



Transitioning to residential care

A guide for people caring for someone with dementia





A dementia friendly New Zealand

Aotearoa, he aro nui ki te hunga mate wareware

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Contents

Introduction	5
Where to begin.....	6
Getting in to residential care.....	8
Younger people living with dementia.....	10
Choosing a residential care facility.....	11
Planning for the move	13
Making the transition	16
Caring partners – your new role.....	18
Good care in a residential facility.....	21
Staying involved	22
Support groups.....	25
For more info.....	26



Introduction

Deciding to find an alternative to caring for someone with dementia at home can be an extremely difficult decision.

This may be particularly true if the person with dementia is a long-term partner or spouse. While nothing can take away how difficult this situation is, being prepared can help making the decision less stressful.

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
- **Supporting a person with dementia:** a guide for family/whānau
- **Understanding changed behaviour**
- **The later stages of dementia and end of life care**

Knowing about the available services, government policies and costs of residential care beforehand can help you make the best decisions, even if they have to be made quickly.

This resource is designed to provide information about transitioning from home to residential care. The booklet provides information on:

- deciding on residential care
- what to look for when choosing a care facility
- how to cope when the person you have been caring for goes into residential care.

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**.

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

Where to begin

There is no 'right' time to make a decision about residential care. It may be something you've been thinking about and planning for a while or it may be a decision that has to be made quickly.

Either way, this is likely to be a very difficult process. There are sure to be all sorts of emotions for you all – the person moving into residential care, the people who care for that person, and family/whānau – so finding someone to support and assist you at this time can be helpful.

Sometimes choosing to make the move into residential care can cause division in families, for example when family members have different ideas of who should provide the care and where. In these situations it is very important to get help, your local Alzheimers organisation can arrange this for you.

A person with dementia has the right to be cared for in a safe, protective environment. But even with help from friends and family/whānau and other support services, there may come a time when care within a family or private home is not the best for either the person or whoever is caring for them.

Residential care may then be the most appropriate alternative. This certainly doesn't mean you and other people who have been caring for the person must step back from your role. Rather, it means you now have the support of dementia care professionals and can work in partnership with them to continue caring and supporting the person with dementia.



Getting help

You do not need to do this alone. Transitioning into residential care can be an overwhelming process so it's helpful to have expert support and advice. Contact your local Alheimers organisation to see how they can support you.

You might like to read the Ministry of Health's booklet '*Long-term Residential Care for Older People: What you need to know*'. Published in 2012, this booklet explains both the needs assessment

process for aged residential care and the financial means assessment for eligibility for the Residential Care Subsidy.

The booklet also provides information about what a person can expect when they go into an aged care facility, how much they have to pay and where they get more information if they need it. The booklet is available to download or you can order a print copy by going to the Publications area at www.health.govt.nz and search for the booklet's title.

Getting in to residential care

There is a formal process that needs to be followed before a person can move into residential care. The first step is that the person with dementia will have to be formally assessed, this is called a needs assessment. The next phase is called the service coordination and this is discussed in more detail later.

Needs Assessment

Assessments are done by your local Needs Assessment Service Coordination service (NASC). (Your local NASC organisation might operate under a different name such as Support Works or Community Supports.)

You may already have had contact with this service in organising support in your home or respite care. You can contact this service directly, or your GP or someone from your local Alzheimers organisation can refer you. If the person with dementia is in hospital, staff there will arrange the assessment.

If a person has specific care needs relating to their dementia, a specialist (such as a Psychiatrist of Old Age or Geriatrician) may be involved in the assessment process.

A needs assessment ensures a person with dementia:

- is informed of support services that would help them to stay in their own home (such as home care, district nurses)
- has access to specialist medical advice or rehabilitation that may improve their health so they can remain at home
- has help with making decisions around care and residential care
- is informed of the needs assessment and the financial means assessment criteria for access to public funding for residential care.

The assessor visits a person and their family at home or hospital and works out how much support the person with dementia needs.

Service coordination

Service coordination is the next step in the process, where the support services that are identified are coordinated and put in place for the person with dementia.

With the permission of the person being assessed, where possible, the service coordinator uses the information from the assessment to explore all options that might be helpful. They then help coordinate these services.

As part of this, the person with dementia and the people who care for them will be asked what solutions they think will help them. In many instances, and certainly in the earlier days of living with dementia, these solutions will include increasing or changing services or support received at home. This can include a mix of publicly funded services and user-pays services, as well as increasing or organising help from family/whānau and friends.

If residential care is recommended, the service coordinator will let you know what level of care the assessment shows is appropriate for the person concerned (there are four different levels of residential care available). They will also help you prioritise what's important, discuss available options, and provide a list of residential facilities for your consideration. (Just because the person has been assessed as eligible for a particular level of care does not mean they must go into care. It may be that with extra support that can be provided the person's entry to residential care is delayed.)

Types of residential care facilities

If the needs of the person with dementia mean they can't be supported to live at home, you will be advised which type of residential care facility will give them the care they need.

There are four types:

- Rest homes
- Dementia units
- Long-term care hospitals
- Specialist long-term care (psychogeriatric) hospitals.

A person with dementia might move into any one of these types of residential care facility, depending on their individual needs and how much care they need.

When the person's condition and their needs change, they will be reassessed. The assessment may show that they now need a different level of care. If this is the case the person with dementia may need to be moved to a different facility as not all facilities offer all four levels of care.

Younger people

living with dementia

Because there are fewer people aged under 65 with dementia, it can be very hard to find a suitable residential care facility for someone who developed dementia at a younger age.

While some people will be happy in a rest home or hospital where most residents are a lot older, others may feel out of place and the activities on offer may be unsuitable. Arranging care for younger people living with dementia often means you will need to compromise in some ways because you are likely to have fewer choices. Perhaps the rest home or hospital isn't quite right,

but is near enough for friends and family to visit often. Or perhaps there's a suitable place but it's further away.

There is no easy solution to this but it may be helpful, if possible, to organise trial stays before a permanent move to see what works best.

If there's an activities coordinator at the rest home, they may be able to arrange activities suited to the younger person living with dementia, so try to find out how the facility plans an individual's care.



Choosing a residential care facility

Choosing the right kind of residential care facility to suit the person with dementia's personality and needs is vital. It is recommended that you take time to choose the one that's best for the person's individual and medical needs, but if the decision for the person with dementia to go in to a care facility has to be made quickly, this is not always possible.

Look around: It's best to visit at least three facilities so you can compare them, look at what's different and what they have in common. It might help to take a friend or relative with you to give you another opinion.

Ring ahead: Before you go, ring and make an appointment with the clinical or facility manager.

Spend time there: Some facilities invite prospective residents, their families and those who care for them for a meal. This gives you all a good chance to talk to others and get a feel for the place.

Ask questions: It can be hard to remember what you need to ask, so take a checklist of questions with you. Ask how staff will get to know the person with dementia, how they cater to their preferences and needs, and how they will involve you so you can continue to support the person with dementia.

You can find a checklist of questions to ask, and things to look for at www.alzheimers.org.nz

Go again without making an appointment:

Once you have made your first visit and the manager has answered all your questions, make a second visit without an appointment to get a 'feel' for the facility. You may want to make a number of visits and it's a good idea to visit at different times of the day and during the weekend. Some days may seem better than others, but remember that first impressions count.

Prioritise: Sometimes you may not be able to get everything you want for the person with dementia, and you may not be able to get into the facility of your choice. In that case, decide what's most important – for example, you may go for a facility that has smaller rooms but is closer to your home so you can visit easily. Think about what might be most important for the person with dementia for example: the ability to walk in a garden area, or a place which feels homelike, or whether it small enough to find their way around – all might be important considerations.



Try not to feel pressured: If the situation is urgent you may find your preferred choice is unavailable and you may feel pressure to take the first bed available. Try to resist that pressure, but remember that while less disruption is better, you can always move the person when a space in your preferred facility comes up.

Trust your gut: Rely on your intuition, commonsense and what feels right for you. Again, your first impressions are usually the right ones.

Go online: Check out the facility's website, talk to other people about their experiences there if possible, and go online to www.agedadvisor.nz to see what others are saying about the facility.

Standards and inspection

All rest homes and hospitals have to meet the requirements of the Health and Disability Services (Safety) Act 2001. The Act requires residential care facilities to meet the Health and Disability Sector Standards. These standards are compulsory and auditable. You can review the audit results on the Ministry of Health website www.health.govt.nz/your-health/certified-providers/aged-care

Patient rights

The Office of the Health and Disability Commissioner (HDC) has information about patient rights and the services you can expect from a residential care facility. You can find out more about the HDC Code of Rights at www.hdc.org.nz

Planning for the move

Once a place becomes available in a residential facility a decision may need to be made quickly, so it's very helpful to have the move planned ahead of the time.

Explain what's happening

Change can be very disturbing for many people with dementia, so before the move explain simply and gently where and why they are moving. You may need the support of a health professional to have this conversation.

If at all possible, introduce the person with dementia to the new facility gradually so the place becomes a little more familiar and a little less confusing and frightening. However, this is not always possible, especially if the move has to be made quickly.

Some people like to compile a 'care guide' which gives a brief background of the person going into care, and outlining their daily routine, likes/dislikes, what may trigger distress and what soothes/comforts. Include activities the person enjoys and is able to do, and who the key people are in this person's life.

Another suggestion is to make a small photo album with short pieces of text to explain who/ what is in the photo, this will give the care facility a way to get to know the person and develop a rapport with them.

Keep as much familiarity as possible

Ahead of time have the person's room ready with a few photos and familiar items such as recognisable pictures or paintings on the wall, and familiar bed coverings. Keep room simple so the person is not overwhelmed. More things can be added as time goes on as appropriate. Label all personal items with large, easy-to-read identification. Check if the facility has a labelling service as this may save you some time.

Expect a period of adjustment

During this initial moving stage it will take time for both the person with dementia – as well as you – to adjust to the new situation.

You should expect a period of adjustment, but people do settle. Many people with dementia actually do better in a structured environment because they feel more secure and get more stimulation. Staff at care facilities are skilled in assisting people to become comfortable in the new environment. Make a time to meet with the activities staff member so they can know what may help settle the person you have been caring for.

Visiting during the adjustment period

There is no right number of times to visit or length of time to stay during this settling period.

Some people want to visit a lot during this time, while others will want to take time out to rest and gain their own strength and process their own feelings. Talk with facility staff if you have any concerns and need support during, or at the end, of a visit. A good tip is to leave just before a meal or tea break so the person with dementia has something positive to move their attention to.

Take care of yourself

It's important to take care of yourself when the move takes place. Residential staff will be looking after the person with dementia, so think about who's going to help you during this time.

It will be important to think about who may be able to offer support, both on the day of the move and as everyone adjusts to the change. Ask for help from family or friends, or your local Alzheimers organisation. Particularly in the early days it may be good to have something positive planned immediately after you have visited such as meeting a friend, or going to a movie.



Making the transition

The move into long-term residential care is a big step and may be difficult, stressful and emotional for all concerned. Some people with dementia and those who care for them feel a tremendous sense of loss and separation after such a move and some feel relief or mix of both.

The transition for a person with dementia

While everyone is different, even if a person with dementia can't express feelings and wishes verbally, they may still be upset about leaving home.

They may also feel confusion, sadness and fear at the sense of loss of independence and increased reliance on others. Other common emotions are grief, nervousness over unfamiliarity, anticipation, anger, relief, resignation or feelings of powerlessness.

These emotions may be expressed by changed behaviours such as increased agitation, pacing, trying to leave the facility, aggression, withdrawal, tearfulness or clinging.

It may take time for them to adjust to living in residential care. However, it's not always difficult and some people settle in quite quickly.

The transition for family carers

Some carers feel there's a gap in their own life after a person they have cared for has moved into long-term residential care. They may feel a wide range of emotions at this time, including:

- **Worry:** Wondering if they've done the right thing and if the person with dementia will be well looked after. It's important to remember that the decision was made based on balancing what's best for everyone involved.
- **Guilt:** Many feel guilt, perhaps because they feel they ought to still be doing the caring tasks, or as though they have betrayed the person.
- **Grief:** Caring for a person at home helps retain a sense of the way things used to be, and the physical parting may add another dimension to the grieving process.

Having someone go into residential care can also have positive effects for the people who have been doing the caring, including the following:

- Their lives need no longer be centred around the practical tasks of caring or organising help, so they feel less stress.

- They may feel they have freedom to do things for themselves, when they want to do them.
- They may be more able to sleep.
- They may find the lightening of their responsibilities a relief, especially if they or the person with dementia has been physically unwell.
- These positive effects may also cause you to feel guilty about having this sense of 'relief' – but again it is normal to feel this and this may be balanced as the time you now spend with the person with dementia may be more relaxed and enjoyable – because someone else is doing the physical day-to-day caring.

Help and support

People who have been caring, or family members of someone with dementia who's gone into long-term care, may find it helpful to talk to others who understand their situation and feelings. They could be friends or relatives, or they might be people like them in a support group, or they could be staff at their local Alzheimers organisation.

Many residential care facilities run relatives' groups because they understand the difficulties experienced by many relatives once the move has occurred.

Some Alzheimers organisations offer short courses for families and carers about transitioning from home to residential care. You can get information and support at any time from your local Alzheimers organisation – phone 0800 004 001 or go to **www.alzheimers.org.nz**

Also contact Carers NZ at **www.carers.net.nz** for online support and to find out what support might be available in your area.



Caring partners – your new role

As someone who's been carrying out a caring role, preparing yourself for the period after settling someone with dementia into residential care is just as important as preparing them for the move.

You will likely be dealing with a variety of mixed feelings, and certainly your daily activities will suddenly change.

But none of this means you no longer have a caring role because someone else is doing all or most of the physical tasks of caring. In fact, you're essential because you are the 'expert' when it comes to caring for that person with dementia.

Your role alongside professional care workers is to inform, advise, recommend, help make decisions and encourage the best possible quality of care for their new resident. You can also continue to help out with caring tasks if you want to – how much you do is entirely up to you.

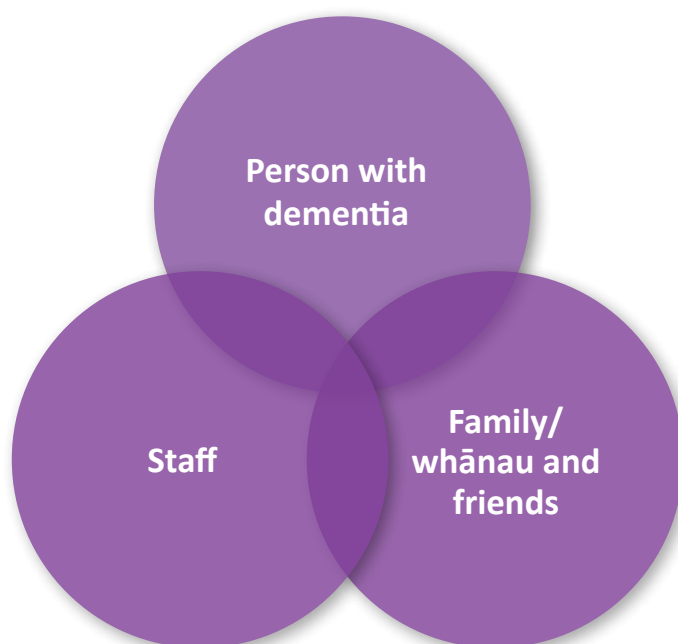
How you can continue to care

The caring partnership you can create alongside the residential care facility should see the person with dementia getting the best possible care.

The advantages of a caring partnership include the following:

- Care is individualised so it meets the needs of the resident, their family/whānau and friends.
- Staff, residents, families and friends work together to meet these needs.
- There's good communication and an understanding of the resident's life history as well as who they are now.

Think about this partnership as three circles overlapping:



On the other hand, you may feel completely exhausted after the move and want to take time out from the caring role. That's absolutely fine, too.

However, the door should always be open for you to get involved in whatever way you wish. This may be anything from sharing a meal together, helping with showering, to receiving regular information from the facility.

How the facility should involve you

The facility should always welcome and encourage your involvement, and should involve you in caring in the following ways:

- Asking you for information about the family background, past employment, activities and hobbies, likes, dislikes, language, religion and culture of the person with dementia.
- Encouraging you to make their room as home-like as possible. This could involve displaying family photos or bringing in objects such as ornaments or religious figures that may have sentimental value.
- Liaising with you to develop a care plan that sets out the person's needs, goals, strategies and actions to ensure their needs are met.
- Reviewing their care plan with you regularly.
- Regularly informing you about general care issues.
- Consulting you regarding the management of the person's confusion, changes in mood or restlessness.
- Inviting you to help out with activities, including outings or events at the facility.
- Consulting you about daily living issues, such as the time the resident likes to get up and go to bed, bathing times, what to wear, what to eat, when they like to have meals and so on.
- Encouraging you to read the resident's day-to-day notes or communication book.
- Acknowledging your arrival and departure with a warm greeting or farewell.
- Inviting you to attend residents/family meetings where the day-to-day running of the facility is discussed, and encouraging your feedback on things such as meal times, menus, activities, communication and accreditation.

Speak up: If the facility doesn't actively promote the involvement of families and friends you can speak to the manager about how you wish to be involved and the ways they can help you to do this.

Remember your rights: Should you feel the facility isn't involving you, you may need to get information and support from Health and Disability Advocacy. Find out more details at www.advocacy.hdc.org.nz or freephone **0800 11 22 33**.

How to get the care you want

Here are some tips to ensure you get the care you want for the person with dementia.

- Communicate the person's needs clearly, for example:

"My husband doesn't like to eat at midday. We need to arrange a later meal time."

"I want to be told of any changes in his behaviour, no matter how small."

- Give important information to the facility, for example:

"My father doesn't like to talk much."

"Mum likes a shower early in the morning."

- Explain what is most important to you about the care provided, for example:

"My wife has always prided herself on her appearance and it is important that she is well groomed when visitors arrive."



Good care

in a residential facility

For more detailed information see the factsheet *Good Care in a Residential Facility*.

Good care is based on how well a residential facility responds to each resident's needs. Some aspects of good care will vary between individuals according to their needs and preferences.

Some facilities may not always hit the mark on all aspects of good care, so you may have to weigh up a number of issues and prioritise what care aspects are the most important to you.

You might find that in the particular facility you visit there's a need for improvement in some areas. If so you should first discuss your concerns with management. If you still have concerns you may wish to seek advice from your local Alzheimers organisation, which can direct you to the appropriate organisations in your area.

The following is a list of important aspects of good care:

- Staff are trained and skilled in dementia care and the management of special needs.
- Staff should be encouraged to adopt and implement a care approach that seeks to know and understand each resident in the context of their culture and life experiences.
- Relatives and friends are involved as much as possible and treated as partners in caring, not just as someone who can help at meal times.
- Staff should have the clinical skills in pain assessment and management, and should acknowledge and utilise the experience of families and carers in this area.
- Best-practice nursing care means that restraining the person by physical means or with the use of medication is rarely necessary except in extreme circumstances and should therefore not be in regular use in any care facility.
- There is access to specialist psychogeriatric assessment and advice.
- Referral to specialist palliative care is made at the right time.
- The advice of other allied health professionals, such as physiotherapists, occupational therapists, speech pathologists, dieticians or psychologists, may also be very useful in achieving the best quality of life for the person with dementia.

Remember: The key to good care is ensuring the environment is as home-like as possible and is centred on a flexible approach to providing the best possible support for the resident.

Staying involved

Once the initial settling period is over, your involvement in the care of the person with dementia is always welcome, although – again – the level of involvement is entirely up to you.

Visiting

Visiting is usually very important to both the person with dementia, their family/whānau and those who have cared for them, as a way of everyone staying connected.

The person with dementia may enjoy seeing other members of the family/whānau or old friends. Children should be very welcome in residential facilities, so encourage grandchildren to visit. If they're young, think about preparing a visiting bag that contains treats and activities to keep them entertained. If the facility allows, think about bringing in an appropriate pet.

Visiting can sometimes be difficult, especially as the abilities of the person with dementia decline. Try to find some ways to make visiting as easy and enjoyable as possible, such as:

- bring in newspapers and magazines to look at together
- read mail together
- play games that have been enjoyed in the past
- listen to music recordings, or audio books
- watch a well-loved movie or home movie
- look at photo albums together
- help decorate and tidy the room
- help with personal grooming – washing or brushing hair, painting nails
- help with writing to friends and relatives.

Outings

The person with dementia might also enjoy an outing.

You could try:

- a short drive in the car, perhaps stopping for afternoon tea
- a visit to another person in the facility
- a stroll or ride in a wheelchair around the facility's garden.

Leaving

Leaving after a visit can be a very difficult time for both the person with dementia and their visitors.

To make it easier, you might try:

- taking something to do with them, and once you have finished it's time to go
- asking the staff to divert the person's attention, or leave when a meal is about to be served so there's something else to do
- letting the person know at the beginning of the visit how long you can stay and why you have to leave – for example, "I can stay for an hour but then I have to go shopping"
- keeping farewells brief and leave straight away – lingering, apologising or staying a little longer can make future farewells even harder.

Wanting to go home

A common phrase heard from people with dementia in residential facilities is "I want to go home", which can be very upsetting for visitors.

Wanting to go home may be caused by feelings of insecurity, depression or fear. It may be that "home" is a term used to describe memories of a time or place that was comfortable and secure. It may be memories of childhood, or of a home or friends who no longer exist.

- Try to understand and acknowledge the feelings behind the wish to go home.
- Reassure the person they will be safe – touch them or hold them to reassure them.
- Reminisce with them by looking at photographs or by talking about childhood and family.
- Try to redirect them with food or other activities, such as a walk.
- Don't disagree or try to reason with them about wanting to go home.
- A point to note is that if you did take the person home, it might not be what they really want as it is not usually a house or building the person with dementia is referring to but the desire to be in a place that is comforting and familiar.



Visiting in the later stages

Doing things that use as many of the senses as possible – sight, taste, smell, hearing and touch – are a good thing to try.

Depending on what the person with dementia enjoys and needs, you might try:

- massaging legs, hands and feet with scented creams or oils
- bringing in perfumes and flowers so they can enjoy the scent
- a gentle kiss or hand-holding for reassuring contact
- let them see you smile, looking at them with affection
- play music, which they may find familiar and comforting
- visits from friends and relatives – even though they may not be recognised or remembered, they can still stimulate the person, giving them feelings of comfort and familiarity
- listening to a favourite book or poem being read
- a stroll or push in a wheelchair around the grounds.

There's no right number of times to visit or amount of time to stay. The important thing is to make each visit as rewarding as possible.

Support groups

Your local Alheimers organisation coordinates support groups for people with dementia, carers and includes special interest groups, such as men who have caring roles and support groups for younger people with dementia.

Many people find comfort and practical help by going to meetings with others who know what it's like to either live with dementia or care for someone with dementia, whether they're at home or in a residential facility.

Support groups bring together families and friends of people with dementia under the guidance of a group facilitator. The facilitator is usually a health professional or someone with first-hand experience of caring for a person with dementia.

Many facilities run relatives' groups because they understand the difficulties many families face after the move has happened. Find out if the one you are associated with, or planning to become associated with, runs such groups.

Other support

There's support available for both you and those who support you. Your local Alheimers organisation or your GP 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 Alheimers organisation
- support with ready-made meals
- subsidised taxi chits to help with transport costs
- 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.

**Just remember
you are not alone.
Help and support is
available from your local
Alheimers organisation
0800 004 001.**

For more info

General information and support

Alzheimers NZ

www.alzheimers.org.nz
0800 004 001

The Ministry of Health

www.health.govt.nz

Age Concern

www.ageconcern.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

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

Driving

New Zealand Transport Agency

www.nzta.govt.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



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



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