

Understanding dementia.

A guide for carers and support people

February 2020

Bupa New Zealand

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You are probably reading this book because a relative or friend has, or may have, dementia.

This may be something you suspect, or perhaps they have been diagnosed by a health professional. Either way this is likely to be a worrying time for you.

We know that much of your concern or fear may come from not knowing how to cope, what to expect, or what is likely to happen in the future. This guide will provide you with some useful information about dementia, and how you can help to look after your relative or friend. We also remind you to look after yourself, because we understand that caring for someone with dementia can be difficult.

There is also a ‘useful contacts’ section at the back which gives details of further sources of information and support.

Bupa is one of New Zealand’s leading providers of dementia care. This guide draws on our wide experience of caring for people living with dementia and our understanding of the sadness and stress it can cause for the person, relatives and friends. We recognise that every person with dementia is different and every carer’s situation is different.

We hope you will find some useful advice, information and support in this book.

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Beth McDougall

Dementia Care Advisor, Bupa New Zealand

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Section 1

Understanding what dementia is.

Understanding

Dementia is a broad term used to describe the deterioration of brain function that results in loss of memory, reduced language skills, impaired reasoning and loss of daily living skills. This is dementia - the disability. However, as a person lives with their dementia they may or may not display behavioural and emotional problems.

There are over 100 different known types of dementia. The most common types are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

A person may have a combination of different types of dementia; in particular Alzheimer's disease and Vascular dementia. Each of these disabilities tends to affect particular areas of the brain and will cause different changes in a person's behaviour.

Over 60,000 New Zealanders have a dementia diagnosis. It affects one in three people who are over 90 years old. In New Zealand, the impact is felt by over 300,000 people — family, friends, and carers — so you are not alone in caring for someone with dementia.

Symptoms

Although there are common symptoms of dementia, each person can be affected in different ways. Depending on the type and progression of the dementia, symptoms can include:

- Memory loss, especially of more recent events. In the early stages of dementia, the person may misplace objects or forget what they were planning to do
- Difficulty finding their way around, especially in new or unfamiliar surroundings
- Problems finding the correct words, or understanding other people
- Poor concentration
- Problems learning new ideas or skills
- Difficulties with thinking and judgement, such as finding it hard to set a table
- Psychological changes such as becoming irritable, saying or doing inappropriate things or becoming suspicious or argumentative
- In the later stages, dementia will cause intellectual,

behavioural and physical problems, including loss of speech, immobility, incontinence and frailty.

However, these symptoms do not always mean dementia. They can also be caused by stress, depression, diabetes, vitamin deficiency, infections or many other illnesses. It is therefore always important for each person to be examined by a doctor and for an accurate diagnosis to be made, possibly by a specialist.

It can be difficult to determine exactly when dementia starts, as it usually begins with mild forgetfulness. The speed of progression varies widely between different people. In Alzheimer's, it typically takes seven to ten years from diagnosis to severe dementia and death.

There is no cure for dementia, because the causes are not fully understood. However, drugs can be prescribed for people with mild and moderate dementia that may slow down the rate of decline for a period of time.

Getting a diagnosis

If you are concerned about a friend or relative, then seeking help as soon as possible is advisable. Their General Practitioner should be the first point of call.

The GP will want to rule out other conditions that may produce similar symptoms.

An early diagnosis can:

- Help you to identify sources of information, support and advice
- Help you to cope with caring for the person
- Enable the person to benefit from treatments and memory advice currently available
- Help you to plan for the future and allow the person with dementia to make choices.

Dementia can be diagnosed by a GP, or the person may be referred to a specialist (a Neurologist, Geriatrician, Psychologist or Psychiatrist).

Since all types of dementia have similar symptoms, it can sometimes be difficult to tell

which type a person has. A diagnosis is usually made based on the description of the intellectual disturbance and its progression, psychological changes and risk factors.

The diagnosis may involve standardised memory tests, such as the GP COG, which is a series of questions and tests that investigate memory, language and mathematical skills. Physical examination, a review of medication and blood and urine tests may be undertaken to help exclude other causes of memory and intellectual problems or to distinguish between different types of dementia.

Other investigations may include a brain scan, typically computerised tomography (CT) or magnetic resonance imaging (MRI). Some people will be referred to a memory service that specialises in diagnosing conditions like Alzheimer's.

They are entitled to ask for a referral to a specialist for a second opinion. They should

ask for a referral if they feel it would be helpful.

If a diagnosis of dementia is made, the GP or specialist will be able to give you details of local support services and groups.

Getting the most out of a consultation

If you are supporting the person being diagnosed, or are seeking advice because you're worried about someone else, it may be useful to write down any questions or worrying signs beforehand to ask the GP or specialist. Keeping a diary can be very useful. It can be difficult to remember everything you want to say during a consultation. You may also want to write down the important points the doctor tells you. Don't be embarrassed to ask the doctor to explain any words or phrases that you don't understand.

People living with dementia are often unaware that they have a mental impairment and therefore may be unaware that they need help. It can be very difficult to accept help if they don't feel that they need it.

Finding out that a person has dementia is distressing, but understanding that there is a cause for their changing behaviour can be reassuring and it helps you to know what to expect in the future.



**The needs of
the person
will change.**

Make sure
their needs
are checked
regularly.

Types of dementia

1. ■

Alzheimer's dementia

Alzheimer's dementia is the most common type of dementia. In New Zealand, around 50 to 70 percent of those who have a dementia diagnosis have Alzheimer's dementia

With Alzheimer's dementia, the number of nerve cells in the brain gradually reduce and the brain shrinks. These nerve cells can't be replaced, so a person with Alzheimer's dementia gets progressively worse as more cells are destroyed. The nerve signals that are essential for activities such as language and problem solving, and for controlling movements by instructing muscles when to work, are impaired.

Alzheimer's dementia usually starts with forgetfulness, problems with figuring things out and difficulty in finding the right words. Family or friends may notice changes in behaviour. As the dementia progresses, memory loss gets worse and some people have difficulty in learning new skills. Changes in behaviour may become more obvious, with people saying or doing things that are out of character.

Everyday tasks such as getting dressed, washing, cooking, travelling and handling money become difficult. People living with Alzheimer's dementia can lose their sense of time and place – they may, for example, get dressed in the middle of the night or walk off and get lost. New surroundings and new people may be confusing.

There will be difficulty recognising previously well-known family and friends. Some people also become depressed because they realise what is happening to them. However, many people living with Alzheimer's dementia don't realise they have it.

During the later stages of dementia people living with Alzheimer's dementia may become entirely dependent on others for their care.

2.

Vascular dementia (Multi-infarct dementia)

Vascular (or blood vessel) dementia, which is sometimes called Multi-infarct dementia, accounts for over 20 percent of all dementias. It is caused by small blood vessels in the brain becoming blocked.

These blockages prevent oxygen from reaching the nearby brain cells, leading to their death. It is like having many tiny strokes in the brain, causing a gradual decline in mental ability.

Vascular dementia can usually be identified by a sudden change in a person's behaviour. The exact change will depend on the area of the brain where the small strokes have occurred. As more of the brain is damaged by tiny strokes the dementia starts to resemble Alzheimer's. In the early stages, Vascular dementia can be treated by managing blood pressure and cholesterol levels. This treatment may help to reduce the risk of further incidents in the brain.



3.

Dementia with Lewy bodies

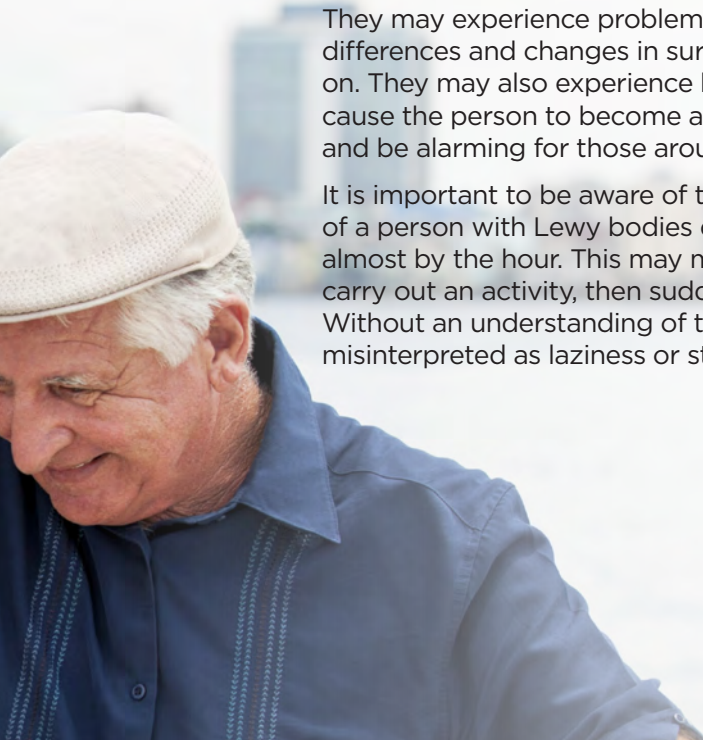
Dementia with Lewy bodies is expected to account for 10 to 15 percent of all cases of dementia in older people. Lewy bodies are tiny protein deposits found in nerve cells. Their presence in the brain interrupts the action of chemical messengers, and disrupts its normal functioning.

This condition has similarities to both Alzheimer's and Parkinson's diseases. It causes an impairment of memory, language and reasoning, and it progresses at about the same rate as Alzheimer's dementia, although it is characterised by pronounced fluctuations.

It can also affect the areas of the brain that control movement, balance, vision and visual recognition (knowing what it is that we see). Consequently, people with Lewy bodies dementia may also show symptoms of difficulty in moving, resulting in them falling, slowness, stiffness and tremor.

They may experience problems with judging differences and changes in surfaces they are walking on. They may also experience hallucinations, which can cause the person to become agitated and disturbed and be alarming for those around them.

It is important to be aware of the fact that the abilities of a person with Lewy bodies dementia can change almost by the hour. This may mean they are able to carry out an activity, then suddenly be unable to do so. Without an understanding of the dementia this can be misinterpreted as laziness or stubbornness.



4.

Other types of dementia

There are other types of dementia, including Fronto-Temporal dementia (Pick's disease) which initially affects behaviour and personality more than memory, and alcohol-related dementia that typically happens in middle age.

There are also more rare types of dementia, including progressive Supranuclear Palsy, Binswangers, HIV and Creutzfeldt-Jakob dementia (CJD). People with Multiple Sclerosis, Down's syndrome, Motor Neurone disease, Parkinson's disease and Huntington's disease may also be more likely to develop dementia.

In the later stages, dementia will cause severe intellectual behavioural and physical problems, including loss of speech, immobility, incontinence and frailty.



The person

It is often the case that the short-term memory is the first to deteriorate. With dementia, what you learnt first is what you lose last, so the information and skills learnt at a young age stay with the person the longest. A person living with dementia may not be able to remember what happened a few moments ago but can recall detailed information about their life as a child. However, as the dementia progresses their long-term memory may also fade.

We give some practical tips for coping with the symptoms of dementia later in this booklet. But it is important to remember that, even as someone's memory and skills deteriorate, the person you care for is still a person with their own views, reactions and feelings, even if it is difficult for you to understand them.



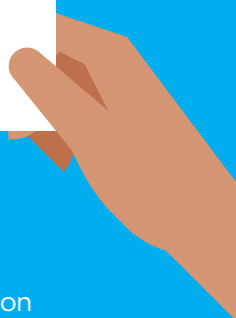
Explaining it to others

Some of the behaviours of the person you care for may raise questions from many people. These may be family members including children, friends or neighbours, and others such as sports friends and club members or the hairdresser.

Try to respect the privacy and dignity of the person you care for in explaining the situation. But remember that many people have family experience of caring for someone with dementia, and will be very understanding. They may become a source of advice or support, and you will also have the reassurance that others will be keeping an eye out if necessary.

It may be difficult to explain the situation to children. They may have a close relationship with the person, or be confused by their new behaviours. There are some lovely children's books available, such as "When I Visit Granny Jean" by Elizabeth Maltman, which may help them understand.

Useful tips and ideas



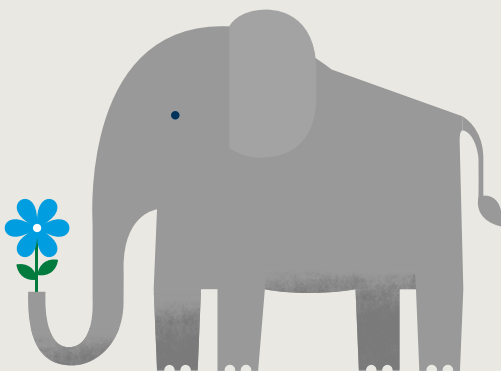
- Try to be as honest as you can.
- Explain that the person has a disability and might act differently to usual, or be forgetful.
- Some children can feel that it's their fault, or that the person's frustration or aggression is directed at them. Dementia books for children can be found on the internet.
- Encourage the child to ask questions so you can understand what they are concerned about.
- Try to focus on the things that the person with dementia can still do, not the things they can't do any more.
- Encourage them to still spend time with their relative if it is safe to do so.
- Try to find activities that they can still do together, such as playing cards, gardening, or discussing the past.

Planning for the future

In the later stages of dementia it will be helpful for you and others who are helping provide care, to remember details about the person and to know what choices they would make.

It is therefore wise to do two particular things, as early as possible after the person's diagnosis:

1. Talk to them about future choices and if they are able to, write down what they would like to happen at particular stages, especially at the end of life.
2. Get them to record as many things as possible which are key elements of their life and personality. There may be some things which even you were not aware of.







Section 2

Living well with dementia.

Living

This book contains a range of advice and suggestions on caring for someone with dementia. But there is one principle that runs throughout. That is the importance of remembering that the person with dementia is still the same person, only with a disability. This will help them, as you try to make sure that you and others always treat them with respect, and as an individual who still has a personality and feelings.

It may also help you by remembering that the illness isn't their fault. You may find it easier to be sympathetic and patient, as you would be to anyone who is unwell, even when you are frustrated, tired or stressed. The person isn't deliberately being difficult or lazy or demanding, or even just getting old. They are going through difficult and frustrating changes as their world becomes increasingly more confusing.

**See the
person not
the dementia.**

The person
you care for
is still unique
and special.

Activities

Activities can really help to improve the quality of life for the person with dementia, as well as providing stimulation and helping them to express themselves.

In the early stages of dementia, encourage the person to continue any outside activities they already enjoy, if possible. They may just need a bit of encouragement or prompts, such as reminding them when they are due to play bowls, go to church or bingo, or go fishing. Write key dates on the calendar.

Leaving the associated equipment in an obvious place, or giving them a phone call before they are due to go, may help to prompt their memory. Keeping up activities that they enjoy doing can help to maintain a sense of self-identity and purpose.

While respecting the person's privacy and dignity, it might be sensible to tell a friend or the activity organiser of their condition, so that they can provide any extra support or help that is needed.



Calm time

You might want to find some activities that the person finds calming, or that allow you to spend calm, peaceful time together. For example, you could sit together knitting, model making, painting, watching cricket or listening to music.

You may want to recapture fun and enjoyment, so think about dancing or singing, a game of darts or a trip to a beauty salon. Whatever you do, remember that it's about enjoying the activity, not the quality of any end result. If you just end up laughing together, that's still a good outcome.

Don't forget that for many people household chores can be a satisfying activity, and may provide comforting routine. Dusting, hanging out the washing or washing the car may need a bit of prompting and a watchful eye, but provide an engaging activity.

If the person finds it easier to talk about the past, or there are items they enjoy reminiscing about, you could keep them together in a

box for the person to look through, or to get out when conversation is flagging. Younger relatives or old friends might really enjoy doing this with the person.

The exact symptoms and capabilities of the person will depend on the type of dementia they have and the length of time they have had it. They may also change from day to day, or as the day progresses. In particular, the capabilities of a person with Lewy bodies dementia can change from hour to hour. People living with dementia often have a short concentration span and can easily become frustrated by an inappropriate or ambitious task.

In the later stages of dementia when concentration is short, activities should be similarly brief. Reminiscing about times past, enjoying a photograph or completing a simple task will be enough and as the person fades from the task or conversation, this is a sign that this positive encounter is coming to an end. You will have helped them to feel good but it is time to stop, until the next time.

Have some quiet time

Find activities
that enable
you to have
peaceful time
together.

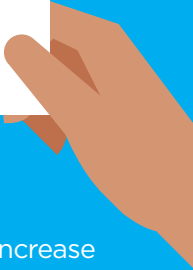
Television and radio

Many people enjoy watching television or listening to the radio. However, as they become more confused and their short-term memory deteriorates, they may find it confusing and distracting. Too much music or too many voices may sound like a blaring, confusing noise to a person living with dementia.

Try turning the television and radio off, particularly when the person is doing other things. See whether this makes them calmer, or if they find it easier to focus on other tasks.

Try different stations, such as finding old movies or history programmes on television, or a golden oldies radio station. Ask them whether they like it, and observe their behaviour. See if television programmes or music from their past promote a sense of calm.

Useful tips and ideas



- Give plenty of encouragement to increase their confidence.
- Be patient. Don't step in and take over.
- Give instructions and guidance as short, clear sentences. Pointing and demonstrations can be more useful if spoken words are not easily understood.
- Avoid giving too many choices or challenges as people with dementia can find it hard to process multiple options.
- Break tasks down into chunks or give single stage tasks such as sweeping.
- Keep tasks short to allow for the person's reduced concentration span.
- Keep your sense of humour and try to enjoy spending quality time together.

They may not remember the activity for long but their positive feelings might last for more than a day.

Challenging stress & distress

Because dementia takes away a person's ability to communicate over time, they need to find other ways to do this. Behaviour that challenges us is the person living with dementia trying to explain an unmet need. Often this behaviour can have something that causes it.

Stressed or distressed behaviour can be aggressive or challenging, and be difficult for both the person living with dementia and the carer. It may include hurtful comments, verbal aggression and threats, kicking, pinching or lashing out at people or objects.

Try to think about what they might be thinking or experiencing. Ask them questions to help you understand, think about the circumstances in which the outburst occurs, or try a different approach next time. Doing this might help you to avoid the situation in the future, or at least be understanding or know how to react when it occurs.

Hard as it will be, try not to react, or be aggressive or loud in return. Unless they are endangering themselves or you, give them plenty of space. Perhaps even leave the room to allow both of you to calm down. Try not to dwell on negative feelings about it.

Perhaps the most important thing to remember, when coping with changed behaviour, is to not take it personally. The person wouldn't deliberately hurt your feelings, or be aggressive, but dementia may make it difficult to understand what is going on, or for them to be aware of their behaviour.

Don't punish the person after the incident. For example, by ignoring them or not allowing treats, as you may do with children, even though you may be angry or hurt. People living with dementia can rarely remember what they have done and so lose the ability to learn from experience. They may be equally upset by what they think

is going on, the atmosphere, or by having lost control, so try to provide lots of reassurance by talking, hand holding or giving a hug if appropriate.

If you are worried by a person's behaviour who is living with dementia, ask for a referral to a specialist, such as a Psychiatrist or Psychologist specialising in older people, or a community nurse, who will be able to give you advice.

Possible causes of stress and distress



- Frustration, such as wanting to go out or do a particular thing and being told they can't, or being unable to do it.
- Annoyance at not being able to make themselves understood, or at you for not understanding.
- Intruding on private actions, such as going to the toilet or bathing.
- Was the person startled by a sudden approach, or an approach from behind or the side?
- Pain or discomfort, which would make any of us irritable.
- Being frightened, perhaps because they do not understand who you are, or because you touched them when they weren't expecting it.
- Being confused about the situation, for example thinking you've taken something, or not knowing where they are.

Communication

Communication is vital for all of us. In the early stages of dementia the person may struggle to find the right words, especially to describe objects.

As their dementia progresses they may forget your name and the name of others close to them, and may also confuse generations of their family such as thinking their wife is their mother. This can be distressing for carers and close family and friends.

The memory loss caused by dementia can cause frustration for carers when it results in repetition or failure to understand answers. The vital thing to remember is that the person is not trying to be annoying – they ask the question because they do not know the answer. They genuinely forget that they have asked the question and that you have answered it.

Although it can be wearing, try to remember that each time you answer the question you are reassuring the person at that moment in time. If you do lose patience they will not understand the reason and may be hurt or frightened by your reaction.





Useful tips and ideas

- Take time to answer questions slowly and clearly, with eye contact. Stop doing other things while you speak to them.
- Reduce distractions, such as the television or radio.
- Answer the question and then encourage them to start an activity that you know they enjoy, to try to engage them with something else.
- If they are asking for something, or to do something, is it practical to get it, or do it? Can other things wait? Does it really matter which order the day is done in if it makes the day less stressful for you both?
- Gently question a bit further to see if there is a reason for the question. For example, if

the person is asking whether another relative is coming to visit today, it might be because they think they need to prepare a meal for them, or look out for something to give them. You can reassure them that there's no need for a meal, or that you could pass the item on.

- If what they are saying starts to become incoherent, repeat the first few words they said and they may be able to pick up the thread again, or if you phrase the words as a question you might get an answer in reply.
- Dementia makes it harder to process information, so give the person time, and the opportunity, to ask for confirmation.

Treating the person with respect and patience may require you to give reasoned explanations, but they will not always be able to understand or remember the explanation later. In general, try to provide answers that are reassuring and calming at that moment. Although it can be hard to control your frustration, confrontation and argument will simply make your day more stressful, and may frighten and upset the person you care for.

Your relationship

You may also find it difficult to cope with the way the person responds to you. For example, they may not remember all the things you do for them, or that you visited that morning, or may ask why you're there. They may accuse you of not caring, or of never visiting, or compare you unfavourably to other members of the family, which can be extremely hurtful.

Try not to take it personally. Imagine living in a world of "not knowing", feeling confused and frightened, and not remembering that people are supporting and caring for you - you would feel very alone and upset.

A whiteboard or book for people to write down visits and outings that have happened, and when the next ones are, may be helpful.

Labelled photos of family members and regular visitors may be helpful. Photos of people at younger ages may be easier for the person to recognise.

Other people

Encourage other people to include the person with dementia. You might need to explain that they need to give the person time, and to keep questions simple. People may ask you what the person wants - you can set the example by referring the question to the person living with dementia, and giving them time to answer. We understand how important it can be to you as a carer that other people respect the person living with dementia.

If you know there are topics which the person finds it easier to talk about, or to remember, suggest these to visitors. Remember that many friends and family members will want to visit and chat, but may not know how to do it.

Body language

As dementia progresses, a person may become increasingly confused. But language is only one form of communication and other forms such as body language, tone of voice and facial expressions can tell us a lot about how people are feeling.

The following points may be useful in maintaining effective communication as the dementia progresses:

- Speak clearly using simple and short sentences. Offering too many choices or asking for complicated decisions is likely to be confusing. For example, ask “Would you like an omelette?” rather than “What would you like for lunch?”
- If speaking is difficult then try to tune in to their facial expressions and body language, as these can give you signals about how the person is feeling. Angry gestures or unwillingness to do something may be their way of communicating. Likewise, smiling or being calm show how they are feeling.
- Touch and physical contact, such as holding their hand, can be reassuring where appropriate.
- As the person’s world becomes increasingly confused they may mix up reality and fantasy. If they say something which is obviously untrue such as “I have to go and collect the children from school” then try not to respond with “No you don’t”. Instead try something that doesn’t directly contradict them, such as “You used to walk to pick up the children from school didn’t you?” Try to enter their world and imagine what they are thinking. Trying to explain the difference between their fantasy and reality is unlikely to help and you may find it frustrating if they don’t understand.
- Humour can be a great release and help you to feel closer. Try to laugh with the person about misunderstandings.



Dressing and personal care

What we wear helps to express who we are and how we feel. Maintaining a person's choice and involvement in their clothes for as long as possible can help to keep a sense of identity and dignity. Many older people are used to taking a lot of pride in how they look.

Hairdressing and grooming

Appearance is important to most of us, and it affects the way we are perceived by other people. Being well groomed may be important to the person living with dementia, and, rightly or wrongly, it may help other people to treat them with the respect they deserve. It may seem superficial, but if the person you care for is well dressed and well groomed you may also find the situation less difficult.

Particularly for women, a trip to the hairdressers or beauty salon can be a real treat and an enjoyable experience. It may be something that the person did weekly and they will recognise the place and the people. For men, a trip to the barbers may be a routine they recognise.

**They may
get it wrong.**

Deal with it
using humour
and keep it in
perspective.



Useful tips and ideas

Making it easier

- It may be useful to label the drawers or cupboards where clothing is kept. Pictures may be better understood than words. Storing whole outfits together might also help.

Making it fun

- Try to leave enough time for getting dressed so you both don't feel rushed or stressed.
- If the person is largely able to dress unaided, use the slow process as time for you to relax, just guiding or helping as required.
- Offer simple choices such as "Would you like the red jumper or the blue jumper?", rather than offering too many options, such as "What would you like to wear today?"
- If they get it wrong, keep it in perspective – does it matter if their buttons are not fastened correctly, or the top doesn't go with the skirt?
- Lay the clothes out in the order that they should be put on, i.e. starting with underwear and finishing with a cardigan or jumper. Or hand each item to the person in the correct order.
- They may need instructions about how to dress. Keep these simple and short, such as "Now put your socks on your feet". Demonstrating what to do may also be useful. You could do this by getting dressed together, if appropriate.
- The individual may have particular things they always like to wear such as matching jewellery or a handkerchief in their pocket. Try to maintain these.

Hairdressing and grooming

- Depending on the needs of the person, it may be better to get a hairdresser or manicurist to come to the house.
- Explain what you are going to do at each stage, getting their attention and making eye contact. Imagine being confused but having your head doused in water, or someone coming towards you with scissors.
- Involve them in decisions by offering simple options, such as a choice of two nail colours.
- If the person is enjoying it, make the experience as pleasurable as possible, perhaps with a scalp or hand massage.
- Don't neglect toe nails. Over-long or sore toe nails can make walking difficult and painful and reduce mobility.
- Take the opportunity to relax while the person is being looked after by someone else!



Eating and drinking

In the early stages of their dementia the person may be able to cope with providing their own food, with some help with the shopping and a few prompts around the kitchen, or perhaps a meal delivery service.

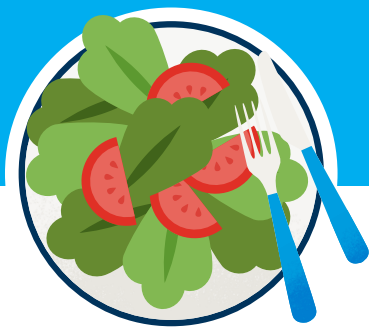
As the dementia progresses it may require someone to be present for at least one meal a day to ensure that they are actually eating enough. They may forget to eat, or not remember how to cook food properly.

Over time, the person may not be able to remember if they have just eaten, forget what they like and don't like, not recognise foods, or request strange combinations. Once again, try to remember that they are not just being difficult or contrary, even though it may be hurtful if you are preparing meals for them, or are concerned about encouraging them to eat.

Although older people often have a reduced appetite, weight loss is not inevitable, particularly in the early stages of dementia. Not eating and drinking enough can worsen the symptoms of dementia and affect the person's general health. If they are losing weight, you may need to think about the arrangements that are in place. While a balanced diet is to be encouraged, the key thing is to eat and drink plenty, and regularly.

Useful tips and ideas

- Leave snacks such as biscuits or fruit around the house – perhaps next to the person's favourite chair, on the kitchen table, or by the bed.
- Putting pictures on cupboard doors, or even removing the doors completely, may help the person to find the food they want, or act as a prompt to eat.
- A bar style fridge with a glass door may also be helpful.
- If the person has a favourite food, it's better for them to eat it frequently than not to eat enough.
- People with dementia may not remember to check the use by dates of food or even realise that decayed food is unsuitable to eat, so regular checks on their food stocks may be needed.



Changing tastes

People's tastes may change as their dementia develops. They may suddenly start – or go back to – having sugar in their tea, or go off their favourite food, or revert to childhood dislikes. A rational discussion about the fact that someone has always liked a particular dish is not likely to be successful. Try to be in the present – ask what they really fancy for dinner, or as a treat. They may surprise you, or it may be a dish from their past. It may seem like a bit of extra work, but it could be worth it for a stress-free meal time.

Eating out

You may worry about taking the person out to a café or restaurant, but in the early stages of dementia it can still be seen as a treat. However, others may find it confusing and disruptive. Sometimes it may even reconnect skills that you thought had been lost.

Try to sit the person living with dementia with maximum light and their back to other customers. This will be less distracting for them.

Drinking enough

Some people will limit the amount they drink if they are worried about getting to the toilet in time (there are practical tips on this in the section on 'Using the toilet and continence problems').

Drinking enough is vital to health, and dehydration can worsen the symptoms of dementia, so do encourage the person to drink plenty of fluids. You could leave covered jugs of water or fruit juice easily available, such as next to their favourite chair, or out on the kitchen counter, or suggest having a cup of tea or coffee more often than you might otherwise do.

Drinking plenty while you are present, so that you can remind them or help them to go to the toilet, is a good idea.

Reduce the amount in the evening to help prevent continence problems during the night.

Visitors

We all have routines when we have visitors, and would feel uncomfortable if we didn't do them. If the person is living in their own home, it may be important to them to offer you a cup of coffee when you visit, or to invite you to stay for lunch. Don't feel you need to do everything they ask - just keep an eye out that they are safe, or offer to help. If you have time, cooking together, or helping them to cook for you, can be a relaxing and familiar way to spend time together.



**Every day
is different**

Keep an
eye out to
ensure they
are safe.



Useful tips and ideas

Eating together

- Provide cues in the run-up to meal times to help the person recognise that it's time to eat and help to stimulate their appetite. For example, talk about the approaching mealtime; involve them in setting the table and in the food preparation.
- Joining the person for a meal may enable them to copy your actions, such as picking up the knife and fork, even if they can't remember how to do it.
- Buy a wipe-clean table cloth so that you don't have to worry if there's a mess.
- If the person doesn't eat a meal you've prepared, try not to be angry, even though it may be stressful for you. Try asking what they didn't like – there may be a simple reason.
- Allow plenty of time for eating.
- Serve small portions, and keep the remainder warm. You can then ask "Would you like some more?" This is better than serving large portions which go cold.
- Try to use plain plates and bowls, have contrast between the foods, and between the food and the plate. The person may not want to eat something if they can't see clearly and understand what it is.
- As the dementia progresses try using pictures to identify what they would like. Use recipe books, packaging, or even take photos of favourite family meals. You can decide which meals you have the time or inclination to make, and offer the person a choice of those.

Physical problems with eating

Physical changes as a result of dementia can include a reduced sense of taste and smell, loss of co-ordination and difficulties in feeding themselves. Other physical problems may include:

- Mouth problems – the person may have bad or few teeth, poorly fitting false teeth, mouth sores or ulcers. If you suspect this is the problem then try to get the person to see a dentist as soon as possible.
- Problems with swallowing – sometimes, people with dementia have a delayed or diminished swallowing reflex. It may be necessary to consult a speech therapist for specialist advice.
- Not recognising food – the person may not recognise food or may try to eat non-food items.



Helping with eating

For the person living with dementia, losing the ability to eat may lead to strong feelings of loss or frustration. Therefore, try to make sure the help they are given at meal times is sensitive and appropriate.

Finger foods that don't need cutlery may help the person to eat without assistance, reduce frustration, maintain their independence and, importantly, reduce work for you. If you are eating as a family, it may be tactful to ensure everyone is eating at least some finger food. Specialist crockery and utensils, such as adapted cutlery which is easier to hold or plates with raised edges, may also be helpful.

- Try to be at eye level when helping the person to eat as maintaining eye contact helps to keep them engaged.
- Try to make sure you have plenty of time so that the mealtime doesn't have to be rushed.
- Try to assist the person to eat slowly and gently, attracting the person's attention before placing the food in their mouth.
- Serve small portions, so that the food doesn't get cold.
- One tip from our own care staff is to ask someone to assist you to eat, so you can see how it feels, and how to do it well.

**Useful tips
and ideas**



Living alone

In the early stages of dementia the person may be able to cope relatively well on their own, supported by some adaptations around the home and regular visits to support them.

This may continue to be the best option for anything from a few months to a few years. However, dementia is a progressive condition and their symptoms and abilities will decline.

Preparing and planning, during the early stages, for their inevitable increased dependency can give you some time to consider the best options for all concerned.

Familiar surroundings and routines

Familiar surroundings and routines can be reassuring for a person living with dementia and they may be happier living in their own home for as long as possible in the early stages.

People living with dementia often respond well to routines, which can help to give a sense of meaning and security.

Displaying a daily routine may help to prompt them to remember to shower, eat, etc. Planning the times when the various activities should be carried out can help them to structure their day. This could be a diary left open in a visible place or on a noticeboard. It can also include particular events each day, such as visitors, trips to day centres or clubs, putting the bins out, washing, dusting, etc.

A large clock can be useful so that they can easily see the time and match this to their daily activities. Try to get a clock which includes a date and day of the week display to help them keep track of the days as well as time. Analogue clocks are best.

Putting associated items together can help to prompt tasks, such as the tea and coffee next to the kettle or the washing powder on the washing machine. Remember, however, that a person living with dementia may find it difficult to learn new things, so moving items that have been in the same place for years may be confusing. Labelling cupboards, drawers, storage boxes with words and pictures or photos may be helpful prompts.

Driving

Being diagnosed with dementia does not automatically mean that a person must stop driving immediately, but safety must be the overriding factor. It is likely that as their dementia progresses, they will lose the ability to drive safely. They should discuss driving with their doctor, who may refer them for further specialist assessment.

In New Zealand you must obtain a medical certificate for a driver's license at the age of 75 and 80 years, and every second birthday after that. If

your doctor decides that you are not fit to drive, they are required to advise the New Zealand Transport Agency. Car insurance policies will not provide cover for an unfit driver. Insurance companies require that any condition likely to affect a driver's ability be disclosed to them. If the conditions are not disclosed, the company has the right to turn down a claim. Further information is available at www.nzta.govt.nz

Personal medical alarms

You may find that having a home personal medical alarm can provide peace of mind. There are also other helpful aids such as pressure mats, property exit sensors and bed occupancy mats that can help keep the person living with dementia safe.

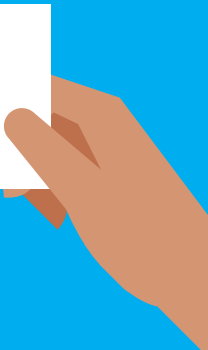
Safety and security

If the person wishes to remain in their own home there are obvious concerns about their safety and ability to cope. People with dementia can place themselves in danger due to their reduced concentration and impaired judgement. They may forget to lock or close doors and windows before they go out or go to bed. They may lock themselves in the house if they feel frightened. Or, if they have trouble recognising people, they may welcome strangers into their home. However there are many things that can be done to enable them to stay at home for as long as possible.

It is a good idea for a trusted neighbour to have a spare set of keys and keep an eye out for any unknown callers.

If you know and trust local work people, such as the postman, gardener or the local dairy owner, explain the situation to them so that they can keep an eye out.

- You might need to replace the telephone with one that is easier to use, for example with bigger buttons. Leave a large typed list of important numbers close to the telephone so it can be used by the person living with dementia, or a neighbour, in an emergency.
- Your local police may offer security advice. It can be useful to make them aware of the person's situation, particularly if they are unable to find their way home.
- Speak to gas, electricity and water companies about services they offer for customers with disabilities. They may be able to install safety devices or adapted controls, and ensure that those who do call understand the situation.
- Gas appliances can be potentially dangerous. You may want to consider replacing gas stoves, ovens or heaters with electric ones. If so, try to do this in the early stages of the dementia as the individual is more likely to be able to learn how to use them then. Consider turning an electric stove off at the main wall switch if the person will be at home alone.
- Make sure water heaters are regularly serviced by a professional.
- Install smoke detectors.
- Check older fires and heaters to ensure they are safe. (For example, with an automatic cut-off if they overheat), and replace any that are unsafe. Fit guards to heaters and fires to help prevent accidents.
- Taps can be adapted to only let out a set volume of water to prevent flooding. It is also possible to have temperature control devices installed.
- Removing locks from bathroom doors and bolts from the external doors may make access in an emergency easier.



**Useful tips
and ideas**

Managing finances

Arranging for regular bills to be paid by direct debit may be easier, or arrange for bills to be sent to a relative or carer.

However, if the person is not comfortable with this then it is a good idea to contact the suppliers to explain the situation so they are not suddenly cut off, particularly from utilities such as power.

Most companies have a department that deals with the requirements of people with a disability.

The impaired judgement caused by dementia can be a risk for finances, if the person has the use of cheque books and credit cards. A joint account, that requires two signatures for bank withdrawals may offer a solution. However, a couple that doesn't already have a joint account should take advice before setting one up if it is possible that, at some stage, either party may have their assets assessed for the costs of residential care.



**Some
questions can
be difficult.**

Provide
answers that
are reassuring
and calming.

It is recommended that financial affairs and Enduring Powers of Attorney are set up as soon as a diagnosis is made. Even gathering documents together in one place will help. This could include bank statements, bills, wills, pension details and insurance policies. If they consider this to be private, or are suspicious of your motives, you can reassure them that it is 'just in case', and that you don't need to see the details.

Property managers and welfare guardians

If the person living with dementia no longer has the capacity to set up an Enduring Power of Attorney then an application can be lodged with the Family Courts to appoint a Property Manager or Welfare Guardian, or make specific personal instructions for care. You will need advice from your doctor and lawyer.

For further information visit:
www.justice.govt.nz/family/about

Enduring Power of Attorney

Before the dementia progresses too far the person should be encouraged to set up an Enduring Power of Attorney. All adults should set up an Enduring Power of Attorney for property and welfare to protect their interests and those of their family, in case they lose the capacity to make their own decisions. In the very early stages of dementia it can still be possible to set up an Enduring Power of Attorney.

From September 2007 'Enduring Power of Attorney' legislation has been re-enacted and there are now strict criteria for appointing an Enduring Power of Attorney. A power of attorney is a formal document giving someone the power to act for you, if you lose the capacity to make decisions yourself.

There are two types of Enduring Power of Attorney – one for your money and property affairs and the other for your personal care and welfare. You may wish to appoint different people to have Enduring Powers of Attorney for these different areas.

Your money and property

You can appoint more than one attorney for your money and property. You can activate this Enduring Power of Attorney straight away. If you do, then your attorney(s) can act for you on your instructions until you are judged as not being able to make these decisions yourself – from that point they have the power to act for you. Otherwise the Enduring Power of Attorney comes into force only when you lose capacity to make financial decisions.

Without an Enduring Power of Attorney, no one else can deal with your property or financial affairs on your behalf. Your family, partner, and even your spouse may need to go to court to get this power.

Your personal care and welfare

You can only have one attorney for your personal care and welfare and this power of attorney is only activated once you are judged as not being able to care for yourself. An Enduring Power of Attorney must be set up by a solicitor or trustee company.

Benefits

You should check that the person living with dementia, and you as a person living with someone with dementia, are receiving all the benefits to which you are entitled. Always check whether government support affects any other benefits you are receiving. It could entitle you to more, but it could also reduce a benefit you are already receiving. See page 96 for a list of contacts.

Caring for others can sometimes be challenging. You may be able to get assistance and financial support. Specifically, the Domestic Purposes Benefit. Short breaks can be arranged through the Needs Assessment and Service Coordinators (NASC).

Financial support

1. Help with living expenses

- Sickness benefit
- Superannuation

2. Help with medical and related costs

- Pharmaceutical subsidy – ask your pharmacist
- Higher user health care – ask your GP
- Disability allowance
- Community services card

3. Help with carers support

- Domestic purposes benefit
- Carer support allowance or respite care subsidy
- Residential care subsidy



Personal preferences

We all have our own unique likes, dislikes, feelings and experiences. Maintaining a sense of self and identity can help the person living with dementia to feel more confident and reassured.

For some this can mean wearing their hair in a particular way, or following the same routines. They will still get pleasure from the things that they have always enjoyed.

Whenever possible, appreciating and following the individual preferences of the person you are caring for may help you to find ways that make caring easier for you. Because the person living with dementia won't necessarily be able to understand changes, this can lead to arguments and upset for both of you.

For example, if someone living with dementia wants to eat lunch now, or wear a cardigan that doesn't match, letting them do so might make life calmer and happier for both of you, rather than trying to discuss it with a person who cannot follow or remember the discussion.



Using the toilet and continence problems

Continence problems can be very distressing for both the person living with dementia and the person living with them.

Controlling urges to go to the toilet is something we are taught at an early age, and losing this ability can make a person feel that they are losing control of their dignity and their life.

Many people find it very hard to accept that they need help with such an intimate task. They may try to hide their continence problems. Treating the issue in a matter of fact way, or using humour lightly, may help prevent it becoming a bigger problem.

Incontinence is a specific physical problem. It is when a person loses or is losing control of their bladder and/or bowel. It is only one reason why a person may have problems with their toileting. Continence problems may develop due to forgetting where the toilet is, mobility problems, depression, difficulties arranging clothing or mistaking other items, such as bins, for the toilet. There may be some underlying physical reason and you should discuss this with your GP.



Useful tips and ideas

Getting into the habit

- Establishing a routine of set times will keep the bladder and bowel well trained.
- Giving a warm drink at breakfast and visiting the toilet about 20 minutes later may be successful.
- Watch for signs of the person 'needing to go', such as fidgeting or pulling at their clothes.
- Try to establish a routine of going to the toilet before getting dressed.

Ways to make using the toilet easier

- Leave the door ajar or the light on so that they can see inside.
- Remind the person where the toilet is. A picture of a toilet on the door may help and even signs or arrows to direct them to it.

- Installing handrails will make getting on and off the toilet easier and may reduce the fear of falling.
- Try to make sure their clothes are easy to undo, using Velcro fastening instead of fiddly buttons or zips may help.
- Moist toilet tissues can make wiping easier and are available from most supermarkets.
- Make sure the bathroom is comfy, for example well lit and warm, as confused people don't tolerate discomfort well.
- If the toilet is difficult to get to, for example upstairs, then a commode may be useful.

Getting help and advice

Problems with continence are often manageable. Your GP should be the first place to go for help and advice. They will also be able to give you details of the local support services in your area. For example, your local hospital may have a Continence Adviser who can make a home visit.

Advice and guidance on all aspects of continence are also available from the Continence Foundation, details of which are listed from page 96 onwards.



**Help them
feel at ease.**

Prevent it
becoming a
big problem.

Washing and bathing

Personal hygiene routines can be a source of anxiety for people living with dementia and their carers so this needs to be handled sensitively.

The person will have been carrying out their own personal hygiene activities for many years, since they were a child.

Requiring help or becoming dependent on others can be embarrassing and awkward for both them, and you as their care partner, so this is a key area where prolonging independence for as long as possible and offering unobtrusive help is important.

It's important to talk to the person to try to find out their preferences and feelings. Try to establish exactly what the person can still do for themselves and what they need help with, for example miming the action of brushing your teeth may be enough of a prompt to maintain independent brushing.

Remember that although most people now shower or bathe daily, this was not the case 40 or 50 years ago. In this time, the norm was to have a bath about twice a week and showers were much less common. So be aware that the routines you are used to may feel excessive to a person living with dementia.



Useful tips and ideas

- We all have our own personal care routines, especially in the mornings and before bed. Encourage the person to continue with their own routines for as long as possible.
- The person may require some prompting, such as handing them the hairbrush for them to brush their own hair.
- Encourage involvement and choice by asking questions such as “Would you like bubble bath in your bath?” Simply asking “Do you want a bath?” could prompt a response of “no” and it may be difficult to encourage the person to have one.
- Thorough drying is important in order to prevent sores or chaffing. This can be made easier by allowing the individual to sit for a while in a clean towel or absorbent bathrobe.
- If the person spends long periods sitting or in bed, try to check for red areas or sores on their skin whilst the person is undressed. These can be the first signs of pressure or bed sores. If you have concerns, talk to your GP.

Privacy

Most of us consider the bathroom to be a private place, and the person may be unwilling to undress or be undressed by you, or to bathe in front of you. You may also find it uncomfortable. Allowing the person some privacy may in fact make bathing easier for you both:

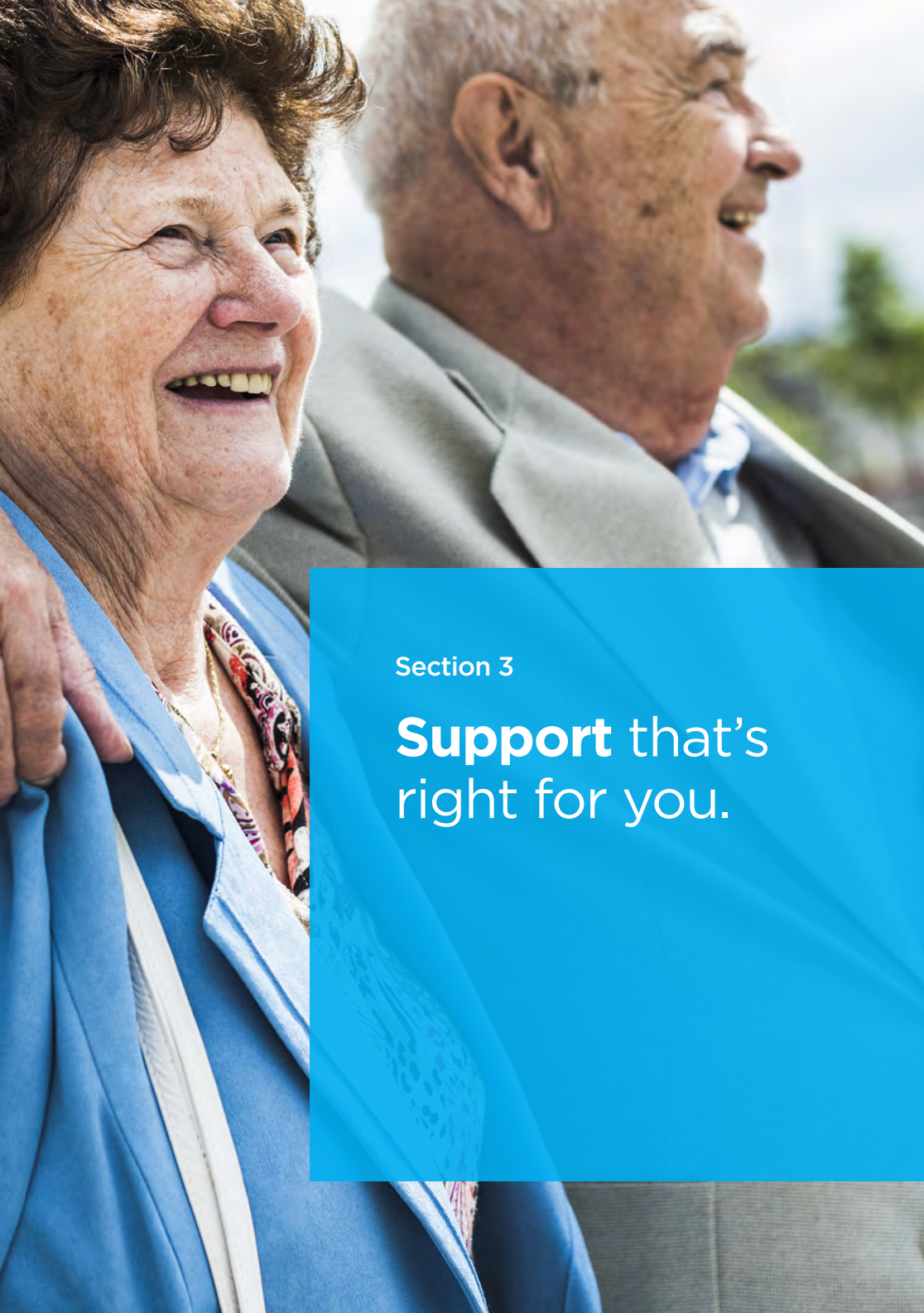
- You could leave the room while they undress and get into a dressing gown, before walking with them to the bathroom.
- Run the bath for them and let them step into it wrapped in a towel.
- Have a thermostatic valve fitted so that they cannot scald themselves if they run the bath themselves.
- You won't necessarily need to help them wash, or at least not every time. So long as they are bathing regularly it will be fine.



**Give them
some privacy.**

They may
feel more
comfortable.





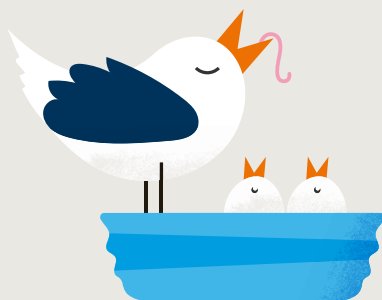
Section 3

Support that's
right for you.

Support

Everyone's experience of dementia will be different, so it can be quite unpredictable. If you know one person living with dementia, then you know one person. But it's important to know that you are not alone and that there are people and organisations who can offer support.

Looking after someone living with dementia at home can be a wonderful experience, but it is crucial that you care for yourself. Physical, financial, emotional and social support is important to ensure you stay well. Ask for help, schedule time out of the house, join support groups and take a break or a holiday occasionally.



**You are not
alone in caring
for someone
with dementia.**

Help is always
available.



Getting help

Don't be afraid to ask for help, or feel that you are failing if you cannot cope. Much of the responsibility for care, especially in the early stages, often falls onto one relative or friend, who may well be you.

This can be extremely stressful and exhausting, and others involved may not realise just how many demands are put on you.

You may very much want to continue to care for the person yourself, but remember that to do so you need to be as fit and well, physically and mentally, as you can be. So getting some help and moral support will enable you to cope and continue to care.

Help from whanau and friends

Try to have clear and regular communication with family and close friends from the outset. It's a good idea to hold meetings with family and friends at the beginning and as the individual's needs change so that the necessary support can be discussed and shared. This can help to prevent feelings of guilt or resentment and fall-outs at later stages.

It may be possible to agree on a rota of visits among family and friends living nearby. Even popping in for a cup of tea might relieve all the pressure being on you. Perhaps someone could have a game of cards with the person, or sit and watch the cricket on television with them, or join them for an hour dead-heading flowers in the garden, which would give you an hour to do other things, or just sit down for a rest! Family members may be able to bring old photos or objects that would prompt memories and reminiscence.

Family members who live further away might be able to offer financial assistance or blocks of time to enable the main carers to have a break.

It is possible that the person you are caring for may find it distressing to spend time with other people they don't recognise. But family and friends can help in other ways, such as by getting some shopping, or cooking a meal. If they offer – say yes!

Community care assessment

Each District Health Board has a Needs Assessment and Services Coordination team (NASC), which has the responsibility to assess the needs of people who may require care services. They approve publicly funded services and can help you to gain assistance from private agencies, non-government agencies and volunteer services too. Your GP can refer the person for a needs assessment or you can contact the service directly.

This assessment is carried out in the person's home, so that the Needs Assessor can see as much as you can, encouraging the person living with dementia to be honest and open about the issues they are facing.

There may be a charge for some of the services arranged, and to enable the provision of services, the person living with dementia is likely to have their finances assessed. Once the assessment is complete the assessor should write a 'care plan' for the person, detailing what services are required and when. Copies of the care plan should be left with the person and with you, as their care partner.

Home care givers can help with the personal care of the person, for example, getting the person up in the morning, washing and dressing them and putting them to bed at night. Housework and shopping assistance may also be provided. The number and frequency of visits will depend on the needs of the person - determined at the time of their needs assessment.

Day programme and drop-in centres may be available locally. These can be a source of great enjoyment for the person, as they provide social contact and often a meal and some activities. Additionally, they provide you with the opportunity to have a break! Transport to and from the centre is often provided.

To get in contact with such centres, including those run by charities or non-government organisations, contact your Needs Assessor, Alzheimers New Zealand, Dementia NZ or Age Concern (details on page 96).

Arranging help privately

You may be able to arrange domestic or personal care-support privately, through a nursing agency or home-care agency. Most nursing agencies also provide care staff. These will be listed in the Yellow Pages. Your Needs Assessor can also provide this information.

Personal recommendations can be helpful and your local Needs Assessor, Practice Nurse, District Nursing Service, Dementia NZ or Alzheimers New Zealand may be able to advise you. See page 96 for more details.

There is a wide range of specialist equipment available which you may find useful in assisting with daily living.

Outside help

The person living with dementia may not realise or want to admit that they need help, and people can be very proud.

Help might be more easily accepted if it is introduced in the earlier stages of dementia.

There are lots of different types of outside help available from various sources. These can differ from region to region, so a good starting point is to contact the Older Peoples' Health Service at your local hospital, or the local branch

of the Alzheimer's Society, Age Concern or Dementia NZ. Your GP can help. See page 96 for more details.

Advice and information

Many charities – such as Alzheimers New Zealand, Dementia NZ, Age Concern, Citizens Advice Bureau and Lifeline – have telephone advice lines, websites and free leaflets covering a wide range of subjects. Some will be aimed at older people in general but there is also a wealth of information available that is specifically aimed at people with dementia and those caring for them. Many of these organisations are listed on page 96.

If you are caring for someone at home, these sources of advice also provide practical information to help you cope. Alzheimers New Zealand run courses for carers – which we highly recommend. These courses cover all forms of dementia.

Helpful equipment

- Medical alarms and other helpful aids to help keep the person with dementia safe.
- Prompts such as noticeboards, large or talking clocks or thermometers.
- Mobility aids such as wheelchairs, walking frames, stair lifts or hand rails.
- Continence aids such as raised toilet seats, bed pans and pads.
- Washing aids such as walk-in or sit-in showers, bath seats or hoists.
- Specialist cutlery, cups or crockery to enable the individual to feed themselves for as long as possible.
- Kitchen adaptations such as glass fronted refrigerators.
- Medication aids such as boxes for tablets with a section for each day of the week and times of the day.
- Safety devices such as pressure pads that can detect movement, gas detectors, devices to control the temperature of hot water and restricted flow taps.

Toll-free Bupa dementia helpline

Service with practical advice from experienced dementia advisors, Monday to Friday 8am - 5pm.

0800 336 368 (0800 DEMENTIA)



**Take advantage
of support
organisations.**

The more you
know, the
easier it will be.



Thinking about a care home

People living with a person who has dementia often feel guilty at the thought of moving the person into a care home. You may feel that you have let the person down, or that you should have coped for longer.

You may have previously promised the person that you would always look after them at home, and now feel forced to break that promise.

Talk this through with someone who understands, and who can help you come to terms with your decision. Remember that any promises were probably made in a completely different situation, when you had no idea of all the strains and stresses that lay ahead. Caring for the person with dementia at home may now not be the best thing for them as their needs have changed. It may help to talk to other carers at a support group, but don't let others who are still caring at home add to how you are feeling. Everyone's situation is different.

A different way of caring

The move to a care home doesn't need to mean giving up your caring role completely, unless this is what you want – it's just a different way of caring. Your involvement can still be very important. Some care partners feel that residential care helps them to have a better relationship with the person, as their time together can be more special, less stressful, and more like it used to be before the constant worry about practical care.

When to look for a home

The effects of dementia worsen over time, and most people living with dementia may need to go into specialist care before they reach the last stages of their dementia. Some accommodation, such as extra care apartments, will accept people living with dementia but most of them may have to move to a care home or hospital for the final weeks or months of their life. As Ministry of Health guidance recommends that people living with dementia are moved

as few times as possible, a care home is usually the best solution when somebody has to move on from their own home. This might happen for a number of reasons, for instance:

- The person living with dementia is becoming unsafe on their own, e.g. leaving the oven on or being unsafe outside.
- Carers are having to provide increasing physical support for things like getting in and out of bed.
- Caring for the person is becoming too much for the person living alongside the person living with dementia.
- Levels of confusion or frustration are causing the person to become very upset or to do things which may be inappropriate.

It's common to feel uncomfortable about the idea of a care home and you may feel guilty for even considering it, but most people living with dementia will reach a point when they will be safer and more comfortable in specialist care. They would not want to make life difficult for their family and friends but are

probably unaware of the impact that they are having on others. They may also be finding life at home increasingly challenging, confusing and frightening themselves. Living in a care home not only provides personal and health care within a setting that is safe, it also provides the opportunity for activities and companionship, and importantly it can offer peace of mind to all concerned.

How to find the right home

Before moving to a care home or private hospital, the person living with dementia must have been fully assessed by a Needs Assessor. Generally, an assessment is also provided by a Geriatrician, Psychiatrist for older people or a specialised nurse. These assessments are done to ensure that the person living with dementia has no treatable or reversible problems, are medically stable and to provide you with advice as to the level of care that your relative or friend requires. Care options include a general care home, a specialist dementia community or a private hospital.

Try to visit a few potential homes, so you can see the differences between them and be sure that the home you ultimately decide on will be right for the person that you care about. Bupa New Zealand has a free checklist to help you record and compare your views about each home. This can be found towards the end of this book.

Every dementia community, hospital and rest home is regularly inspected by the Ministry of Health (MOH) and the local District Health Board. You can also access the MOH website to see the home's certification report. You can find the most recent audit for each Bupa care home on our website. Annual residents' satisfaction surveys are also published here.

As long as a home is comfortable and clean, you'll almost certainly feel that the skills and attitude of the staff are more important than the look of the home. Ask about specialist dementia care training and examine how the staff and manager interact with residents and the person you care for (if they have come with you).

**A good care
home will see
the person.**

**They will
understand
their needs.**

A good care home will treat the person as an individual, with their own preferences and abilities, not as someone who has to fit into the rules and routines of the home, so look out for evidence of this. A good home will put the person first and their dementia second. For example, do they talk about:

- The person's life history
- How their food preferences will be catered for
- How they'll provide the kind of activities the person likes, or the ability for the person to be somewhere quiet and calm
- How their room can be personalised, so it becomes their home space
- Will they be allowed to stay in their own room if they wish
- How you could be involved in their care, if you want to be

A care home can never be quite like your own home, but it should provide a safe, reassuring and familiar place for somebody living with

dementia and for those who visit them.

The home may arrange for somebody to meet the person living with dementia and assess whether their care home is able to provide the necessary care. Most people living with dementia will also need some degree of nursing care in the later stages of their life, so it's important to check that the home can provide this and can therefore look after the person right through to the end of their life.

Your needs

Think about your own needs as well. For example, if you want to visit frequently and the best care home is difficult to get to; the second best care home that is much nearer might be the right home to choose. Can you visit at times that are convenient to you, or are there set visiting times? Is there a relatives' group you can join if you want to?

At Bupa, we ask residents and their relatives to complete a 'Map of Life' so we can really get to know each resident, and meet their emotional and social as well as physical needs.



Where to look

1. Bupa New Zealand

bupa.co.nz

Explore Bupa Care Homes and learn more about dementia

2. Eldernet

eldernet.co.nz

Information on each home and vacancies

3. Senior Line

0800 725 463

Ministry of Health residential care information service

4. Alzheimer's New Zealand

alzheimers.org.nz

Support for people living with dementia

5. Dementia New Zealand

dementia.nz

6. Support for people living with dementia

Health and Disability services

7. Local friends, family or other carers for recommendations



Care home checklist

This checklist is designed to help potential residents and their families when they're looking for a care home. It will help you to compare different homes and gives suggestions on what to look for and ask about. We want to help you think about the things that are important to you when choosing a home. You can use the boxes to give yes/no answers or to score each home in the different areas.

Home 1 name	
Home 2 name	
Home 3 name	
Location	

**A care home
may be the
best option.**

You can still
be part of
their lives.

Welcoming and friendly	Home 1
Are you greeted warmly?	
Are staff attentive, interested and able to give the information you need?	
Do you receive clear answers to your questions?	
Does the home look clean and homely?	
Are you treated as an individual and are your needs acknowledged?	
Are you reassured, supported and informed?	
Are residents spoken to respectfully?	
Do staff introduce themselves and others thoughtfully?	

Medical care	Home 1
How often will care needs be reviewed?	
Will you/relatives be involved in making decisions about care?	
Can residents have their own GP if desired?	
Are there other visiting services? E.g. hairdresser, podiatrist, physiotherapist.	

Home 2	Home 3	Notes

Home 2	Home 3	Notes

Caring staff	Home 1
Do staff appear genuinely kind and caring?	
Are staff encouraging and relaxed as they interact with residents?	
Do staff look as if they've got time to spend with residents?	
Do staff know individual residents well?	
Are residents treated with dignity and respect by staff?	
Are individual needs and preferences catered for?	

The care home as a community	Home 1
Are visitors welcome at all times?	
Are residents able to come and go from the care home?	
Will family be advised if the resident is taken ill?	
Are there outings that residents can join?	
Are community events held in the care home?	

Home 2	Home 3	Notes

Home 2	Home 3	Notes

Personal touch	Home 1
Is respect, comfort and dignity evident in conversations?	
Are residents listened to and understood?	
How do staff get to know about a new resident's background, likes and dislikes?	
Do residents have the freedom to plan their day?	
Are residents relaxed, comfortable and well cared for?	
Is the atmosphere focused on the comfort of the people living in the care home?	
Are privacy, personal space and time respected?	
Are there activities that residents can choose to join in?	
How does the care home support spiritual beliefs?	
Do people have opportunities to pursue activities and interests independently?	
Do people look interested in what is going on or in what they are doing?	
Is there a feeling of enjoyment and laughter?	

Home 2	Home 3	Notes

A homely place	Home 1
Is there a sense of comfort?	
Do individual resident's rooms look distinctive with personal touches?	
Do staff respect a person's room as their personal space by knocking and seeking permission to enter?	
Is the atmosphere relaxed and comfortable?	
Is it easy to find your way around the building?	
Are there pleasant and inviting spaces inside and out?	
Can residents take part in the daily activities within the home if they wish – e.g. cleaning, gardening, cooking?	

Conclusions	
Home 1	
Home 2	
Home 3	

Home 2	Home 3	Notes



Visiting someone in a care home

Visiting someone in a care home, particularly a specialist dementia care home, can be difficult to begin with. However, once you have spent more time there and developed relationships with staff and other residents, you will soon feel more at ease.

Getting to know the person

Working with the care staff can help the person living with dementia to feel more at home and get more enjoyment out of their time in the home. Try to tell the care staff as much as you can about the person so that they can understand their needs and are aware of their particular likes, dislikes, habits and circumstances which may trigger stress and distress.

When a person living with dementia moves into a care home, they will be fully assessed and asked questions so that the home can find out all about them. It would be very useful for you or another person who knows them well to be there at the first meeting so that you can provide information. However, be careful to let the person living with dementia express their own views and feelings, even if they are not what you were expecting, and try not to contradict their statements. If necessary, share your personal understanding with the staff after the meeting.

A care plan will be written for the person, which will include all the information about their needs, preferences and abilities. The care plan should be regularly reviewed as the person's needs change over time.

Telling their life story

You may have known them for your entire life if they are your parent, but the care staff have just been introduced to them. That's why it is a good



idea to get the person to record their personal history and any particular preferences or choices in the early stages of their dementia. Telling their story can be a big help to care staff and offer topics to talk about or base activities on and ways to interact and stimulate the person. Some individuals may become very withdrawn when they enter a care home. Being able to do very individual things like listening to their favourite piece of music, or having their hair done a certain way, can be very reassuring.

You could help the staff and person you care for to fill a memory box with meaningful items such as photographs, books, items from their family or favourite hobbies which will help staff to engage positively with them.

Understanding the person's past will also help care staff to understand the person's behaviour as their short-term memory deteriorates and their long term memory becomes more real to them. This could include factual information, for example that someone who was a baker may want to get up very early in the morning. But it may need to include difficult subjects, such as the loss of a child. You may need to help with this exercise if the person has difficulty communicating, but telling the person's life story can help care staff.

Useful tips and ideas



- See and understand the person first, not the dementia.
- Give prompts for conversation topics which are more likely to engage the individual.
- Know what makes this person happy and sad
- Identify activities and outings which may be of particular interest to the individual.
- Avoid topics or activities that may be upsetting to the individual or trigger negative emotions or memories.
- Introduce the person to other residents who may have similar interests or backgrounds.
- Be aware of their fears, superstitions and things which concern them.
- Remember their dreams.

Joining in

Discuss with the care home whether you are welcome to join the person living with dementia for activities or meals. You may enjoy your visits more and interact better with them if you join in whatever they are doing – don't worry if you feel a bit self-conscious to start with! All care homes should have a varied range of activities for residents. Perhaps you could time your visit to tie in with a specific activity that you could join in with, such as singing or art, particularly if conversation is difficult. It could turn out to be a lot of fun for you both and give you some quality time together.

You may be able to join them for a meal, or to assist them to eat, if that is what they need.

Many relatives of people living in care homes get very involved in the life of the home, such as organising an activity. They find this enables them to remain closely involved in their loved one's life, while also enjoying social contact and feeling useful themselves.

Working with the team

Although you probably know the person living with dementia extremely well, the care staff will be experienced in caring for people with dementia and may have ideas or suggestions that are new to you, based on their experience or on conversations with the person. Do discuss these with the staff, and be willing to let them try new things. They may also speak to you if they see behaviour that puzzles them, to see whether you can help them to understand it.

For example, concern about a gentleman who is always slumped to one side in his chair with his arm over the side was removed when relatives explained he always used to sit like that, stroking his dog at the side of his chair.



Taking care of yourself

It is really important that you care for yourself, whether it is because you are also leading your own life or wanting to provide the best possible care to the person living with dementia.

You don't have to cope alone. There are many sources of support and help available, which might be useful even if you feel you are coping well at the moment.

The simple things are important. Getting enough rest, eating well, taking breaks from caring, getting some fresh air and exercise, and having support from others will all make it easier to cope with the pressures and frustrations you may face.

Money

You may have had to give up work or reduce the hours you work to become a carer. You may also be incurring additional costs of care such as equipment or aids. Depending on your situation you may be entitled to benefits. Check with your local WINZ (Work and Income New Zealand) office to ensure you are getting everything you are entitled to.

The NASC team will assess your needs and help you get in touch with any services they feel are necessary, such as counselling or training on how to lift safely. Some services may need to be paid for depending on your means.

Support groups

Support groups in your area can be a great help as they give you the opportunity to talk to other people in the same situation. You can share tips and advice as well as your worries, and be sure of an understanding listener. Even if you don't normally like groups, it may be worth trying because you will find you all have something in common. Full contact details are listed on page 96 onwards.

Alzheimers New Zealand and Dementia New Zealand run support groups where carers and those with dementia can enjoy social interaction and hear particular speakers talk on issues of interest. Some people find that local support groups can be a real life-line when coping becomes difficult. They are also a good

way of making new friends and ensuring that you still maintain some social contact for yourself.

Try also to keep in contact with your own friends and still do the things you enjoy, so that you maintain an existence as an individual and not just as a person living with someone with dementia. Don't feel guilty when you take time out for yourself — you deserve a break and will feel better for having it.

If you feel that you are not coping, then visit your GP for advice as soon as possible.

Further resources

As part of an ongoing commitment to understanding and promoting awareness of dementia, Bupa supported the production of 'Ten Glorious Seconds'. It's a short film that shows the emotions of a wife who is trying to connect with her husband who has advanced dementia. You can see it online at www.tengloriousseconds.com

Useful contacts

Most of the advice from the sources below is free of charge, but please check if you are requesting information to be sent to you. 0800 telephone numbers are free.

Bupa New Zealand

For all aged care needs: retirement villages, care homes, hospital and dementia care.

0800 60 80 99 | bupa.co.nz

Age Concern

Serving the needs of older people.

(04) 801 9338 | ageconcern.org.nz

Alzheimers New Zealand

Making life better for all people affected by dementia.

0800 004 001 | alzheimers.org.nz

Cancer Society Helpline

Provides a wide range of information pertaining to cancer.

0800 226 237 (0800 CANCER) | cancernz.org.nz

Carers Support

Help for New Zealand families and carers.

0800 777 797 | carersair.net.nz

CCS Disability Action

CCS disability action includes all people with a disability.

0800 227 2255 | CCSdisabilityaction.org.nz

Citizens Advice Bureau

Providing a free, impartial and confidential service of information, assistance and referral to people in our communities.

0800 367 222 | cab.org.nz

Chinese Lifeline

A Chinese telephone helpline that provides support and guidance in time of stress.

0800 888 880 | **lifeline.org.nz**

Dementia NZ

Supporting the delivery of high-quality services by dementia organisations working in the community.

0800 433 636 | **dementia.nz**

Disability Parking and Transport

If you have questions about mobility parking.

0800 227 2255 | **CCSdisabilityaction.org.nz**

Eldernet

Eldernet provides you with timely, relevant, and comprehensive information about services that are available for older people.

(03) 388 1204 | **eldernet.co.nz**

Family Care Magazine

Subscribe to this magazine written for carers of elders in our community and also provides useful information and contacts.

0800 278 232 | familycare.net.nz

Healthline

For 24 hour free health advice.

0800 611 116 | health.govt.nz

Health and Disability Commissioner

If you have concerns about the quality of healthcare delivery.

0800 11 22 33 | hdc.org.nz

Justice – Family Court

Provides information on the role of the family court, Enduring Power of Attorney, Property Managers and Welfare Guardians.

0800 224 733 | justice.govt.nz/family/about

Lifeline

A telephone helpline that provides support and guidance in time of stress.

0800 111 777 | lifeline.org.nz

Needs Assessment Service Coordination (NASC)

Provides the location of your nearest Needs Assessment agency.

Contact your local District Health Board hospital

NZ Continence Association

Provides you with all the information about continence and support products.

0800 650 659 | continence.org.nz

NZ Federation of Disability Information Centres

Provides a range of information and support for older people with disabilities.

0800 693 342 | disabilityinfo.co.nz

Parkinson's New Zealand

Provides support, education and information for people living with Parkinson's, their families, carers and health professionals.

0800 473 4636 | parkinsons.org.nz

Rent, buy or own your home

An advisory service by Housing NZ Corporation for people with physical disability.

0800 801 601 | hnzc.co.nz

Senior Line

Ministry of Health, information on residential care services.

0800 725 463 | adhb.govt.nz/seniorline

Specialist Health Services

Assessments, treatment and rehabilitation services for older people. Provides inpatient, outpatient and community based services.

Contact your local District Health Board hospital

Stroke Foundation

Information on respite care and how it can be accessed.

0800 78 76 53 (0800 STROKE) | stroke.org.nz

Shanti Niwas Charitable Trust

Provides a support line for older people of Indian and South East Asian communities in New Zealand.

(09) 622 1010 | shantiniwas.org.nz

Work and Income NZ (WINZ)

New Zealand Government's Ministry that provides income for those who cannot work, disability allowances and residential care subsidy.

0800 559 009 | CCSdisabilityaction.org.nz

To order more free copies of this book contact:

0800 60 80 99 | info@bupa.co.nz



What's your Dementia Commitment?

Learn simple ways to help a person living with dementia and receive a free badge or wristband and certificate. Become a Dementia Friend

bupa.co.nz/Dementia



0800 60 80 99
bupa.co.nz