



Supporting a person with dementia

A guide for family/whānau and friends





A dementia friendly New Zealand

Aotearoa, he aro nui ki te hunga mate wareware

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Disclaimer

This booklet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person affected by dementia or memory loss (including family/whānau and others who provide support) should seek professional advice about their individual situation. Alzheimers NZ is not liable for any error or omission in this publication, as a result of negligence or otherwise.

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Introduction

While learning that a family member or friend has received a diagnosis of dementia can be shocking, there is much that can be done to help people and their families/whānau to live well with dementia.

There are no easy answers to the challenges that will be faced and no simple rules to follow that will work every time. But what may help is some information about how

you can support a family member, friend, or neighbour to live well following a diagnosis of dementia.

This booklet gives you information and tips on:

- helping a person with dementia with their personal care, such as washing and dressing
- nutrition, sleeping and travelling
- communication and ideas for meaningful activities
- ways you can look after yourself – which is very important, too.

This booklet is one of a series of booklets about dementia.

Other titles in the series are:

- **About Dementia:** a guide for people diagnosed with dementia
- **Living well with dementia:** a guide for people diagnosed with dementia
- **Understanding changed behaviour**
- **Transitioning into residential care**
- **The later stages of dementia and end of life care**

More detailed fact sheets about many of the topics covered in this booklet series, can be found at your local Alzheimers organisation or our website www.alzheimers.org.nz

Remember you are not alone – help is only a phone call away. Contact your local Alzheimers organisation for support or information on 0800 004 001.

Dementia

What is dementia?

Dementia is an umbrella term used to describe a group of symptoms that affect how well our brains work. Alzheimer's disease is the most common form of dementia. Dementia can affect anyone, and as people get older the chances of developing dementia increase.

The symptoms each person experiences depends on the parts of the brain that are affected. However, the most common dementia symptoms include changes in memory, thinking, behaviour, personality and emotions. These changes affect a person's ability to perform everyday tasks and may interfere with their everyday lives.

Dementia is progressive, which means that for most people the changes gradually spread through the brain and lead to the symptoms getting worse. Dementia is different for everyone – what they experience, and how quickly they are affected is unique to them. What they (you) can do, remember and understand may change from day to day.



After the diagnosis

A diagnosis of dementia can be a very hard piece of news to deal with. Chances are high the diagnosis wasn't completely unexpected as it's likely you have been noticing symptoms in your family/whānau member or friend for some time.

You may want and need information and support. Remember, whatever you need and however you are feeling, your local Alzheimers organisation is ready to help you and put you in touch with other agencies that can also provide what you need.

Getting support and information

The GP who is looking after your family/whānau member or friend who has dementia should be a good source of advice and support. They, along with the practice nurses, should explain things so you can understand them, answer your questions and make you both feel comfortable and respected.

Although it's not you who has been diagnosed with dementia, you will very likely be present at the person's visits to the GP and you need to understand what's happening to them.

Some useful hints to use when seeing the GP:

- Make an appointment at a time of the day that works best for you and the person with dementia.
- Make a list of questions before you go – it's a confusing time and there's a lot of information to take in.
- Keep a folder about conversations you have had and any brochures or information sheets you have collected, and ask the doctor to write things down if that would help you.
- Don't be afraid to speak up if you don't understand what's being said – maybe ask to have it explained in a different way.

The GP can also refer you to specialist services and support agencies. They include your local Needs Assessment and Service Coordination (NASC) service. The NASC is contracted by the District Health Board to assess what services are needed to help people with dementia keep living in their own home, or transition into residential care.

Such services may include:

- home help
- personal care (such as showering, dressing, medication management)
- respite care
- relief for people caring for the person with dementia
- day programmes
- residential care.

Sharing

Just as the person you are supporting has to deal with telling people about their diagnosis, you will probably have to tell people too. Giving your friends and family this news can be difficult and everyone reacts differently and often unpredictably.

While you need to ensure you have the person with dementia's permission to tell others – especially soon after a diagnosis – you cannot get the support you will need as you care for the person with dementia unless you tell others what's going on.

If you don't know who you should tell, ask your GP or your local Alzheimers organisation for guidance.

Adjusting

It's totally normal to feel a whole range of emotions after a family/whānau member or friend has been diagnosed with dementia. Living with dementia is a big adjustment and sometimes it's hard to know how you 'should' be feeling.

- **Don't deny your feelings:** Whatever they are, allow yourself to feel the way you're feeling.

- **Share your feelings:** Talk to another family, friend or whānau member.
- **It's okay to cry:** It's true what they say – tears can make you feel better.
- **It's still okay to laugh:** Laughing releases 'feel-good' chemicals in your body.
- **Write it down:** Some people find it helps to record their feelings and experiences.
- **Get out and enjoy life:** Do something you enjoy and focus on how good that makes you feel.

Ask for help

Caring for someone with dementia often isn't easy. You and the rest of your family/whānau will be doing a lot of adjusting. Just remember there is help out there for you – both practical and emotional.

There are support groups for people who have family/whānau members and friends dealing with dementia, so ask your local Alzheimers organisation to put you in touch with one near you. In the meantime, we hope you'll find some initial practical help in this booklet.

Taking a break

We all need to take a break from whatever we are doing, even if that means taking a break from caring for someone you love. There's no need to feel guilty or that you aren't fulfilling your responsibilities.

Caring for someone affected by dementia can be stressful, as well as physically and emotionally tiring. It can also be socially isolating for family/whānau members if they can't – or don't feel they can – leave the person they are caring for.

But it's important that anyone in a caring role can take regular breaks. That might be just a short break – to meet friends, participant in a hobby or sport, do errands or some business. Ideally they should also feel they can take a weekend away or go on holiday.

Breaks are also good for someone with dementia. It's good for them to get out, see other people, socialise and maybe go somewhere new. It's also good for them to get used to having other people supporting and caring for them.

How to take a break

Ask family/whānau members to step in

Other family/whānau members and friends may be happy to help out by giving you a break from caring.

Often it's just a matter of asking. Try suggesting specific ways they can help you get a break – also ask them about bringing a meal or helping with the housework or shopping to give you a break in those areas, too.

Day programmes or services

Not only do these give you both a break from each other, they provide the person with dementia with social contact and interesting activities. It gets them out into a new space and gives them experience of having others care for them.





Respite care

Respite care can be in a day programme or in a short-term residential care facility that's funded by your local District Health Board (DHB). In some areas in-home respite is available where care is available in your own home and this gives the carer some time off.

Some people will feel quite comfortable about using respite care early on, while others will take a while to get used to the idea. However, some families say it's good to start using regular respite care as early as possible so everyone can get used to having a break from each other.

It can be helpful to think about respite care as a partnership between yourself and the respite provider, working together to make the most of the time. Talk to the staff at respite care facilities about what type of respite care is available, and what will work best for you and the person with dementia.

Advice and support for people who provide care is available from Carers New Zealand, www.carers.net.nz. If you want to know more about how to take a break, talk to your doctor about suitable options or contact your local Alzheimers organisation 0800 004 001.

Helping others understand dementia

Caring for someone with dementia can be made more difficult if people around you don't understand what dementia means or how it affects someone who is living with it – including you.

Helping friends and family/whānau members understand what's happening and why you need help will make your job easier.

Coping with the stigma that is still associated with dementia can be difficult and demoralising. De-bunking the myths and bringing dementia out of the shadows is something we can all do – the more we all talk openly about dementia the better it will be for everyone.



What to try

- Give them information about dementia, such as this booklet and other resources produced by Alzheimers NZ (available at your local Alzheimers organisation or www.alzheimers.org.nz)
- Explain that while a person with dementia may look fine, they have a condition that affects their daily life
- explain that dementia is not contagious – and that it could happen to any of us
- ask visitors to come for short visits and not have too many come at once
- suggest that visitors bring activities to do with the person, such as a simple project or puzzle, or that they go out for a short time together, maybe going for a walk
- prepare visitors for any communication problems and help them deal with them
- accept that some friends may drift away – but remember you can make new friends from dementia support groups.



Staying healthy

Caring for someone with dementia can be very rewarding. It can also be difficult, exhausting, lonely, and at times, overwhelming.

The physical and mental demands of caring for someone with dementia can take its toll on your own health and wellbeing. If you are worn down, in mind and/or body, caring will become even more difficult and you may not be able to continue balancing your own needs with those of your family/whānau and the person with dementia. Over time you will build resilience to cope with the strain of being a carer of someone with dementia. Accepting help and support from those who care about you and will listen to you strengthens resilience.

Here are some tips to help build resilience.

Take care of yourself

- **Eat a healthy, balanced diet:** Eat plenty of fresh vegetables and fruits, avoid large amounts of highly processed or high-calorie food, and drink alcohol only in moderation.
- **Try to get enough rest:** If your sleep is disturbed at night, sleep during the day whenever you can.
- **Keep in touch with family and friends:** You deserve and need a social life outside your carer role.
- **Find ways to relax:** Whether that's spending time in prayer, meditation, self-reflection or counselling, do what you can to relax, get perspective, and boost your energy and morale.
- **Exercise:** Walking is great stress relief, while even gardening can lift your mood and relieve nervous tension (these activities can also be good for someone with dementia).
- **Stay positive:** Your attitude makes a difference to the way you feel so try to focus on the good things, making every day count. Also, focus on the things the person with dementia can still do, rather than the things they can't.
- **Take each day one step at a time:** Don't worry about what happened yesterday because you can't change it, and don't stress about what you need to do tomorrow as you'll deal with that when it comes. Just focus on what you need to do right now.



Managing your feelings

You may experience a range of very different and often extreme feelings. This is particularly difficult because, as dementia gradually causes the person's abilities and personality to change, the nature of your relationship will also change.

There is no simple way to deal with these feelings but it may help to know that the complex and changeable emotions you feel are completely normal.

Some of the most common feelings experienced by families and whānau members who support a person with dementia may include guilt, grief, loss and anger.

Remember:

- **Be kind to yourself:** Be patient with your feelings. Find a balance between the happy and sad person, the angry and peaceful, the guilty and the glad self.
- **Have patience with yourself:** Life is changing and it will never be the same. You're having to learn to deal with a lot of new situations and no-one is perfect.

For more information see the factsheet *Looking after Yourself*. For more advice and support see www.carers.net.nz or contact your local Alzheimers organisation on 0800 004 001, www.alzheimers.org.nz.



Men who take on caring roles

Many men find themselves caring for someone with dementia. Usually that person is their spouse or partner, but they might also support their children or siblings affected by dementia.

While caring for someone with dementia is demanding on everyone, for many men it can be even more challenging if they are not used to looking after the physical needs of others. They may need extra help to learn new skills to keep the household running smoothly and to keep everyone well fed, clean and cared for.

Losing a partner's emotional support

Just like anyone who is caring for someone with dementia, it's vital men maintain (and are helped to maintain) their social and emotional support networks, this might include sport and special interest groups. Ultimately, this will help keep themselves and those they are caring for physically and emotionally healthy.

Finding support

Some men find it helpful to talk with other men who are also caring for someone with dementia, and their local Alzheimers organisation can put them in touch with other men in this role.

But don't forget that family/whānau are an essential part of any support system. The important thing is that anyone – male or female – finds a safe place to air any issues they are having as they care for someone with dementia.



Communication

Losing the ability to communicate can be one of the most frustrating and difficult problems for people with dementia, their families and other people who care for them.

How dementia affects a person's ability to communicate will differ from person to person, but as the illness progresses, a person with dementia finds it more and more difficult to express themselves clearly and to understand what others say.

Any frustration from that could cause them to feel more stressed, angry and resentful.

Communication difficulties could include:

- finding the right words, or getting words mixed up
- talking fluently but not making sense
- processing and understanding what other people are saying to them
- losing the normal social conventions of conversation, interrupting or ignoring people
- trouble with reading and writing.

Health checks

Some communication problems could be caused by failing hearing or eyesight, so as a first step, have these checked. Eyeglasses or hearing aids could improve the situation. If the person already has glasses, keep them clean, and check any hearing aids to make sure they're functioning properly.

Use body language

There's more to communication than words. When we communicate, more than half of what we say is conveyed through body language, while another large proportion comes from the tone and pitch of our voice.

If you can't find the words to make yourself understood, remember that facial expressions, pointing and gestures can help.

But remember, the same goes for negative body language. Sighs, hands on hips, raised eyebrows and angry expressions will likely be picked up, so try to be kind in your tone of voice and facial expressions.



Be patient

People with dementia still have feelings and emotions even if they don't understand what's being said, so always consider their dignity and self-esteem. Allow time for a response. Don't finish their sentences for them, and don't cut them off. Allow them to express themselves however they can.

Where appropriate, use touch to keep the person's attention and to communicate feelings of warmth and affection.

**For more information
about communicating with
a person with dementia
look for the factsheet
Communication at
www.alzheimers.org.nz**

Caring for someone who lives alone

Each person with dementia is unique and so is the situation in which they find themselves. While most people live with a partner or in some type of family situation, increasingly many people live alone.

A diagnosis of dementia does not automatically mean people are immediately incapable of caring for themselves. Helping a person to stay in their home, in familiar surroundings, for as long as possible is a worthwhile goal. However, because there are some risks associated with that, it can be very worrying for the people who care about them.

The type of support needed depends on the individual situation. A person with dementia living alone may:

- forget to cook regular meals
- miss taking prescribed medication or take too much medication
- forget to bathe or change their clothes regularly
- have a lack awareness of potentially hazardous situations, such as fire or electrical appliances
- miss paying bills such as power, rates
- show poor judgment about who they let into the house

- forget to feed or care for pets
- have unrealistic ideas or suspicions that can lead to trouble with neighbours, the police or the community.

Some of these situations may be able to be dealt with fairly simply. For instance, if the person is forgetting to prepare meals, arrange for delivered meals, such as meals-on-wheels, and make a phone call or arrange a visit to remind them to eat the meal. If the person is receiving home based support, the support worker can help with giving reminders to eat or heating prepared meals.

When someone is diagnosed with dementia a team of people usually becomes involved in their medical care and support. Talk to those people, as well as other family/whānau and friends, and work out a plan of how to best support them to stay living at home for as long as possible.

Some situations, however, may compromise the person's safety and wellbeing and a move to more supervised care may be a better, safer option.



For more information about assisting someone with dementia living alone see the factsheet *Living Alone with Dementia*. For help with someone going into residential care see the booklet *Transitioning into Residential Care*.

Keeping active

There are so many things that give us purpose and pleasure each day, and it's the same for a person with dementia. They need to have quality of life just as before, the only difference being now they may need help in order to achieve that.

Ideally, activities should:

- be the same or similar to what the person with dementia once enjoyed – there's no reason they need to stop if they can keep doing it with help
- promote self-esteem – maybe something the person can still do without help, or something that makes them feel good about themselves
- keep up skills the person has, without learning new ones
- give the person with dementia an opportunity to enjoy themselves, and have social contact
- be sensitive to and appropriate for that person's background
- help the person to relax and give them pleasure.

Enjoyment doesn't require memory. A person with dementia may enjoy an outing even if they don't remember where they have been. What's important is that the

moment is enjoyed. Give them the time and space to do as much as possible, as simple and unhurried activities that are meaningful are best.

Helpful guidelines when planning activities

Use retained skills: Make use of skills the person with dementia still retains, such as buttering bread, washing up, or watering, sweeping and raking in the garden. These are also ways in which they can contribute to the household and feel useful. Encourage an area of responsibility, no matter how small.

Focus on one thing at a time: Break down activities into simple, manageable steps. Ask the person to do one thing at a time. Prepare a safe working area: People with dementia often have difficulty with visual perception and coordination. If there's a working surface, make sure it's uncluttered, with few distractions, and that there's not too much noise. Keep the lighting good, but without too much glare.



Remember that abilities can fluctuate from day to day or the time of day: What worked well one day may not work the next, so stop the activity and try something else if it's not going well. Also, think about what time of day the person with dementia is at their best and adapt the timing to suit. For example, some people are better having a walk in the morning while others get restless in the afternoon so a walk later in the day may be better.

Allow for emotional/spiritual outlets: For many people, music or contact with babies, children or animals gives them pleasure and enjoyment. Because many people with dementia have excellent memories for long-past events, looking through old photos, memorabilia and books lets them think about earlier times and the positive feelings associated with them. For others, maintaining religious involvement or involving themselves in spiritual activities such as praying or meditation, or even enjoying art or nature can provide a sense of meaning and peace.

Include sensory experiences: These could include hand, neck and foot massage using fragrant essential oils, hair brushing, smelling fresh flowers or potpourri, visiting public gardens or parks, or giving them a rummage box full of things that interested them.

Include music and dance: Many people keep their sense of movement and rhythm longer than other abilities, so they still enjoy listening to music and/or dancing. For some, going along to a dance or a dance performance will provide pleasure.

Keep active: Getting out for a walk (perhaps with a dog) is a great activity, both for the exercise and the extra stimulation from being outside in the world. If it's rainy, think about hiring an exercise bike or treadmill to keep up the exercise indoors. A walk around a shopping mall can be a good option, it is best to avoid the busy times and go early or later in the day.

Weighing up **risk** with **benefit**

Dementia affects each person differently. However, symptoms such as confusion, memory loss and disorientation are common, while problems with mobility and co-ordination can also put their safety at risk. Therefore, as a carer, when you are thinking about keeping the person safe, you need to balance the benefits with the possible risks. Every day we all take risks, for example cycling to work can be seen as risky, however, the benefit of the exercise and to the environment of not running a car outweigh the risk of getting hurt. For some people the reverse could be true and they would consider cycling too risky. So each situation will be different and unique and needs to be considered with care.

It is important not to be too risk adverse when supporting someone with dementia, and to consider any impact or benefit to their overall wellbeing such as self-esteem, maintaining their independence, mental health and of course physical benefits.

Also, it pays to revisit a situation as time passes, something that was once considered too risky may now be okay, situations change and it is important to be flexible and adaptable. One unfortunate episode does not mean you should never try something again.

Remember, with difficult decisions it is helpful to discuss your options and concerns with other people, canvass their opinions and weigh up what you feel most comfortable doing and what is best for the person with dementia.



Safety in the home

The best living environment for a person with dementia is one that helps them be as happy and independent as possible. Familiarity is important for people with dementia. What they have around them at home should help them know where they are and how to find what they want and where they want to go. If things are changed around, they may become confused and disorientated, and that could lead to injuries.

Safety outside the home

Some people with dementia may become disoriented and get lost in unfamiliar surroundings, or even in previously familiar surroundings. Therefore it's important they carry appropriate identification at all times, including their name and address and an emergency contact number. Other things to consider include identity bracelet, GPS on mobile phones or other mobile tracking devices.

Safety tips

- Keep rooms uncluttered – arrange furniture simply and don't move it around.
- Reduce the risk of trips and falls by getting rid of loose rugs, frayed carpets or mats, and long electrical cords.
- Nightlights in the hallways and in the toilet may be useful to help light their way to the bathroom at night.
- Dispose of medications which may no longer be required and hazardous materials, such as kerosene, and safely store any you still need.
- Replace more dangerous forms of heating, such as bar radiators, with safer heating options, such as column heaters.
- Use a thermostat on the water cylinder to control the hot water temperature (the thermostat should be set at 60°C so it's hot enough to kill bacteria but not hot enough to burn when it comes out of the tap).
- Smoke detectors are important for everyone – arrange to have them installed if they're not already up. A person with dementia may need someone else to check the batteries and make sure the alarm is loud enough.
- For people living alone, a phone call every morning to check all is well is a good idea.

Driving

For more
information
about driving
see the factsheet
*Driving and
Dementia.*

A person with dementia may not need to stop driving straight away. However, dementia is progressive and will affect their ability to drive, so they will need to stop driving at some point.

People may feel a loss of independence or identity when they can no longer drive. For someone in the early stages of dementia, making the decision to give up driving can be very challenging.

Safety concerns

If you are worried about a person's ability to drive, try talking to them or their doctor about your concerns.

You could contact your local police or Land Transport Licensing Authority www.nzta.govt.nz. They might be able to contact the person to say that a medical and driving test has become necessary.

You can also contact your local Alzheimers organisation on 0800 004 001 to talk about any specific concerns or situations you're facing.

Alternatives to driving

There's a lot you could do to reduce a person's need to drive:

- Offer to drive them to appointments, social gatherings, shops and services.
- Encourage them to use buses, trains or taxis when possible – and help the person with dementia to use them.
- Encourage walking – tracking and route-finding technology, such as GPS, can help.
- Encourage the use of home delivery services for food, medical prescriptions and ask about other services such as delivery of library books.
- Ask family and friends to help.

Helping to stay connected

When people stop driving they often stop making social trips – visiting friends, family, going to parties or doing hobbies.

It's important people with dementia stay connected so try to do all you can to help them continue these trips as much as possible.

Travelling

For more
information
about travelling
see the factsheet
*Travelling and
Dementia.*

While staying in a familiar environment is generally a good thing for people with dementia, travelling is often necessary and can give everyone a welcome change of scene.

Travelling in the early stages of dementia is usually better as many people with more advanced dementia don't react well to being out of their routine. However, sometimes you do need to travel and with some thoughtful planning and the right conditions, you can enjoy a successful trip or holiday.



General travelling tips

- Be prepared to do everything for two – you may need to make all the arrangements and hold all the money and documents
- Encourage the person with dementia to wear an identification bracelet with emergency contact details at all times.
- Take enough medication to cover the time you're away, and take a list of recent and current medications, as that may be helpful if they become unwell.
- Be aware of public toilet blocks that have more than one entry or exit point – use disabled toilets where there's space for you to be in there together.
- Allow plenty of time to do everything you need to do and to get everywhere.
- Consider breaking the journey at convenient points to reduce tiredness and fatigue.
- Always ask for help – people cannot help if they don't know there's a problem.
- Keep a sense of humour and laugh at the funny things that happen along the way.

Pain

As far as it's known, dementia does not cause pain, but people with dementia are as likely to be affected by the same problems that cause pain in all of us. But people with dementia may not be able to communicate that they are in pain. They may not understand what their pain signals mean or, if they do, they may not have the language to tell you about it.

They may show they're in pain or discomfort by acting out in other ways, which the people who care for them may or may not understand. As a result the pain may go unnoticed and untreated.



Recognising pain

Recognising that someone with dementia is in pain is not always easy but there are some signs that could point towards them being unwell, or in pain or discomfort.

These may include:

- changes in behaviour – they may seem withdrawn, lethargic, frustrated or even angry
- sleeping more than usual
- crying
- flinching, facial or verbal expressions that indicate soreness in a particular part of the body
- the person doesn't want to move.

Treating pain

All signs of pain should be taken seriously. Always talk about your concerns with the person's doctor who can check if something's wrong and help you manage any pain or discomfort.



Sleeping

Sleeping can become a problem for many people with dementia, and sometimes it's the most difficult problem they face.

The person might sleep during the day and be restless at night, they might get confused between night and day, or they might not need as much sleep as before because they're not as active.

Problems with sleeping or late evening restlessness are often a stage in dementia that eventually passes. Many people with dementia tend to sleep more as their condition gets worse.

Look for causes

Think about what could be causing the problem – is it their environment, or maybe the medications they're taking? Could it be depression? Other medical problems?

Keeping a sleeping log might help you find a pattern that points to a problem, that may have some obvious fixes.

**For more tips
and advice about
sleeping well see
the factsheet
*Sleeping.***



Eating well

Eating a well-balanced, nutritious diet and drinking enough fluid is important for everyone, and especially so for someone living with dementia.

Possible reasons people with dementia may not eat well include:

- forgetting to eat
- confusion at the table (such as pouring a glass of juice into a bowl of soup, buttering the serviette or eating dessert with a knife)
- being unable to prepare meals for themselves
- changing appetite
- problems with their mouth, chewing and swallowing.

Many eating problems are temporary and will change as the person's abilities change, but here are some tips that may help improve the situation:

- Keep eating simple – offer easy-to-eat food
- Rather than large meals try the 'little and often' approach

- Keep in mind a person's past history with food – don't give them food they didn't like in the past, or make them eat in a different way or at different times of the day.
- Watch food temperatures – some people with dementia aren't able to tell if food is hot or cold.
- The person may get dehydrated because they have forgotten to drink or can't recognise thirst anymore – set a routine for offering them drinks (jelly, custard or ice cream can be substituted in small amounts).
- Check for problems that could be causing pain with their teeth, dentures or the mouth in general, such as ulcers.
- Where possible, a good strategy is for the person with dementia is to eat with others so they can pick up cues about what to do.

**For more tips
and advice about
sleeping well see
the factsheet
*Eating well.***

Incontinence

When someone cannot control their bladder or bowels they become incontinent. For people with dementia, their brains no longer send or receive the messages to recognise the feeling of having a full bowel or bladder.

The person with dementia might also not remember what they are supposed to do if they do recognise that feeling, or they may no longer be able to hold on until they reach a toilet.

Medical checks

Incontinence can also be caused by medical problems, so see a doctor to have a full medical assessment. The doctor can also refer you to a continence nurse who can give you specialist advice and support.

Caring for someone with continence issues

Accidents are bound to happen, so try not to worry too much. But problems around toileting can be humiliating, embarrassing and messy.

For the person who is caring for someone with dementia, managing issues with continence can sometimes feel like the last straw. It can get tiring and frustrating, and seem like a constant round of washing and drying clothes and bed linen.

There are many products available to manage continence and basically make everyone's life easier. So ask for help and advice on what you can use to minimise your workload and help the person with dementia get on with their usual day.

Problems with continence are not easy for the person to accept, so remember to respect the privacy and dignity of the person with dementia and be sensitive to their feelings.

Reviewing the environment could be helpful to promote continence. Check that the toilet is easily identified, for some people a white seat on white toilet bowl in a white room is not helpful, consider using colour to make the toilet stand out. Also, check the door to the bathroom/toilet is easy to identify and that it stands out from other doors in the house.

Constipation

Not being able to pass a bowel movement (poo) can be another common problem for people with dementia.

Some tips to avoid constipation include:

- ensuring a high-fibre diet (that includes plenty of vegetables, fruit and wholegrains) and drinking at least six to eight glasses of water a day
- encouraging physical activity every day
- keeping track of when the person goes to the toilet – people with dementia might forget they have gone.

Ongoing and unresolved constipation can lead to serious medical issues and can contribute to increased confusion. It is very important to discuss any concerns you might have with a health professional.





Intimacy and sexuality

The need for closeness is a very important and natural part of our lives, including the lives of people with dementia.

Intimacy is the giving and receiving of love and affection. It involves caring touching, empathic understanding, comfort in times of need, and a feeling of safety in relationships.

Sexuality is the feeling of sexual desire, which is expressed through sexual activity. Like intimacy, sexuality is a natural expression of a human need.

How dementia affects intimacy and sexuality

People with dementia will vary in how they give and receive affection, and how dementia affects their ability to do that. Because of the condition, some people with dementia may become demanding and insensitive to others' needs. They may also want more or less affection themselves.

How they express their sexuality might also change. Some people with dementia may want to stay sexually active while others might lose all interest. Because of

the dementia, others might do sexually inappropriate things.

Ways to maintain intimacy:

- Include different forms of touch in everyday routines so the person with dementia gets some physical contact.
- Massage, holding hands and hugging are ways to continue providing loving touches.

There are many other ways dementia can cause changes in the way a person acts around intimacy or sexuality – including inappropriate activity. For more detailed information see the factsheet *Intimacy and Sexuality*.


Personal care

Helping someone with dementia with their personal care can be extremely time consuming and emotionally exhausting. You will very much be in each other's personal space and that can take some adjustment – for both of you.

There are many reasons why a person with dementia might have difficulty carrying out their personal care. Dementia affects each person differently, and you also will react to the situation in a different way to someone else, so you will need to find an approach that suits you both.

It's important to remember to encourage the person with dementia to continue to do as much as possible for themselves for as long as possible. This means things will take longer to get done, and may lead to frustration at times, however, it will help them to remain independent and feel better about themselves for longer.

Here are some of the reasons that bathing and dressing may be challenging, along with some possible solutions.



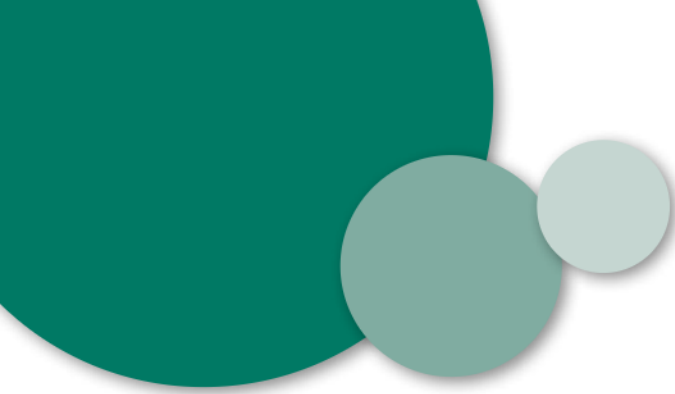
For more detailed information on how to help someone with their personal care, such as cleaning teeth, showering, and other hygiene needs look for the factsheet *Assisting with Personal Care*.

Concerns about privacy

Possible reasons	Possible solutions
Washing and dressing are intimate, private activities. Many people may have never undressed in front of others before so may feel embarrassed or humiliated.	<ul style="list-style-type: none"> • Pull down the blinds or close curtains and doors to create a feeling of privacy. • Cover mirrors if the person with dementia doesn't recognise themselves and gets frightened. • Give the person a lot of reassurance and be patient. • If they are able to manage most of the task, help them only when necessary • Provide encouragement and ensure the experience is a positive one by using soaps etc that the person likes.

Fear of bathing

Possible reasons	Possible solutions
Some older people, and especially those with dementia, feel the cold more and might be reluctant to undress.	Make sure the room is warm and inviting.
Noise, other people, bright lights and clutter in the room can be distracting.	Have enough lighting and make sure it's the same brightness in all rooms. Soft background music may help create a calming and relaxing atmosphere.
They may not be used to bathing or showering each day.	Try to stick with the person's previous bathing routine, and/or time their bath or shower for the time of day they are most relaxed.



The task is too confusing or complicated

Possible reasons	Possible solutions
Getting undressed, having a wash and brushing teeth can be very complex tasks because of the many steps involved.	<ul style="list-style-type: none">• Break down the tasks into simple steps and gently explain each step using simple, respectful language.• Try offering limited choices, such as, “Would you like to have a bath or a shower?”• Encourage the person to do as much as possible themselves.• Lay out the soap, facecloth, towel and clean clothes in the sequence you will need them, making sure they are all within easy reach.
Some people with dementia may have a different perception of hot and cold water, and how water feels.	<ul style="list-style-type: none">• Let the person with dementia feel the water before getting into the bath or shower. Sometimes gently pouring water over their hands reassures them the water isn’t too hot.• Saying something like, “The water feels nice” or “This feels good” can also be reassuring and calming.

A fear of water

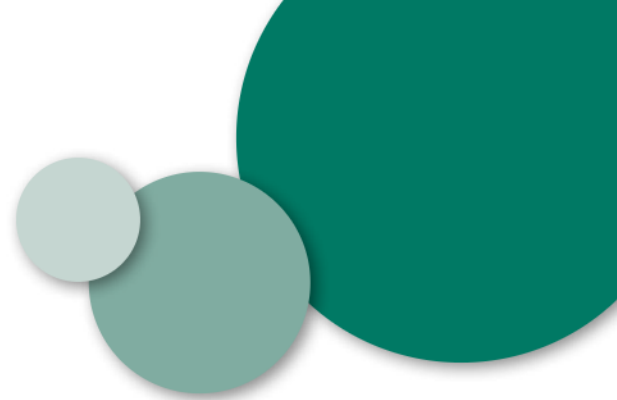
Possible reasons	Possible solutions
They may be unable to gauge the depth or temperature of the water so are frightened to step into it, or may be worried they will fall.	<ul style="list-style-type: none"> • Some people prefer smaller or deeper baths – check what the person with dementia prefers. • Allow plenty of time for the bath and encourage them to do as much as they can for themselves. • Prepare the bath ahead of time. • Install a hand-held shower and grab rails.
They may fear drowning, particularly if water is being poured over their head.	<ul style="list-style-type: none"> • Try separating hair washing from bathing. Some people with dementia associate bathing with having their hair washed and become upset because it frightens them to have water poured over their head. • Washing their hair from a basin rather than a bath or shower may be a better option.
Depression or a physical illness can cause a loss of interest in personal hygiene. They may now have problems with balance or walking, or with their eyesight, or have trouble fastening buttons or closing a zip. The side effects of some drugs can also cause dizziness or stiff joints.	<p>Organise for the person with dementia to have:</p> <ul style="list-style-type: none"> • a thorough medical examination to find any possible physical or medical reasons contributing to any challenges while dressing • their vision or glasses prescription checked • an evaluation for depression.

Forgetting how to dress

Possible reasons	Possible solutions
Some people with dementia can't remember whether they are getting dressed or undressed. They may know they are holding a piece of clothing but can't remember which part of the body it goes on.	<ul style="list-style-type: none"> • Try using the 'task breakdown' technique to separate the task into simple, manageable steps and do them one step at a time. • You may have to gently remind the person about each step, or do several of the steps yourself. • Give them reassurance and praise for each successful step – this will make both of you feel more positive.
They may forget to change their clothes, put them on in the wrong order or put on too many layers.	<ul style="list-style-type: none"> • Put out the clothes in a pile with the first item to be put on at the top. • Try laying out lightly coloured clothing on a dark bedspread – the contrasting colours may help them see the clothes if they are having eyesight issues. • Put away distracting things, such as out-of-season clothes.

Deciding what to wear

Possible reasons	Possible solutions
It's important to encourage a person with dementia to choose their own clothes, although it might be difficult for them to make even simple decisions.	<ul style="list-style-type: none"> • Simplify the number of choices – offer two outfits to choose between, or a choice such as between "a white or blue shirt". • Take inappropriate or out-of-season clothes away from the dressing area.



Putting on many layers of clothing regardless of the weather

Possible reasons	Possible solutions
Some people with dementia find it hard to judge hot and cold weather.	<ul style="list-style-type: none">• If the extra clothes aren't causing them any problems, it's probably easier to leave well alone.• Pack away extra clothing so it's not visible and put out only what's appropriate to wear.

Choosing new clothing and footwear

Possible reasons	Possible solutions
It's important to maintain the person's individual style as much as possible. Everyone has their own style of dressing and buying new clothes that are very different from how they used to dress may cause problems.	<ul style="list-style-type: none">• Choose clothing that's easily washable and doesn't need ironing.• For some people, buttons, snaps, hooks, zippers and belt buckles are too difficult to manage, so maybe replace them with Velcro tape.• Busy, bright patterns on clothes can be distracting – choose clothes with simple patterns and with solid contrasting colours because these tend to be easier to see.• Slip-on shoes are easier to put on – make sure shoes have non-skid soles.



Wearing the same outfit day after day

Possible reasons

In the past, many people didn't change their clothes as often as we tend to today, so the person you are caring for may want to wear their clothes beyond the time you believe they should be in the wash.

Possible solutions

- Rather than arguing, think about buying a couple of the same outfits so the person still has the comfort of wearing familiar clothes.
- Tactfully take the dirty clothes at the end of the day and put down clean clothes in their place.
- Compliment the person on their appearance when they are wearing clean clothes.
- Being reminded to change your clothes can be an embarrassing and humiliating experience, so choose your words carefully when suggesting they change.
- Even if the person with dementia does want to wear the same clothes, encourage them to dress themselves as much as possible because keeping their independence builds up their pride and self-esteem.

Undressing at inappropriate times

Possible reasons	Possible solutions
Some people with dementia may undress themselves frequently and at inappropriate times. While it can be embarrassing and inconvenient, they are not usually doing it to make trouble.	<p>Evaluate the situation:</p> <ul style="list-style-type: none">• Is the person too warmly dressed?• Do they need to go to the toilet?• Are they tired and trying to get ready for bed?• Are they bored? <p>Take whatever action is appropriate to respond to the situation.</p>



Support to live well with dementia

There's support available for both you and those who support you. Your local Alzheimers NZ organisation and your doctor can let you know you about services in your local community.

These might include the following:

- Information, education, support and advocacy services offered through your local Alzheimers NZ organisation.
- Support through your Needs Assessment and Service Coordination Service (NASC), such as:
 - > assistance with household tasks
 - > assistance with personal care needs, such as showering, dressing or supervising medication
 - > day programmes
 - > carer relief
 - > respite services
 - > residential care
 - > support with ready-made meals
 - > subsidised taxi chits to help with transport costs.



**Just remember
you are not alone.
Help and support
is only a phone
call away.**

For more info

General information and support:

Alheimers NZ

www.alheimers.org.nz
0800 004 001

The Ministry of Health

www.health.govt.nz

Age Concern

www.ageconcern.org.nz

Health and Disability Commission

www.hdc.org.nz

Senior Line

www.seniorline.org.nz

Citizens Advice Bureau

www.cab.org.nz

Carers New Zealand

www.carers.net.nz

Advance care planning and end of life care

Advance Care Planning Co-Operative

www.advancecareplanning.org.nz

Hospice New Zealand

www.hospice.org.nz

Enduring Power of Attorney (EPA)/Wills:

Family Court

www.courts.govt.nz/family

Law Society

www.nz-lawsoc.org.nz

Ministry of Social Development

www.msd.govt.nz/epa

Public Trust

www.publictrust.co.nz

Benefits, home support and residential care

Work and Income New Zealand

www.winz.govt.nz

Needs Assessment and Service Coordination (NASC) information

www.health.govt.nz – search for NASC

Eldernet

www.eldernet.co.nz

Ministry of Health

www.health.govt.nz

Driving

New Zealand Transport Agency

www.nzta.govt.nz



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