helpful hints for increased understanding and skills .......................................................................... 9
Observing changes in the family/whānau ............................................................................................... 10
Coping strategies and techniques ............................................................................................................. 13
  Self-reflection ....................................................................................................................................... 16
  Keeping a stress diary ............................................................................................................................. 17
  Taking time out ...................................................................................................................................... 18
  Debriefing .............................................................................................................................................. 19
  Loss and grief ...................................................................................................................................... 20
Support and advocacy services ............................................................................................................... 24
  Alzheimer’s New Zealand ..................................................................................................................... 25
  Age Concern New Zealand .................................................................................................................. 26
  Residential care facilities ..................................................................................................................... 27
  Home-based services ............................................................................................................................ 27
  Health and Disability Commission ..................................................................................................... 28
  Unions or professional organisations ................................................................................................. 30
Introduction

This learning guide explains the personal implications for family/whānau and you, as the support worker, of providing 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:

- 23922 Manage the effects of providing support for people living with dementia in a health or wellbeing setting (level 4, 4 credits).

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

Follow the tips in the notes column.

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

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

Finish this learning guide before you start on the assessment.

What you will learn

This topic will help you to:

- manage the effects of proving support to the family/whānau of a person who is living with dementia.
- manage the effect on you, the support worker, of providing support to people living with dementia.
- use strategies to respond to changes in the family/whānau of a person you support who is living with dementia and for yourself as the support worker.
- access appropriate local and national support advocacy services for the family/whānau and for you as the support worker.

More info

If you have a trainer, they should give you all the forms that you need for this topic.
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.

Common symptoms of dementia include:

- gradual loss of memory.
- 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.

Although we do not know what causes dementia it appears likely that there is a link between age, environmental factors and family history. Dementia can affect anyone, regardless of their intellectual ability or ethnicity. Dementia is known as a ‘progressive’ illness, as the symptoms appear to get worse over time.
Effects of providing support

Caring for someone with dementia requires a lot of energy and hard work and can be both rewarding and challenging. It can be an emotional rollercoaster ride for family/whānau, especially during the onset of dementia, which can be extremely distressing and stressful. Each family/whānau member will be affected by, and cope with, the person’s changing condition in different ways.

There are a number of effects that family/whānau and support workers may experience when caring for someone living with dementia. The nature of these effects will depend on:

- the stage of dementia reached by the person.
- their behaviour.
- the coping mechanisms of the family/whānau.
- what supports they have in place.
- the relationship they had with the person before the person developed dementia.

Some family/whānau of a person living with dementia may:

- deny there is a problem.
- be embarrassed by the person’s behaviour.
- be unsure where to seek advice.
- not want advice.
- be unable to face the changes in the person and the new requirements of looking after them.
- become overwhelmed by the situation and their sadness.

These effects may lead to:

- stress.
- emotional, physical and financial stress that can lead to burnout.
- losses – the family/whānau or support workers may experience a number of losses.
- role changes – for example, from being part of a partnership to becoming a decision maker.
- the need to increase their knowledge and skills so that they can support a person living with dementia.
- abuse – the person living with dementia may be abusive to carers, may not recognise them and may not understand that carers are supporting them. Carers may also be abusive to those they are caring for.
Managing the condition of a person you support can be very difficult. Seeing a person’s inevitable deterioration can be incredibly stressful and demoralising. The effect on you of being a support worker could include:

- increased demand created by the character, behaviour, conditions and compounded circumstances of the person.
- the impact on your own physical health, mental health and social and spiritual life.

Because of these factors it is important that carers and support people:

- have time to themselves.
- know what support groups and services are available to them.
- have access to reliable information.
- feel supported.
- can ask questions.
- can ask for help when they need it.
Effects, causes and impacts of providing care

Stress

Stress is the way our bodies and minds react to the things that are happening to us. This reaction is normal and happens to everyone; the level of stress experienced will depend upon the circumstances and the person’s resilience. Some stress is useful and protective when it makes us move from danger – for example, when we jump out of the way of a bus. But prolonged or severe stress can be harmful and may lead to physical and/or emotional problems.

Stress first affects our body and then goes on to affect our thoughts and feelings.

Some physical effects of stress are:

- a sore jaw and/or a headache.
- an increase in the heart rate and/or a tight feeling in the chest.
- sweating, muscle tension and rapid breathing.
- shaking hands and/or a feeling of knots in the stomach.

Stress also affects thoughts, feelings and emotions. The person may have trouble making decisions, concentrating and remembering things. They may be impatient with others and be unable to relax. They may feel anxious, lose confidence and feel socially isolated.

Possible causes of stress

Causes of stress when supporting a person living with dementia include:

- the constant demands of the caring and supporting role as the person becomes more dependent.
- the need to keep a constant watch on the person for their safety (in case they wander, get lost or do unsafe things).
- the person not recognising close family members, friends, or their support worker.
- the person unable to communicate their own needs and wishes.
- the person constantly and repeatedly asking the same questions.
- the person hiding or losing things and/or is suspicious or accuses others of doing or hiding things.
- the person living with dementia is not able to sleep, which interrupts the sleep of the family/whānau.
Stress overload

Too much stress is called stress overload. People affected by stress overload may find that they:

- eat more or a lot less.
- experience a pain in their stomach.
- behave erratically – for example, drink or eat excessively, drive carelessly or make too much use of medication.
- cannot sleep properly and feel tired all the time. They may wake early or have trouble getting to sleep.
- experience a lot of ‘nervous’ energy and a feeling of restlessness.
- cry a lot.
- get angry very easily and snap at people.
- get sick more often with colds and flu because their immune system is not working well.

Burnout

When the stress we are under is excessive and happens over a long period of time, it can lead to burnout. In burnout you are overwhelmed by demands or responsibilities that you feel unable to meet. As the stress continues, you begin to lose the interest or motivation that led you to take on the responsibilities in the first place.

Because burnout is gradual, it can be difficult to identify and deal with. It is important to recognise the symptoms of excessive stress as the earlier the symptoms are recognised and addressed, the better the chance of avoiding burnout.

The signs of burnout tend to be more mental than physical. They include feelings of frustration, irritability, anxiety and a sense of failure in what you are doing. This may lead to hopelessness or sadness, depression or detachment or withdrawal. The person feels that they are being drained of emotional energy and feels overly tired a lot of the time.

Family/whānau may have doubts about their ability to care for the person or about their own mental health (their coping skills, for instance). They may withdraw from others around them.

These emotions can cause the person to feel trapped in the situation. This in turn can lead to a sense of powerlessness, which can lead to feelings of isolation and loneliness that result in even more stress.

These feelings will affect your work and may impact on your relationships when you find yourself too tired to provide affection or to socialise.
The difference between stress and burnout

Burnout may be the result of stress overload, but it isn’t the same as too much stress. Stress, by and large, involves too many pressures that demand too much of you physically and mentally. Stressed people often think that if they can just get everything under control, they’ll feel better. While people are usually aware when they are under a lot of stress, they don’t always notice burnout when it happens.

Burnout is about feeling empty, devoid of motivation and beyond caring. People who experience burnout often don’t see any hope of positive change in their situation. If excessive stress is like drowning in responsibilities, burnout feels like being dried up and no longer able to cope.

Role change and loss

Family or whānau who support someone living with dementia may find that the roles they previously played in their community or family have changed. For example, a spouse may have to take on responsibility for the running of the household, or adult children may need to help organise an older parent whose memory is failing.

For some people this can be rewarding, but for many people who have spent their lives in one role it can be distressing.

As family/whānau find that their usual role in the relationship changes they may experience feelings of grief and loss. They may be dealing with losses such as:

- the loss of a partner and the person they once knew.
- the loss of personal freedom and future plans.
- if they are the carer, the loss of paid employment, hobbies and socialising with friends.

A change of role may also affect a support worker who is asked to work in a dementia unit when they have not done this type of work before.
**Possible causes of stress from changes in role**

While some people find changes of role empowering, others may resent the need to change. Changes of role can lead to feelings of confusion, loss of confidence, isolation and anger.

Family/whānau members may need to start doing tasks that they have never done before, such as attending to banking, finances and decision making previously done by the person living with dementia. They may have to give up their paid employment to care for the person.

Changes of role can include changes in family relationships. For example, the partner of a person living with dementia will move from a sexual relationship to a caring role, or the sons and daughters will move from a parent–child relationship to a caring or nursing relationship as the person can no longer dress, feed or care for themselves.

The progressive nature of the illness means that the support workers’ roles may change. Some support workers may be moved to a dementia unit where they feel out of their comfort zone.

**Possible causes of loss**

Family/whānau experience a loss of relationship as the progressive nature of the illness leads to long-term changes in the person’s ability to remember them, or concentrate on the activities of daily living. Loss covers a wide range of things for family/whānau:

- loss of a lifelong friendship and/or intimate relationship with the person they have known and loved for many years or decades.
- loss of freedom and plans to travel or grow old together.
- loss of the support of the person as a helpmate.
- loss of the person’s physical presence when they are moved from home to a residential care facility or from one facility to another.
- loss when the person dies.
Increased knowledge, understanding and skills

Family/whānau and support workers who care for someone living with dementia will need increased knowledge, awareness and skills. They will need to know:

- how dementia affects that person and how it affects them as carers.
- how to communicate with the person living with dementia.
- what support groups and services are available to them.

They will also need to develop skills to help them ask questions about what they are experiences and ask for help. This can be very hard for people who value independence and self-sufficiency (feel that they do not need outside aid or support).

Helpful hints for increased understanding and skills

Support workers and family/whānau will need to increase their knowledge about dementia and the effects of dementia on the family/whānau as well as on the person.

Carers may need to attend educational courses, do some study and/or search the internet for information. Family members may need to learn how to use the internet.

Carers will need to:

- know how and why the person is reacting and communicating in the way they do.
- be aware of the help available to them from healthcare professionals, new support people, support groups and services.
- learn new strategies to cope with unusual behaviour. Support workers will need to know about person-centred care.

Attending groups and seminars can have a positive effect in that the family/whānau will meet others who are dealing with similar situations. This provides opportunities to offer and receive support and knowledge and to share strategies.

Carers need information about the best ways of communicating with the person living with dementia. They may have to try new ways of communicating or interacting in order to adapt to the person’s changing condition.

Towards the back of this learning guide is information on support and advocacy services.
Observing changes in the family/whānau

Observing, monitoring, reporting and recording changes are all part of your role as a support worker. Therefore you must observe and respond to the changes in the family/whānau you support, report and record those observations in accordance with your organisation’s policies and procedures and provide the necessary information for the family/whānau to get the assistance they need.

As a support worker you will observe and monitor the family/whānau of 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.

You have the opportunity to notice any changes in the family/whānau condition or their ability to cope.

Write

Read the following scenario and then answer the questions.

Kaye and Derek

Kaye was 70 years when her husband Derek started to develop some of the symptoms of dementia. At first they laughed together about how forgetful they both were and they put this down to just getting old. They used to joke about growing old gracefully and how they were getting just like their parents.

However, Derek’s memory became much worse and it was no longer funny for Kaye. This was not the normal ageing process. Before long Kaye needed help from her two sons. She did not like asking them for help, as she had brought them up to be independent. This was a family value that had always been very important for Kaye and Derek, so asking for help was very hard for her.

One of her sons moved to Perth for his job. This left just Kaye and her younger son to look after Derek, who now needed more help and support as he could not do many of the tasks that had been his responsibility in their family life.
Kaye found herself taking on many of the roles that had previously been handled by Derek. For instance, she had to do the banking, pay the bills, organise tradesmen when things went wrong with the house and work in the garden, which was now getting too big for her to manage. Kaye had a heat pump installed because she could not cope with another winter of organising firewood, keeping the fire going in the house and keeping Derek safe from it.

It was hard for Kaye to deal with salespeople and tradesmen, as she had never had to do this before. Although her son was very helpful and supportive, he had his own work and a wife and children to care for.

The need to take on different roles and the many losses she was experiencing (such as a loss of freedom with Derek’s need for constant care) left Kaye feeling overwhelmed, stressed and always worried. She felt that their situation was hopeless and was afraid that Derek might have to go into a residential care facility.

**What were the role changes Kaye was going through?**

**Why was it uncomfortable for Kaye to ask for help from her family?**

**What was the impact on Kaye and Derek in the need to change their roles?**

**What other losses might Kaye may be experiencing?**
Using the information you have learnt so far, briefly describe the impact of stress, loss, role change and burnout on support workers and/or family/whānau.

<table>
<thead>
<tr>
<th>Stress:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Loss:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Role change:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Burnout:</th>
</tr>
</thead>
</table>
Coping strategies and techniques

Coping strategies are plans of action that can be used to ease some of the effects experienced by family/whānau and support workers supporting people living with dementia. All the strategies listed can be taught as a support tool for family/whānau or be used by you, the support worker.

People are most vulnerable to stress when they feel isolated and unsupported; when they are required to make many changes; or when they cannot manage the person’s challenging or unusual behaviour patterns.

Decreasing stress for the family/whānau or support workers assists them to be able to care for the person and helps maintain their health and wellbeing.

The table below describes some actions you can take to reduce stress.

<table>
<thead>
<tr>
<th>What you can do</th>
<th>What to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain healthy diet and good nutrition</td>
<td>Drink plenty of water, eat in moderation from the basic food groups and reduce your intake of salt, alcohol, nicotine and caffeine.</td>
</tr>
<tr>
<td>Rest</td>
<td>Everyone requires adequate rest. This can be difficult when the person being cared for does not sleep well or wanders at night. Taking naps during the day or taking advantage of day programmes or sitter services may be useful in this situation. Attending relaxation groups is a useful strategy. Relaxation classes and meditation teach people to relax at will.</td>
</tr>
<tr>
<td>Exercise</td>
<td>Simple exercises such as deep breathing, stretching and hand, neck and jaw exercises are helpful. If possible, go walking, swimming or cycling or attend exercise classes. Useful stress management includes engaging in sport and recreation.</td>
</tr>
<tr>
<td>Get away from it all</td>
<td>Accept help from family members, neighbours or friends and make use of respite care, day programmes and sitter services. These are all useful strategies for lowering stress. Support workers need to make sure they take their breaks for meals and morning and afternoon tea, preferably away from the work area. Taking frequent annual leave also helps support workers to handle stressful work situations better.</td>
</tr>
<tr>
<td>Let off steam</td>
<td>It is important to recognise that anger and frustration may be part of the process for those who are caring for a person living with dementia. Exercise can help let off steam. Being able to talk to someone who understands the issues and stressors and using support services can be useful. For support workers it is important to not take your worries home with you. Thinking and worrying about the person you are supporting does nothing for the person and can increase your stress levels and eventually drain your energy reserves, which can lead to burnout. Instead, talk to your supervisor or a workplace support person if one is available. Employee assistance programmes can also be helpful.</td>
</tr>
<tr>
<td>Share the load</td>
<td>Using available support services will be useful. Sometimes it is hard to ask for help. However, asking for help to share the load and accepting help when it is offered are useful ways of decreasing stress levels.</td>
</tr>
<tr>
<td>Keep in touch</td>
<td>Call family, friends and other social contacts to prevent the social isolation often caused by increased tiredness, decreased energy levels or embarrassment about any unusual behaviour by the person you are supporting.</td>
</tr>
<tr>
<td>Say “no” to guilt feelings</td>
<td>Feelings of guilt can occur when the family/whānau or support workers feel they are not doing a good job. They may feel that they haven’t been as patient as they should be, or that things are not going well. It is best to discuss such feelings with a trusted person and/or seek help from support workers or others who can offer support. It is important to remember that people who care for a person living with dementia do not always want advice. Sometimes they just need another person to listen. A good rule of thumb is that if people want advice, they will usually ask for it.</td>
</tr>
<tr>
<td>Being informed</td>
<td>When family/whānau members understand how dementia affects the person they are supporting, this can help to lower stress levels by ensuring that they do not expect behaviour that the person is incapable of. For example, expecting the person to dress unaided or to handle money may be unrealistic.</td>
</tr>
<tr>
<td>Training</td>
<td>Look at Careerforce’s online resources on dementia at <a href="http://ilearn.careerforce.org.nz">http://ilearn.careerforce.org.nz</a> Alzheimers New Zealand and Age Concern offer a range of seminars and sessions to inform and educate people who care for someone with dementia. There are training packages, educational courses and seminars for support workers. Ongoing training sessions are helpful to maintain skills and understanding.</td>
</tr>
</tbody>
</table>
Mary cares for her husband Don in their own home. Don has advanced Alzheimer’s, and Mary is finding it increasingly difficult to meet Don’s needs 24 hours a day. She tells you that she feels stressed, often has headaches, and is wondering how much longer she will be able to cope.

Describe two stress management techniques and how they may be helpful for Mary.
Self-reflection

Self-reflection is the process by which you think about and evaluate your behaviour, thoughts and ideas and the impact of these things on the people around you. A great way to conduct a personal evaluation is through writing a diary or in some way documenting traumatic or stressful events. Physical awareness of your body and focusing your mind are also useful tools for self-reflection. Examples of these include yoga and meditation; giving your body and mind time to process and rejuvenate.

Some self-reflective questions that you could ask yourself are:

- What skills do I have for managing this situation?
- What are my strengths in managing this situation?
- What are my weaknesses in managing this situation?
- What problems do I face now as a result of this situation? Why am I having this problem? Why is this bothering me?
- How can I manage this stress in the future? What will I do if it happens again?
- What can I do to avoid this type of stress?

Use simple self-reflection to think of a stress management strategy to apply to a stress that you are currently experiencing or have experienced. Why did you chose that technique? Was it successful or not? The first example has been done for you.

<table>
<thead>
<tr>
<th>The technique used</th>
<th>Why I chose this technique</th>
<th>How successful was it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Becoming better informed by attending a seminar.</td>
<td>I needed to know more about dementia as at the moment I am caring for two people living with dementia.</td>
<td>I learnt so much about the effects of dementia on the person and their family.</td>
</tr>
</tbody>
</table>
**Keeping a stress diary**

The purpose of a stress diary is to help identify small daily stressors as they accumulate, and to recognise how they influence our thoughts, feelings and behaviours. This could be another self-reflection strategy.

Keep a diary of your thoughts, feelings and behaviour for two weeks. Then identify any patterns in your way of interacting and ask yourself, “Do I need to change any of the ways I interact with others?”

The first row of the table below has been filled in as an example.

<table>
<thead>
<tr>
<th><strong>Stressor</strong></th>
<th><strong>My thoughts and attitudes</strong></th>
<th><strong>Results</strong></th>
<th><strong>Change</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mr A asked the same question 21 times today.</td>
<td>Oh my gosh, I really cannot take it today, I’m just not up to it. I feel unwell myself and Jo leaves home to go flatting today.</td>
<td>I had to leave Mr A in the lounge. I felt rude and upset with myself because he is so confused and he can’t help it.</td>
<td>I can’t change his behaviour so I could be more patient with him. I could take a deep breath before I speak.</td>
</tr>
</tbody>
</table>

Friday 18/1/15
Taking time out

It is important that anyone who is providing care and support has time away from the constant demands of supporting the person living with dementia. Sometimes family, friends, neighbours or church group members may offer to help. There are also a number of services that can provide time out.

While using this time to get things done is useful for decreasing stress levels, it is also valuable to spend it in socialising, joining a club, catching up with friends or doing something enjoyable and relaxing. Below is a table showing the types of alternative care available to Jim, a person living with dementia, and how these work for him.

<table>
<thead>
<tr>
<th>Service and description</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day care programme</strong></td>
<td>Jim attends a programme especially for people living with dementia in which a diversional therapist provides motivational activities and opportunities to meet people. At first he was reluctant to go, but now he has got used to the place and the people and he appears happy to go along. This is good, because it gives Mavis, his support worker, a break from caring for him 24 hours a day.</td>
</tr>
<tr>
<td><strong>Respite care</strong></td>
<td>Last month Jim stayed at St Margaret’s Home and Care Services for a week while Mavis went to visit her daughter in Wellington. It was wonderful for Mavis to have a break, and she knew that Jim was safe and being well cared for in her absence.</td>
</tr>
<tr>
<td><strong>Self-advocacy</strong></td>
<td>Self-advocacy is standing up for yourself, making an informed decision about a matter of importance and then taking responsibility for bringing about the change necessary to make that choice a reality. Anyone can act as his or her own advocate. The Health and Disability Commission provides advocacy services to support people in their choices and with their rights. You can read more about this later in this learning guide.</td>
</tr>
</tbody>
</table>
Debriefing

Debriefing is a professional discussion process in which a support worker is assisted to use their abilities to overcome the effects of difficult situations. It provides an opportunity to consider, discuss and express thoughts and emotions related to a recent event or incident in a confidential way. A debriefing can take place at any time.

It is a useful coping strategy because it enables people to:

- reflect in detail on their experience.
- analyse and make sense of what happened.
- learn from their experience.
- discover other useful ways to approach issues or problems in the future.
- think about the impact of actions taken or not taken, so that the action can be done better next time.
- improve communications and teamwork.

Support workers can use informal debriefing at team meetings, support groups or counselling to express their personal experiences, thoughts and emotions.

An effective debriefing meeting should:

- allow adequate time for discussion.
- be close (in time) to any event that has occurred.
- be led by a trained person who is not directly involved in the incident.
- be objective.
- allow for the free flow of discussion.
- engage all those who were involved in the incident and value their contribution to the discussion.

Difficult situations can cause unusually strong emotional reactions that can interfere with your ability to function. Common reactions to difficult situations and/or crisis situations could include:

- inability to concentrate.
- anxiety or panic.
- periods of crying.
- confusion or slowness of thought.
- repetitive thoughts about the event.
- irritability.
- nausea.
• avoidance of reminders of the event.
• anger, rage, blame.
• difficulty in returning to normal activities and/or difficulty in sleeping.
• depression.
• guilt.
• muscle aches and pains.

Loss and grief

It is not uncommon for support workers, family/whānau and other carers for people living with dementia to have feelings of loss and grief. Over time dementia can have the effect of slowly taking a person whom you love, or for whom you have cared, away from you. Each person will deal with this in their own way, but there is a recognised process associated with loss or grief. The steps of this process are:

• denial – hoping that the person is not ill, expecting them to get better and attempting to make abnormal behaviours acceptable.
• anger – getting frustrated with the person, feeling abandoned, resenting the demands of care or resenting people who refuse to provide care.
• guilt – thinking that you have done something to make this happen, regretting getting a diagnosis of dementia, feeling that you have failed if a strategy to help support does not go right, having negative thoughts about the person living with dementia and expecting too much from yourself.
• sadness – feeling depression, not feeling as though you can participate or withdrawing from social activities all together.
• acceptance – coming to terms with the diagnosis, finding happiness in being able to contribute to the person’s wellbeing, being with the person and appreciating your ability to grow from the process.
Coping with grief and loss

The table below lists a number of coping strategies for dealing with loss and grief.

<table>
<thead>
<tr>
<th>Coping strategies</th>
<th>How they can help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing your feelings</td>
<td>Allow yourself to experience positive and negative feelings. It is normal to love and hate someone at the same time.</td>
</tr>
<tr>
<td>Prepare for more</td>
<td>Prepare for the fact that you are going to have to manage your feelings again and again. Accept and acknowledge these feelings.</td>
</tr>
<tr>
<td>Accept your own grieving process</td>
<td>Each of us experiences grief and loss in our own way. What grief and loss will be like for you will depend on how long you support the person living with dementia, your relationship to them and your own history of loss.</td>
</tr>
<tr>
<td>Express your feelings</td>
<td>Talk to someone you trust – they may be a close friend or a counsellor – about what you are experiencing. Ensure you conduct an honest evaluation of whether or not this person is able to help or support you during this time. Also make sure that the person you talk to understands that it is possible to experience grief and loss as a chronic illness progresses.</td>
</tr>
<tr>
<td>Combat isolation and loneliness</td>
<td>Take a break to go out with friends or join a support group.</td>
</tr>
<tr>
<td>Accept yourself and take care of yourself</td>
<td>Learn to accept that there are things beyond your control. Take control of the things you can do something about, such as your own physical, mental and emotional wellbeing.</td>
</tr>
</tbody>
</table>
**Write**

Read the following two scenarios and then answer the questions that follow.

**Scenario 1**

Cath has been caring for Harry at home for eight months. They have been married for 41 years. Cath has a supportive and caring family, and the support she receives from Frobisher’s Home Support has been wonderful. However, she has been feeling stressed recently because there is always something more to learn, as Harry’s condition and his behaviour seem to be changing all the time. She has had to take on more and more of the responsibility of running the home, and feels increasingly tired on many days because Harry isn’t sleeping at night. This has been difficult for Cath because Harry has always been responsible for the maintenance of the house, paying bills and making money decisions.

Choose two relevant coping strategies for Cath and describe how they could be applied to her situation.

<table>
<thead>
<tr>
<th>Description of coping strategy</th>
<th>How could it be applied?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Scenario 2

Claire has been working for Te Awa Care Services for two years. She enjoys her job and likes to attend the team meetings and the seminars for the health care workers and other health care professionals. Two months ago one of the people Claire was supporting died and she has found that very hard to accept. In addition to this, the birth of her new grandson has meant that she has not really had a holiday for over 12 months. The new baby has led to a number of changes in her family. Sometimes she feels stressed and burnt out.

Choose two relevant coping strategies and describe how they could be applied to Claire’s situation.

<table>
<thead>
<tr>
<th>Description of coping strategy</th>
<th>How could it be applied?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Support and advocacy services

There are services available for family/whānau and support workers. The services for family/whānau are in the blue circle on the left hand side in the diagram below. The services for support workers are in the green circle on the right-hand side of the diagram. The circles overlap, indicating that some services are available to all carers.

Doctors and social service agencies can provide up-to-date and reliable information on dementia care and what support services (such as respite care, day programmes and home help) are available.

The learning area of the Careerforce website (http://ilearn.careerforce.org.nz) has excellent information on dementia.

Unit standard 26974 Describe interaction, supports, and reporting for people with dementia in a health or wellbeing setting is an open online course developed by Alzheimer’s New Zealand and Careerforce for people who wish to understand how to support someone with dementia.
Alzheimer’s New Zealand

The role of Alzheimer’s New Zealand is to:

- provide information for people living with dementia, their supporters and families and health professionals.
- provide national advocacy for people living with dementia and their supporters and to raise government awareness of their needs.
- provide support to all member organisations.
- honour the Treaty of Waitangi by developing a working relationship with Māori in the provision of dementia services.

Services

The 21 Alzheimer’s member organisations throughout New Zealand provide support, information and education services for all people affected by dementia, their supporters and family, in their local areas.

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

- support through group get-togethers for the person diagnosed with dementia.
- support group meetings for carers and family members and friends coping with the demands of caring.
- information and education to assist with understanding, diagnosis and treatment.
- day care programmes and befriending services for people living with dementia.
- extensive resource information, including library books, audio resources and regular newsletters.

Visit the Alzheimer’s New Zealand website at www.alzheimers.org.nz

You can download information and order brochures and publications.
Age Concern New Zealand

Age Concern serves the needs of older people by providing national services such as information, leadership and health and welfare awareness programmes.

Age Concern coordinates and supports vital services offered at the local level such as prevention of elder abuse and neglect and accredited visiting. It also influences government policy and national initiatives, raises public awareness and provides national leadership to local Age Concern branches by setting standards of service, providing professional development and acting as a resource for information.

Accredited visiting service

Some older people are lonely and socially isolated. Age Concern’s Accredited Visiting Service (AVS) provides companionship and support. Trained volunteers are matched with older people for mutual benefit. Volunteers gain valuable friendships and community involvement.

Preventing elder abuse and neglect

Age Concern also offers education for people who are working with and caring for older people. It works to raise public awareness of elder abuse or neglect and promotes ways of identifying and preventing neglect and abuse.

Age Concern also provides information, education and resources on the use of an enduring power of attorney that identify what to consider, how to set up a power of attorney and common questions that people ask.

Information

Age Concern provides fact sheets, pamphlets and publications to inform and educate people on a range of issues that affect older people and the people who care for them.

Support workers can use the website and/or the written information to become fully informed on a range of issues related to caring for the elderly and to support the family of those they are caring for.

Visit the Age Concern website at www.ageconcern.org.nz for more information.
Residential care facilities

Residential care facilities provide safe, high-quality care for people living with dementia who are unable to be cared for at home. These facilities provide care that is suitable to the person’s safety requirements and care needs in a variety of places such as:

- rest homes, which are home-like environments that are supervised by registered nurses and have care staff who are able to support residents with daily living activities.
- dementia care units for people living with specific dementia care needs. Usually people live in small clusters in a secure setting.
- specialist long-term care such as psychogeriatric hospitals for people living with high dependency needs and particularly challenging or noisy behaviour. Registered nurses are on 24-hour duty.
- long-term geriatric hospitals (usually private) may also care for residents with advanced dementia. However, physical needs may predominate. A registered nurse is on duty 24 hours per day and doctors visit when required.

Services

The services offered by these facilities are tailored to meet individual needs. Generally they are resident-centred and are required to promote the independence of the person. These services are specific to the person but may include doctor visits, 24-hour care by registered nurses, food, laundry, cleaning and specialist services on referral (such as dental or optometrist visits, hairdressing, podiatry, diversional therapy, spiritual support and socialisation). Residential services must be certified by the Ministry of Health.

Home-based services

Home-based services are provided according to individual needs identified during an assessment of the person’s capabilities and requirements. Community-based agencies and private companies employ support workers and healthcare professionals.

They provide support for people to remain living in their own home. The support may be provided directly to the person (for example, personal care) or indirectly by supporting the carer to continue in their role and providing respite or day care to give them some time away from 24-hour responsibilities.

The type of home-based services available depend on the area (city or rural), the population profile (younger or older people) and whether the person has been assessed as eligible for a publicly funded service. People may choose to pay for these services.
Health and Disability Commission

The Health and Disability Commissioner’s role includes:

- protecting and promoting the rights of people who use any health and disability service.
- resolving problems between consumers and providers of health and disability services.
- improving the quality of health and disability services.

A regulation under the Health and Disability Commissioner Act 1994 established the Code of Health and Disability Services Consumers’ Rights (1996). It is often simply called ‘the Code of Rights’ or ‘the Code’. The Code has been updated several times.

The Code was created to promote and protect the rights of health and disability service users and to promote fair, simple, speedy and efficient resolution to any complaints that these rights were not being met.

Types of support available

The Health and Disability Commissioner provides support for the rights and responsibilities of healthcare workers, healthcare professionals and the people they support through health or disability services.

The Office of the Commissioner’s website www.hdc.org.nz offers a range of articles, seminar notes and publications. These documents help to keep support workers informed and supported with knowledge and increased awareness of the issues involved in supporting people living with dementia.
Education services

Education services deal with the rights and responsibilities of people and providers of services and provide information on:

- common problems encountered by people using particular services.
- how people’s rights are relevant in particular situations.
- the implications of current health sector issues for consumer rights.
- issues of interest to providers, such as the provision of informed consent in different circumstances.

Complaints services

The Office of the Commissioner provides a free complaints services to investigate and resolve complaints made by users of health and disability services. Consumers have the right to have an independent advocate to support them. The advocate will listen to the consumer, give information about the consumer’s rights, help the consumer to choose an option to settle the complaint, and support the consumer to decide what course of action to take.

Advocacy services

The Office of the Commissioner provides advocacy services to support people in their choices and with their rights. Advocates are on the side of the consumer, will keep information confidential and will not disclose information without authority unless there is an issue of safety.

Visit the Health and Disability Commissioner’s website at www.hdc.org.nz
Unions or professional organisations

The New Zealand Nurses Organisation

The New Zealand Nurses Organisation (NZNO) offers support for nurses and health workers in the areas of:

- wages, working conditions and disciplinary issues.
- employment-related issues such as hours of work, regulations and safety equipment.
- campaigning on key issues affecting NZNO members.
- up-to-date information for support/care workers in its journal Kai Tiaki on the care of the elderly, boundaries and other issues.
- education, training seminars and workshops on professional and industrial issues.
- legal services (a team of experienced lawyers is available if needed).

Visit the New Zealand Nurses Organisation website at www.nzno.org.nz

Service and Food Workers Union

The service and food workers union is a national union for workers in service industries, including caregivers in aged care, disability and community settings and catering and cleaning staff.

The union offers industrial support, financial services and campaigns for fair and safe conditions at work. Visit the Service and Food Workers Union’s website at www.sfwu.org.nz

Workplace support

Support workers can obtain support through their workplace team meetings and staff education programmes, which offer:

- discussion and problem solving with their supervisor/team leader and colleagues.
- explanations of and information about organisational policies and procedures, memos, safety training, dementia care and correct documentation.
- presentations by support workers, healthcare professionals and visiting speakers.
- information on the roles and responsibilities of other healthcare professionals in the multidisciplinary team.
- up-to-date information about the person they are supporting.
- formal education, either in the workplace (for example, with Careerforce workbooks) or through other training providers.
Employee assistance programmes

Your employer may engage an external organisation to provide confidential, independent support in the workplace.

Employee assistance programmes are aimed at supporting staff in any personal or workplace issues that may affect their work performance. They often provide access to counsellors or other professionals.

Contact details for these services are usually well publicised in staff areas. Employers may include this service in their health and safety programme.

Write

Think of the forms of support that you use in your role. Identify two types of support that you have investigated recently and add them to the table below. Make sure you have at least one local service and one national service. An example has been done for you.

<table>
<thead>
<tr>
<th>Supports in place</th>
<th>Description of support</th>
<th>How this supported the family/whānau, or me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used the internet to google a website on dementia.</td>
<td>Alzheimer’s support group for carers.</td>
<td>Gave advice on stress management for me and social support ideas for family.</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>