



Alzheimer's New Zealand



Residential Care for People with Dementia Detailed Booklet

Information for people with dementia,
their carers and families

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Alzheimers New Zealand
PO Box 3643, Wellington
Ph (04) 381 2362
Fax (04) 381 2365
Email nationaloffice@alzheimers.org.nz
www.alzheimers.org.nz

Making life better for all people affected by dementia
Kia piki te ora mo ngā tāngata mate pōrewarewa



Alzheimers New Zealand

Alzheimers New Zealand Incorporated is a charitable organisation with 23 Alzheimers member organisations located throughout the country.

Alzheimers New Zealand supports the work of the member organisations and at a national level represents people with dementia, their carers and families, through advocacy, raising public awareness and providing information.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers and families. Alzheimer member organisations located throughout New Zealand provide a variety of services in their local areas, to support all people affected by dementia.

Contact your local organisation for information and support on freephone 0800 004 001.

This booklet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or a carer for a person with dementia should seek professional advice about any individual case. Alzheimers New Zealand Incorporated and/or its officers or employees shall not be liable for any error or omission in this publication, as a result of negligence or otherwise.



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- *Residential Care Line website*
- *Eldernet website*

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Introduction

If you are a person with dementia or are involved in caring for someone with dementia there may come a time when you need to consider, and make, the move to long-term residential care. This booklet:

- explains what is involved in planning for and choosing long-term residential care,
- provides an overview of the financial and legal issues you will need to consider,
- discusses some of the issues for people moving into care and their carers at the time of the transition,
- provides information on how to be involved in the on-going caring of a person with dementia when they are settled in a long-term residential care facility.

Contact details for all of the organisations referred to in this booklet and full details of publications and sources for further information are provided at the end of the booklet.

Staff at your local Alheimers organisation will also be able to help you understand the contents of this booklet and can provide you with any further information you may need about any of the issues covered in it.

Considering Long-term Residential Care

For many people with dementia, there will come a time when more care is needed than can be provided at home, even with support services. It is likely, therefore, that you will need to consider residential care options at some point in time.

There is no one 'right' time to consider the option of residential care. It may be something that you have 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 and not one that you generally plan for or expect to have to go through.

Ideally, you should think about the move to residential care well in advance. That way, there will be plenty of time for a person with dementia, carers, and the rest of the family to discuss the options with the appropriate professionals and to choose the right facility. But don't be hard on yourself if that's not the way it happens. Sometimes a move has to happen quickly, for example because of a change in a person's health. And many people find it too difficult emotionally to think about long-term residential care, until they have to. It can take some people weeks, months or even years to face up to and make the decision.

There are sure to be all sorts of emotions for the person moving into a residential care facility, the carers and family as you all go through the process, so finding support and assistance at this time can be helpful.

Getting help with the process

You do not need to think about long-term residential care and go through the process on your own. It can be helpful to talk through your feelings about the options with other people. And involving the rest of the family in the decision can help as well.

People who can help by providing information and support, putting you in touch with local services or relevant support groups or just helping you to think things through are:

- family doctors (GPs) or psychogeriatricians / geriatricians,
- needs assessors, or social and community workers,
- your local Alzheimers organisation,

- community psychiatric nurses or mental health nurses,
- staff at any day centre a person with dementia attends,
- other people who have had to make a similar decision.

Involving a person with dementia

A person with dementia has a right to be involved in the discussions when considering the options about long-term residential care. It is important that any decision is either a joint one, where that is possible, or made with full consideration of the person with dementia's feelings. They may have already made their wishes known to the carer and these should be taken into account where possible. But remember, the situation may have changed. Sometimes a promise not to let someone go into a rest home or hospital might have to be reconsidered, or broken, in the best interests of everyone involved.

Advocacy can help to make sure that the views and wishes of a person with dementia are heard and respected, and represented to others where a person is unable to do this by him or herself. Advocacy aims to promote maximum involvement in decision making. People who can advocate for a person with dementia include:

- a friend or family member,
- an enduring power of attorney (if a person with dementia has one),
- your local Alzheimers organisation.

Some people with dementia may lack insight into their situation and may not understand why they should move into a residential care facility. In this situation it can be helpful for the carer to try talking to the person about why they think a move would be beneficial. Focus on the positive aspects. If a person will not agree to move, someone else may have to make the decision on his or her behalf (refer to the section on Making the Transition for more information about this situation).

Remember... When thinking about a move to long-term residential care, it is important to remember that a person with dementia has the right to be cared for in a safe, protective environment. Even with help from friends, family, and other support services there may come a time when care in the person's own home is not the best option for either the person or any family carer. Residential care may then be an appropriate alternative. This does not mean the carer must relinquish their role entirely. Instead it allows the carer to care for a person with dementia in partnership with professionals.

Accessing Long-term Residential Care

Needs assessment

The first step for admission to long-term residential care is for a person with dementia to be assessed by the local needs assessment service. You may already have had contact with this service in organising support in your home. This service can be contacted directly (details are available through your local hospital or on the Ministry of Health or Eldernet websites) or you can be referred by your GP or your local Alzheimers organisation. If a person with dementia is in hospital, staff there may arrange the assessment.

To be considered eligible for financial support from the government for long-term residential care (the Residential Care Subsidy) a person with dementia is required to have a needs assessment. Even when planning to pay privately for care (i.e. not eligible for any subsidy), it is strongly recommended that a person with dementia has a needs assessment before entering long-term care. In fact most residential facilities will require you to have an assessment before admission. This eases the transition from private funding to public funding should the need arise in the future.

Needs assessment ensures that a person:

- is informed of support services that would help them to stay in their own home (e.g. district nurses, home care),
- has access to specialist medical advice or rehabilitation which 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. If a person does not meet these criteria there will not be public funds to pay for their residential care until such a time as they do meet the criteria.

A needs assessor visits a person and their family at home or hospital and discusses:

- tasks a person with dementia finds difficult,
- family/whanau or social support available to a person with dementia,
- the kinds of services that could help a person with dementia stay at home.

Needs assessment looks at a person's clinical care and broader support needs, and identifies the level of support a person with dementia requires. In addition, a specialist (psychogeriatrician or geriatrician) may be involved in the assessment process if a person has specific care needs relating to their dementia. Assessment by a specialist is always required for a person moving to a dementia specific facility.

The assessment will categorise the needs of a person with dementia as low, medium, high, or very high, which will then link to the types of care and support services available.

Service co-ordination

Service co-ordination is the process of putting solutions into place that will meet the assessed support needs of a person with dementia. With the permission of the person being assessed where possible, the service co-ordinator uses information from an assessment to explore all options which might be helpful and then assists with the co-ordination of these services. The person being assessed and their carer will be asked for their suggested solutions and in many instances the solutions will include increasing or varying services or support received at home.

For people assessed as having low to medium needs, the service co-ordinator works with them to put together the support they need to stay at home. This can include a mix of publicly funded services, services you buy in yourself, as well as help from family and friends. If it is not possible for a person to stay safely at home, the service co-ordinator may propose entry to residential care, and will recommend the appropriate level of care. Long-term residential care is usually only considered for high and very high categories of need.

If residential care is recommended, the service co-ordinator will inform you of the level of care required, assist in prioritising what things are important, discuss available options and assemble a list of residential facilities for consideration. People may have different priorities and make different choices on the residential facilities they find suitable, based on, for example:

- being near their church or family,
- moving to a facility where their first language is spoken,
- the travel required by the carer to visit.

The service co-ordination process takes time and is not completed until the person concerned has taken up residence in a long-term residential care facility and indicated their satisfaction with their placement.

Types of residential care facilities

The service co-ordinator will advise you as to which type of residential care facility is most appropriate. There are four types of facility:

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

A person with dementia may move initially into any one of these types of facility, depending on their individual needs and required level of care. If their condition then changes, a new assessment may be required to determine which type of facility is now appropriate. This can be organised by the family or staff at the rest home or hospital.

Rest homes

Rest homes allow some independence and privacy in home-like surroundings. Access in and around the facility takes into account the needs of people who have difficulty with mobility, e.g. use a walking frame. Rest homes must employ a registered nurse.

Rest homes are required to provide sufficient staff to meet the health and personal care needs of all subsidised residents at all times. In rest homes, there is at least one care staff on duty at all times with another on-call. More staff members are required to be on duty according to the number of residents.

Dementia units

If someone has care needs specific to their dementia identified in their needs assessment, a dementia unit will be recommended. The physical environments of dementia units are designed to meet the care needs of people with dementia who are mobile but who show confusion that requires specialist care in a secure environment.

Dementia units are small, usually no more than 20 beds, although there may be more than one unit in a facility. They provide staff trained in dementia

care. They may have enclosed gardens and access to the street is restricted. Dementia units employ a registered nurse and must have a minimum of one staff member on-duty at all times, with another readily available on-site.

Long-term care hospitals (private hospitals)

Long-term care hospitals (private hospitals) are for older people who need nursing due to illness and disability. Although they are called hospitals, long stay hospitals are very different from public hospitals. They do not have doctors on duty 24 hours, or specialised rehabilitation. Long-term care hospitals have a minimum of at least one registered nurse and one other caregiver on duty at all times, and extra staff according to numbers of residents.

Specialist long-term care (psychogeriatric) hospitals

Specialist long-term care hospitals provide care for people who have high dependency needs and challenging or noisy behaviour. Staff are trained in dealing with people with these types of behaviours, which may be due to dementia, or the combination of an age-related disability and a mental health condition.

Minimum specialist hospital staffing levels are the same as for private hospitals: one registered nurse and one other caregiver on duty at all times, and extra staff according to numbers of residents.

Choosing a Home

Choosing a suitable facility

Once you know what type of residential care best suits a person's needs, you will need to choose the facility.

It may be that there is only one suitable facility in an area, or the facility of choice is full at the time of the initial decision. A person with dementia can move to another facility when space becomes available so you may wish to have their name put on the preferred facility's waiting list.

Information about facilities

Needs assessment services can provide listings of the residential facilities in their areas. Also, listings of rest homes and hospitals for Greater Auckland and Northland regions can be sent out by Residential Care Line and this organisation also has a website. The Seniorlink and Eldernet websites allow you to search for residential facilities with particular features.

A Question of Care and *The New Zealand Retirement Guide* are publications that provide listings of residential care facilities. These are available from the publishers or you may be able to access them from your local Alzheimers organisation.

It can also be helpful to talk to people who work in this area, such as your local Alzheimers organisation, your GP, or staff at the needs assessment service.

Once you have a list of residential care facilities, make a shortlist and contact them. Explain that you are needing suitable care for a person with dementia and any details about the level and kind of care you require.

Ask for brochures and information about vacancies. You may also want to ask for a copy of the admission agreement at this time. Many facilities have websites showing what they offer.

Visit facilities to see which one suits best. It is good to visit at different times of the day, and to go unannounced.

Good care in a residential facility

from *The New Zealand Dementia Guide* by Dr Chris Perkins

Good care is based on how well the facility responds to the resident's individual needs. Some aspects of good care will vary between individuals according to their needs and preferences. You have to weigh up and feel comfortable about a number of issues and prioritise what is important.

Effective dementia care requires strong leadership and support by managers as well as direct care staff. It also requires more staff to care for residents than general residential care and a focus on person-centred care. Person-centred care provides individualised care to the resident to ensure his or her well being.

Staff need to be encouraged to adopt and implement a person-centred approach to care. A person-centred approach to care provides the individual resident with support at the level required to maintain their physical, social, cultural, spiritual and mental well being. In providing the necessary support for an individual, the service encourages the resident to maintain their independence, cultural preferences and chosen lifestyle as much as possible.

Experience has shown that some separate areas are beneficial for the good care of people with dementia who have special needs such as confusion, restlessness or wandering.

People with special needs can be further supported by trained staff, care planning based on the person's needs, individualised activity programs and good dementia design including safe wandering areas. Any special supports should be addressed in a person's care plan. Carers should be asked for their input into the strategies and actions that may be required to manage a person's special needs.

Other aspects of good care it can be useful to explore include effective pain management, policies and practices for using minimal restraint for managing challenging behaviours, access to specialist psycho-geriatric assessment and advice in the management of dementia, and culturally appropriate care.

Refer to *The New Zealand Dementia Guide* by Dr Chris Perkins for further information on good care.

What to look for in a residential care facility

Try to visit as many facilities as possible before making a decision, so that you can compare them and the care being offered. Spend time looking around, talking to staff and residents, and asking all of your questions. You might find it helpful to make up your own checklist of things to look out for and to ask about. Perhaps take a friend with you so you can discuss the pros and cons later. Also a friend or family member might ask questions you forget.

A person with dementia is likely to settle into a place more easily if they have been able to choose the facility or have had some involvement in the choice so it is important that they are included in this process where possible.

Below are some suggestions for your checklist. They are only a guideline to give you an idea of what to look out for. You will probably not be able to check them all, but some will be more important to you than others.

It is important to find a rest home or hospital as suitable as possible so that a person with dementia does not have to move again. Sometimes a change in circumstances will mean there is no other option, but where possible, a person will want to be able to stay in the one facility even if their needs change.

It is therefore important to clearly understand what levels of care the facility is able to provide (e.g. can they cope with wandering or incontinence) and in what circumstances they would be unable to continue to provide care and would ask for the person to be reassessed and moved on to another facility that can provide the higher level of care.

Checklist

Staff

- For rest homes, how many hours per week is a registered nurse on duty, and when?
- How often does the rest home use agency staff?
- Do staff have an understanding of and specialised training in caring for people with dementia?
- Are staff qualified or are they untrained care assistants? If they are qualified, what are their qualifications?
- How many staff are on duty during the day and at night?
- Do the staff seem friendly, caring, and approachable?

- How do staff respond to residents? Do staff treat residents as individuals and know about their backgrounds and interests?

Care

- How do management involve family / whanau in decisions and ongoing care planning, such as writing the care plan and reviews?
- What is the policy for communication between carers / family members and staff? How are relatives kept informed?
- How would staff deal with a situation/behaviour that bothers the carer?
- Is there flexibility with routine? For example, can a resident have a day in bed or can they get up later, if that is their wish?
- How are challenging behaviours managed?
- What policies and processes does the facility have in place to eliminate or modify restraint?
- Is the facility able to cope with a person's changing care needs or will the person have to move if they develop problems such as incontinence or challenging behaviour?

Ownership / Management

- Who owns the facility?
- If the manager is not the owner, what input does the owner have in the day-to-day running of the home?
- Does the manager have a special knowledge of dementia?
- Does the manager seem tolerant and caring as well as efficient and capable and is he or she friendly and considerate to staff and residents?
- Does the manager openly answer your questions and does he or she understand your worries?
- Are they interested in the residents as individuals and do they try to meet their particular needs?
- Does the home have a carers' group or regular relatives' meeting with senior staff?

Location

- Is it convenient for carers and visitors to get to the facility?
- If the person enjoys going out, are there shops or a park nearby?
- Is there a safe attractive outdoor area?
- Can residents easily go out for fresh air?
- Is the setting pleasant?

First impressions

- Are you greeted in a warm and friendly way when you arrive?
- Is the atmosphere homely and welcoming?
- When you visit, are staff accessible and are they interacting with residents?
- How many lounges / living areas are there? Is there a choice?
- Is it clean and pleasantly decorated and furnished?
- Is there an up-to-date calendar? Is the time on the clock correct? Are there other features to aid orientation?
- Are the residents well presented; appropriately dressed in clean well cared for clothing?

Access

- Are the surroundings safe, comfortable, and easy to move around in for a person with dementia?
- Are the corridors wide enough for a walking frame or wheelchair?
- Are baths and toilets suitably adapted?
- Are there ramps or lifts?

Admission

- Do they offer to compile a detailed list of the person's habits and preferences or will you have to insist on this yourself?
- Will there be a member of staff who is particularly responsible for the person?
- How does the facility welcome new residents and help them settle in?
- Do you think that you will be able to talk to staff about your own feelings and anxieties?
- Does the facility offer day care or temporary stays so that the person can get used to the situation before moving in?
- Is there a waiting list?
- Is there a review of the placement after the first few weeks so that everyone can discuss how the person with dementia has settled in, what has been achieved and what problems have arisen?

Bedrooms and privacy

- Can the person have a single room?
- Can residents bring some of their own furniture and possessions?

- Are the bedrooms bright and pleasant, with room for an armchair and storage space?
- Can residents go to their room when they want to be alone and do staff and other residents respect the need for privacy and always knock on bedroom doors?
- Is there noise or disturbance from other nearby rooms?
- If in future your fees were paid by subsidy, would you have to change bedrooms?
- Can the manager move a person to another room? A change in health status may mean it would be better for them to be closer to the nurses station or dining room.

Personal Possessions

- Does the laundry system make sure that clothes don't get lost or returned to the wrong person? How does the home make sure no-one ends up wearing someone else's clothes?

Bathrooms

- Does the bedroom have an ensuite? If not, how close are the shower and bath facilities to the bedrooms?
- Can residents have assisted showers every day?
- Are there enough toilets in easy reach of the bedroom and living area?

Meals

- Ask the residents about the food. Do residents enjoy their meals? Ask to see a menu.
- Does the home take into account residents' likes and dislikes and cater for special diets?
- What times are the meals? Is there any choice at meal times?
- Can residents choose to eat at different times or in their rooms?
- Is food available at all times of the day and night?
- Are there any cooking facilities for the residents, such as snack-making facilities?
- Are residents supervised and/or fed if they have problems feeding themselves?

Activities

- Do they employ someone to organise activities? If so, how many hours per week and what times, days?

- What qualifications do they have?
- What training have they had in dementia care?
- Are outings and outdoor activities arranged and how often can each resident go? Is there an additional cost for outings or activities?
- Are there games and activities designed for people with dementia?
- Do people come in from the community to visit, to help with activities or entertain?
- Are residents encouraged to get involved with day-to-day life in the home, for example, with household chores or meal preparation?
- Are residents encouraged to do as much for themselves as they can?
- Is there a notice board for events? Try to see the programme of events for the last month too, to see how much variety there is.

Cultural and spiritual

- If a person with dementia has a different background or culture to most of the other residents, do staff seem interested in and respectful of differences such as diet, religious observance, hygiene practices, clothing and ways of relating to other people?
- How are the spiritual needs of individuals catered for?

Health

- What happens if the person is unwell?
- Which doctor visits, how often, and is there a choice?
- What arrangements are made about medication?
- What arrangements are made about regular dental care, eye and hearing tests?
- Do staff try to ensure residents use their spectacles and hearing aids?
- Do staff have knowledge and skills in specific health needs i.e. giving insulin?

Visitors

- Are visitors / children welcome at any time?
- Are there limits on the number of visitors at any time?
- Can visitors join a resident for a meal or make snacks?
- Are visitors able to take the resident out if they want to?

Fees

- Does the facility have a contract with the District Health Board (and therefore accepts subsidised residents)?
- What is included in the weekly charge and what will be required to be paid for separately?
- If you are not receiving the Residential Care Subsidy, are medical costs covered by the fee?
 - GP / Specialists
 - Prescriptions
 - Continence products

Other Services

- Are the following available to residents and what, if any, are the additional costs for these?
 - Laundry, including personal laundry
 - Dry cleaning
 - Dental care
 - Hairdresser
 - Optometrist
 - Podiatrist
- Is transport available for appointments and activities? Can it carry wheelchairs? Are there any additional costs for this?
- Is there a private free phone for resident use? Is there a telephone connection in the bedroom and is there a charge for this?

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.

The standards set out levels of care for minimum safety as well as quality improvement in the areas of: consumer rights, organisational management, pre-entry and entry to services, service delivery, safe and appropriate environments, infection control, and standards for mental health services. These standards are compulsory and auditable.

A useful guide to understanding the special needs of people with dementia

is the *Health and Disability Sector Standards – Proposed Audit Workbook and Guidance for Residential Services for People with Dementia*. This voluntary standard provides guidance for providers of care for people with dementia.

Many residential care providers also belong to an Association made up of other providers and other associated persons (e.g. HealthCare Providers New Zealand). These associations provide support, information and education etc. for their members. There are usually joining criteria such as adherence to a Code of Practice.

People under 65

Because there are fewer people under 65 with dementia, it can be very hard to find a suitable residential care facility. 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 activities may be unsuitable.

Arranging care for people with dementia under 65 often involves compromising in some ways. Perhaps the rest home or hospital isn't quite right, but is near enough for friends and family to visit often. Or perhaps there is a suitable place but it is 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 is an activities co-ordinator at a rest home, he or she may be able to arrange activities suited to the individual; try to find out from the facility how they plan an individual's care.

Transferring to a different facility

People in residential care can move to another facility for any reason. If a person has been in a rest home or hospital for a while or if their health has changed, it is best to have a reassessment to check the level of care required. The local needs assessment service must be involved if the resident is accessing the Residential Care Subsidy and this service can also assist with arranging transfers.

The national contract between care providers and District Health Boards requires that care providers support the transfer of any resident receiving a subsidy and work with the needs assessment service to ensure a smooth transition. Transfer to another District Health Board area requires approval of the receiving needs assessment team for that area prior to the move.

Financial and Legal Issues

Financial assistance for residential care

A person with dementia may be eligible for financial help from the government (Residential Care Subsidy or Residential Care Loan) to cover some of the costs of care if:

- the person is assessed by the needs assessment service as needing ongoing, long-term residential care in a rest home or hospital and,
- a financial means assessment is completed by Work and Income and the financial criteria for a subsidy is met and,
- the residential care facility has a contract with the DHB to provide subsidised care and,
- the person is 65 or over (or 50-64 and single with no dependents).

The rules regarding who is eligible for the Subsidy and which assets you can keep while still being able to access the Subsidy can change over time. It is therefore important that you get the most up-to-date information, through Work and Income or the Ministry of Health's website.

If you want to know more about the financial help the government provides for residential care then you should get a copy of the Ministry of Health's booklet 'Looking at Long Term Residential Care in a Rest Home or Continuing Care Hospital - What you need to know'. It includes information on:

- who can get financial help for residential care,
- the financial means assessment process,
- income and asset testing thresholds,
- how to apply for the Residential Care Subsidy,
- the Residential Care Loan,
- how much you must contribute towards your care costs if you are eligible and if you are not eligible for the Subsidy,
- the services you can expect from a rest home or hospital.

You can obtain a copy of this booklet from the Ministry's website or from your local Alzheimers organisation.

Those aged under 65 who are married, or single with dependents when they

enter residential care do not need to access the Residential Care Subsidy. The Ministry of Health will pay for their care directly to the residential care facility until they turn 65.

Admission agreement/contract

It is important to read the residential care facility's Admission Agreement carefully as it sets out what extras you may need to provide or pay for.

Rest homes and hospitals must consider your accommodation needs and the levels of care set out in the District Health Board contract. This contract requires your rest home or hospital to tailor services to meet your individual needs as much as possible. It requires that your rest home or hospital provides:

- services that are 'resident centred' and that 'promote the independence and quality of life of residents',
- services needed for your care, including:
 - food services
 - laundry
 - nursing care
 - general practitioner visits
 - prescribed medication
 - continence products
 - all health care that is prescribed by a general practitioner

The rest home or hospital may ask for an additional charge for services that are not included in their contract with the District Health Board. This is why it is very important to check the Admission Agreement so you know what is or isn't included in the weekly charge (or covered by the Residential Care Subsidy).

Legal arrangements

from *The New Zealand Dementia Guide* by Dr Chris Perkins

It is also important to be aware of the legal issues relating to the move, and you may want to seek legal advice. Often a person with dementia going into a residential care facility is no longer fully mentally capable of making decisions, providing financial information or signing contracts.

The Protection of Personal and Property Rights Act (PPPR) provides for the protection and promotion of the personal and property rights of persons who are not fully able to manage their own affairs. It encourages people who lack capacity to have as much say as possible in what happens to them, but also protects them from harm. There are four parts to the Act:

Personal Orders – A judge can order a person to undergo treatment, live in a particular place or be admitted to hospital.

Welfare Guardian – The court appoints a person as the welfare guardian to make decisions about the care of the person where they are incapable. Usually a family member is appointed as welfare guardian. If there is no one available, organisations such as Age Concern may have a volunteer willing to take on this role.

Property Manager – If someone who lacks capacity has property worth more than \$10,000, a property manager can be appointed by the court to look after the person's financial affairs. They can pay bills, buy or sell property/shares and run a business. They may also make changes to the person's will if they think it no longer reflects the person's intentions. The property manager is often a family member, but trusts such as the Public Trust or Guardian Trust, can provide this service for a fee. Property managers have to report annually to the court to show they are managing the person's property appropriately.

Enduring Power of Attorney (EPA) – While a person still has capacity they can appoint an 'attorney' to manage their affairs. When writing an EPA, people can be as broad or specific as they like. People often appoint one person to manage welfare and another to manage property.

The attorney takes over the management of the person's affairs when the person is unable to do so (i.e. when they become incapacitated). However, if someone who still has capacity would like their property managed by the attorney, then they can hand over that power whenever they want.

It is important to organize an EPA as early on as possible.

The New Zealand Dementia Guide by Dr Chris Perkins has further information on how to arrange an Enduring Power of Attorney, other orders and appointments through the court, what to do in urgent situations, testing for capacity, advance directives and living wills.

Your local Age Concern Council can also provide an information booklet and advice on setting up an Enduring Power of Attorney.

Making the Transition

The move into long-term residential care is a big step and it is likely to be difficult and emotional for all concerned. Some people with dementia and their carers feel a tremendous sense of loss and separation after such a move and feel that they are deprived of their roles and responsibilities to one another.

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.

The transition for a person with dementia

For almost everyone, moving into residential care is a stressful time. Of course people are different, and their circumstances are different too.

Even if a person with dementia can't express feelings and wishes verbally, they may still be upset at leaving home.

Other feelings a person with dementia may have include: confusion, sadness, fear at the sense of loss of independence and increased reliance on others, 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 escape, aggression, withdrawal, tearfulness or clinging.

It may take time for a person to adjust to living in residential care. Some settle in quite quickly but others feel down for the first few weeks. And it is not always difficult. Some people are not so aware of their environment and settle in very well.

Carers need to be patient and try to understand and accept these feelings. Things which may help a person leaving home are having the opportunity to say goodbye to their home, and reassurance from their carer that they will be visiting.

Trained caregivers know what a person is experiencing and will take the time to be reassuring and supportive. Staff at the residential care facility, who may be familiar with the person if they have had respite breaks there,

and other professionals who know the person may have ideas on how to help a person get used to the change.

The transition for carers

Many carers feel that there is a huge gap in their own life after a person that they have cared for has moved into long-term residential care. A carer, and their family, may also feel a wide range of emotions at this time, including:

Worry – Carers may wonder if they have done the right thing and if the person with dementia will be well looked after. Remembering that the decision was made based on balancing what is best for everyone involved is important.

Guilt – Many carers feel guilt, perhaps because they feel they ought to still be caring, 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 but the physical parting may add another dimension to the grieving process.

Carers may find it helpful to talk to friends or relatives, other carers in a support group, or staff at their local Alheimers organisation about their feelings at this time.

There can be positive effects for carers, too. These include:

- carers' lives need no longer be centred around the practical tasks of caring or organising help. They may feel less stress,
- carers may feel that they have freedom to do things for themselves, when they want,
- carers may be more able to sleep,
- carers may find the lessening of their responsibilities a relief – especially if they or the person with dementia is ill, even with a minor ailment.

When most of the practical caring tasks are being looked after by the staff, a carer may find that their time with the person can be more relaxed and enjoyable, especially as time goes on.

How carers can help a person with dementia settle in to residential care

There are some ways carers can help make it easier for a person with dementia to settle in.

- Try to involve the person in the move if you can and it isn't too distressing for him or her,
- Help them to choose familiar things to take along. These might be small items such as photographs or ornaments, or larger things such as favourite pieces of furniture,
- Be with the person on the day of admission and be prepared to stay for several hours.

Be prepared, however, for a person to feel very unsettled. Often someone with dementia asks to go home. Sometimes they will make this wish clear to family and staff alike, and sometimes it may only be the family who hear it, because the person doesn't want to confide in strangers or seem impolite to them. It is a good idea to discuss with other family members how as a carer or family member you will respond if the person asks to go home. It can help you be consistent, and to feel a bit more prepared for what one carer called 'an emotional body blow'.

Practicalities

Among the practical issues that need to be arranged as part of the move are:

- packing,
- moving furniture if it is being taken,
- putting name labels on clothes and personal items,
- compiling information to help care staff,
- arranging extra security if the house is left empty,
- organising insurance. Most home insurance is invalid if a house is not occupied, so talk to the insurance company about special arrangements. You will also need to organise for insurance for personal items taken into the rest home or hospital.

Options for carers when a person, who needs to, does not want to go into care

from *The New Zealand Dementia Guide* by Dr Chris Perkins

Unfortunately, people may lose insight into their disabilities and believe that they can still care for themselves without help when the time has come that this is clearly not the case. There are a number of options for carers in these situations, beginning with the persuasive and ending with the legally coercive. People using these approaches need to be convinced that:

- a person's quality of life will be better in residential care,
- all relevant objections from a person have been addressed or,
- a person is so impaired in decision-making capacity that someone else should make the decision in their best interest.

This is a very difficult situation and one in which there seems to be only bad outcomes and the family has to pick the least negative. Approaches include:

- The whole family together state that the person needs more care than can be provided at home, which may persuade the person to try residential care,
- Getting someone that the person with dementia respects to make the case, such as their GP, a hospital specialist, a priest or minister, a son or daughter or an older sibling,
- Going in for a trial period, or respite in the hope that the person will like it in care, settle in, and be happy to stay,
- Going via hospital: Often older people who resist care for dementia or any form of mental illness will accept a hospital admission for a physical health problem. Once treatment is completed, the geriatric team can inform both the patient and the family of the need for residential care and can help arrange suitable placement. It is easier to move people who are already out of their familiar surroundings to a new place, than taking them directly from home,
- Waiting until the person can't act on his or her desires: Sometimes people with dementia keep on saying that they want to stay in their own home, but would be unable to do anything about leaving a rest home. If taken to a rest home, they might just accept the care without being very aware of what is happening. Waiting for someone to get this disabled could put them at risk; they probably should not have

been left in the community for so long. Many residential care facilities have qualms about taking in someone who is not able to agree to care, unless there is someone legally appointed to make decisions for them,

- **Legal Procedures:** If someone puts themselves or others at risk because of their dementia, doctors can invoke the Mental Health Act to take that person into hospital and then, after assessment, they can be moved to a suitable rest home. The Mental Health Act is usually only used in emergency situations. Under the Protection of Personal and Property Rights Act (PPPR Act) a judge can order someone to live at a certain place or can appoint a welfare guardian to make decisions about (among other things) where that person should live. If a judge tells a person with dementia that they must go and live somewhere, often the person accepts this. Having a court's backing makes it legitimate for relatives to take a person to residential care, even if he or she objects.

Refer to *The New Zealand Dementia Guide* by Dr Chris Perkins for further information on these approaches.

Ongoing transitions

It is possible that a person with dementia may need to make a further transition if their needs change. This transition may be within the same facility (i.e. from dementia unit to psychogeriatric hospital) or require a transfer to a different facility. Either way you will need to adjust once again to new staff, different surroundings and be prepared for some of the same feelings associated with the initial move.

Ongoing Caring

Care plan

Care plans are written for each person when they are first admitted into a rest home. This plan will cater specifically for the needs of the individual person, describing the help they require for day-to-day functioning, medical, emotional, social and recreational needs.

Information for the care plan is gathered from the new resident, their carers and family, staff, and any other people involved in the person's needs assessment.

The plan should be reviewed from time to time, as the needs of the person are constantly changing as his or her condition changes.

You can help the rest home by providing them with as much information as you can so that the staff are able to understand an individual's care needs and preferences. Useful information you can provide includes:

- daily routine,
- food preferences,
- dressing habits,
- photographs and notes of who's who in the family,
- information on needs, likes and dislikes.

With this information the rest home is much better equipped to treat the person with dementia as an individual.

The care plan also gives the carer a chance to say how much they want to be involved in the person's care and how they would like to be kept informed. It can be helpful for the carer to think about and record what things they want to be informed about (e.g. falls, illnesses, other incidents) and how they want to be informed (e.g. who to call and at what time of day).

Your local Alzheimers organisation can provide you with a Personal Care book, which can be filled in and given to the staff at the residential facility to assist in this process.

Caring partnerships

The carer can still care for a person with dementia in practical ways after they move into residential care. If a carer wants to remain in their role as a caregiver in partnership with staff at the residential care facility once a person has moved then it is important that this happens.

Carers do not need to do anything beyond what they would like to do. Carers may wish to visit the person with dementia, take them on outings, or help in the rest home with some of the person's day-to-day care or at mealtimes.

Taking part in planned activities with staff can help a carer get to know staff better and, with time, they might feel more at ease with sharing the caring. The better the relationship with the staff, the easier it will be for everyone.

Sharing the caring can allow time for carers to develop their own interests beyond caring. Initially this may be simply regaining energy levels. Perhaps this is the first opportunity for carers to grieve about the changes in their life. Over time, seeking out leisure activities and social contact with family and friends can become important.

Visiting

Visiting has a number of purposes; it nourishes relationships and fulfils the needs of both a person with dementia and their visitor.

How often a carer visits depends on what carers need and the needs of a person with dementia. Visits are important. However a carer's wellbeing can also influence how often they visit. There is no expected number of times that a carer should visit, or amount of time they should stay. The important thing is to make each visit as rewarding as possible.

Often people with dementia have 'good times' during the day and this is when it can be good to plan visits. Mornings are usually better than afternoons. Families can liaise with staff to find out the best time for their visits. Staff may be able to suggest or arrange meaningful activities for when a person has visitors. Suggestions include:

- going for a walk together, reading or playing music together,
- visit at mealtimes when help can be given with the meal (or with eating), take favourite food or sweets for the person to enjoy,

- compile a memory book of past events – newspaper cuttings, photographs (particularly special occasions) and reminisce together,
- take letters from family and friends to read aloud,
- take a good friend to help share conversation,
- children and small babies are often enjoyed as visitors,
- if permitted by the rest home, bring a pet when you visit,
- have a visitors' notebook so that staff are able to remind the resident who has visited.

Communication is a basic human need, and a visitor needs to take the initiative for successful communication, both verbal and non-verbal. When speaking, keep sentences short and simple and wait for a response. Introduce yourself with your name, e.g. "Hello Dad, I'm Jan your daughter." Try to maintain eye contact. Use non-verbal communication such as touch and gesture, as a person with dementia is often more sensitive to body language.

Sometimes visits can be very difficult to cope with emotionally, for example if a person with dementia is weeping or angry. If this happens:

- talk to the staff and find out how the person is at other times,
- try varying visit times - for example, perhaps a person will feel better in the mornings when they are not as tired,
- visit just before a meal so that a person has something to go on to.

At first, carers may find visiting difficult. Often, if they are able to keep on visiting, after a while it does become easier. Some carers even find that their relationship with a person that they have cared for improves after they move into a rest home or hospital. Carers sometimes find they are able to bring back outward signs of loving and affection which may have been covered up by the stress of day-to-day caring.

Visiting can sometimes be more difficult as the abilities of a person with dementia decline. What to try:

- Touch. A gentle kiss or hand holding can be reassuring,
- Sensory stimulation. Massaging legs, hands and feet with scented creams or oils can be enjoyable,
- Facial Expressions. A smile, a comforting gaze or a look of affection can often provide reassurance to the person with dementia,

- Music. For many people, music can provide comfort and familiarity.

Try keeping visits short. Ten minutes may be enough for both the visitor and a person with dementia.

Outings

Visitors are advised to discuss their plans for taking a person on outings away from the care facility with the facility's manager or nurse. In most cases a person with dementia will likely enjoy outings. As people with dementia do not always find new situations or places easy, keeping outings simple is often good. Staff might have suggestions on where to go and how to minimise the risk of an unpleasant experience.

If a visitor is intending to take a person back to their former home they need to be aware that this might stir up many memories and that the person may not be willing to return to the care facility, because they have simply forgotten that they are not living there any more. If the person has experienced difficulties settling into the care facility it may be easier not to take them home for breaks.

Managing Concerns

Rights and responsibilities

All facilities must meet Health and Disability Sector Standards and there are also voluntary Standards for Residential Care for People with Dementia. You will be given a Code of Patient Rights when you sign the Admission Agreement and this will also be displayed for residents and families to refer to at any time.

Communication with staff

Communication is important. If there are aspects of a person's care which relatives are not happy with they may want to let staff know about this. If something is likely to affect the well-being and happiness of a person in care it is important that the nursing staff know about it. There may be a simple explanation for what has happened.

When carers feel that things must change, they need to monitor the results. If nothing changes, they need to be prepared to re-address the issue with the person in charge. Every residential care facility should have a complaints procedure and people entering residential care and their carers should be informed about these procedures at the time of admission.

Situations that are not acceptable in residential care

from *The New Zealand Dementia Guide* by Dr Chris Perkins

Some things that are not acceptable and need action are:

- if a person's condition deteriorates markedly between visits and the carer has not been advised of this,
- if good personal hygiene standards are not maintained,
- if a person is not treated appropriately by staff. This includes forcing a person to do something, not assisting with feeding if they are unable to eat by themselves and not providing enough stimulation or activities,
- if a person is threatened or pestered by other residents,
- if a person's clothes and belongings disappear or are given to other residents for no apparent reason,

- if a person is not cared for appropriately in their or their carer's opinion,
- if a person is restrained without legal order or the permission of their welfare guardian.

Elder abuse and elder neglect

from *The New Zealand Dementia Guide* by Dr Chris Perkins

Elder abuse is when an older person experiences harmful physical, psychological, sexual, material/financial, or social effects caused by the behaviour of another person with whom they have a relationship implying trust.

Elder neglect is when an older person experiences harmful physical, psychological, sexual, material/financial, or social effects caused by the behaviour of another person failing to perform behaviours which are a reasonable obligation of their relationship to the older person and are warranted by the older person's unmet needs.

Sometimes elder abuse and elder neglect can be an issue in residential care facilities.

Recognising when elder abuse may be happening

from *The New Zealand Dementia Guide* by Dr Chris Perkins

There are a number of concerning signs that need to be followed up to find out if abuse or neglect is happening. These include if a person in residential care:

- seems afraid of someone,
- stays awake at night,
- becomes depressed or withdrawn,
- has recurrent injuries, especially ones that look like they could be caused by abuse,
- is over-sedated,
- recoils from being touched,
- is poorly nourished or clothed, has poor hygiene or is cold,
- is left alone for long periods without stimulation or visitors,
- doesn't use glasses, hearing aids, dentures or take medication as directed.

Concerns and complaints

If there are aspects of the care you are not happy with, or other difficulties, try to resolve these by talking to the staff member concerned or the person in charge of the rest home or hospital first. It may just be a case of adjusting the person's care plan or something equally simple. Don't feel afraid to express your views. After all, the rest home or hospital is being paid to look after the person, who is entitled to receive the best care possible.

All facilities have complaints procedures which you should be informed about on admission.

If you do not get the help you want after talking to the staff, you may contact your local Alzheimers organisations, local health advocate, Age Concern, or the Health and Disabilities Commissioner's Office.

Normally, you should use the rest home's complaints procedure first, and if you are not satisfied with the outcome, complain to the Health and Disability Commissioners Office.

Rest homes and hospitals generally have contracts with District Health Boards. These contracts outline the resources they are required to provide for residents who are receiving the Residential Care Subsidy. If you feel the facility is not meeting these contractual obligations, you can complain directly to the local District Health Board.

Some people are anxious that if they complain, the person with dementia may suffer. If this worries you, call someone you trust, to talk things over before you decide what to do. An advocate can be useful in this situation, if you would like help and guidance in deciding the best channel for your complaint, and in providing support and assistance as you go through the complaints process.

Finally, it is important to remember that no residential care facility is going to be perfect. But if you satisfy any worries before a person enters the rest home or hospital then people with dementia and carers are more likely to be able to relax and concentrate on enjoying their relationship.

Key Contacts and Further Information

Alzheimers New Zealand
www.alzheimers.org.nz

National Office

Level 3, Adelphi Finance House,
15 Courtenay Place,
Wellington
Postal Address: PO Box 3643, Wellington
Phone: (04) 381 2362
Fax: (04) 381 2365
Email: nationaloffice@alzheimers.org.nz

Your local Alzheimers organisation can be contacted toll-free by calling 0800 004 001 or see the contact details below.

Alzheimers Ashburton & Districts

Location: Nurses Hostel, Ashburton Hospital, Elizabeth Street, Ashburton
Postal address: PO Box 305, Ashburton
Phone: (03) 308 0176
Fax: (03) 308 0176
Email: ashburton@alzheimers.org.nz

Alzheimers Auckland

Location: 877 Manukau Road, Royal Oak, Auckland
Postal address: PO Box 24-237, Royal Oak, Auckland
Phone: (09) 622 4230
Fax: (09) 636 0540
Email: alzheimers@alzheimers.co.nz

Alzheimers Canterbury

Location: 314 Worcester Street, Christchurch
Postal address: PO Box 32-074, Christchurch
Phone: (03) 379 2590
Fax: (03) 379 7286
Email: admin@alzcanty.co.nz

Alzheimers Counties Manukau

Location: Alzheimers Centre, William-Roberts Road, Pakuranga, Manukau City
Postal address: PO Box 51-291, Manukau, Auckland
Phone: (09) 576 7776
Fax: (09) 576 5891
Email: info@alzcm.org.nz

Alzheimers Gisborne

Location: Morris Adair Building, Gisborne Hospital, Ormond Road, Gisborne
Postal address: PO Box 1020, Gisborne
Phone: (06) 867 0752
Fax: (06) 867 0713
Email: gisborne@alzheimers.org.nz

Alzheimers Hastings

Location: 917 Railway Road, Hastings
Postal address: P O Box 11-103, Hastings
Phone: (06) 878 7502
Fax: (06) 878 7025
Email: hastings@alzheimers.org.nz

Alzheimers Manawatu

Location: Marion Kennedy Centre,
642 Featherston Street, Palmerston North
Postal address: PO Box 527,
Palmerston North
Phone: (06) 357 9539 and (06) 357 9543
Fax: (06) 357 9545
Email: manawatu@alzheimers.org.nz

Alzheimers Marlborough

Location: 12A Muller Road, Blenheim
Postal address: PO Box 4024, Blenheim,
Phone: (03) 577 6172
Fax: (03) 577 6172
Email: marlborough@alzheimers.org.nz

Alzheimers Napier

Location: 46 Nelson Crescent, Napier
Postal address: PO Box 4084, Marewa,
Napier
Phone: (06) 834 0417
Fax: (06) 834 0418
Email: napier@alzheimers.org.nz

Alzheimers Nelson

Location: Community Groups Centre, 50
Halifax Street, Nelson
Postal address: 50 Halifax Street, Nelson
Phone: (03) 546 7702
Fax: (03) 546 7703
Email: nelson@alzheimers.org.nz

Alzheimers Northland

Location: 321 Western Hills Drive,
Whangarei; Kaitaia Community House,
12 Puckey Ave, Kaitaia; 6 Homestead
Road, Kerikeri
Postal address: PO Box 1179, Whangarei
Phone: (09) 438 7771 (Whangarei);

(09) 408 1123 (Kaitaia);
(09) 407 3010 (Kerikeri)
Fax: (09) 438 7771
Email: northland@alzheimers.org.nz

Alzheimers Otago

Location: 283-301 Moray Place, Dunedin
Postal address: PO Box 5304, Dunedin
Phone: (03) 471 6154
Fax: (03) 471 6155
Email: adards.otago@xtra.co.nz

Alzheimers Rotorua

Location: Community House, 1st floor,
1115 Haupapa Street, Rotorua
Postal address: PO Box 430, Rotorua
Phone: (07) 349 0053
Fax: (07) 349 0064
Email: alzheimersro@xtra.co.nz

Alzheimers South Canterbury

Location: 114 Stafford Street, Timaru
Postal address: PO Box 821, Timaru
Phone: (03) 684 8824
Fax: (03) 684 8824
Email: southcanterbury@alzheimers.org.nz

Alzheimers Southland

Location: Community House, 46 Kelvin
Street, Invercargill
Postal address: 46 Kelvin Street,
Invercargill
Phone: (03) 214 0984
Fax: (03) 214 0928
Email: alzheimerssouthland@xtra.co.nz

Alzheimers Taranaki

Location: Shop 13, Metro Plaza,
33 Devon Street West, New Plymouth
Postal address: PO Box 7058,
New Plymouth
Phone: (06) 769 6916
Fax: (06) 769 6916
Email: adardstaranaki@globe.net.nz

Alzheimers Taupo

Postal address: PO Box 595, Taupo
Phone: (07) 378 0060 (evenings)
Fax: (07) 378 0460

Alzheimers Tauranga

Location: Wesley Centre, 13th Avenue,
Tauranga
Postal address: PO Box 8067, Tauranga
Phone: (07) 577 6344
Fax: (07) 577 6346
Email: alzheimers.tga.org@xtra.co.nz

Alzheimers Waikato

Location: 1 Mill Lane, Hamilton
Postal address: PO Box 5720, Hamilton
Phone: (07) 839 2427
Fax: (07) 839 2429
Email: waikato@alzheimers.org.nz

Alzheimers Wairarapa

Location: WOOPs, 45 Victoria Street,
Masterton
Postal address: P O Box 865, Masterton
Phone: (06) 377 0066
Fax: (06) 377 3559

Alzheimers Wanganui

Location: Suite 5, 136 Victoria Avenue,
Wanganui
Postal address: PO Box 7018, Wanganui
Phone: (06) 345 8833
Fax: (06) 345 8833
Email: alzheimers.wang@xtra.co.nz

Alzheimers Wellington

Location: 55 Hutt Road, Petone
Postal address: P O Box 39393,
Wellington Mail Centre, Wellington
Phone: (04) 939 0133
Fax: (04) 939 0133
Email: wellington@alzheimers.org.nz

Alzheimers Whakatane

Location: St John's Complex, 25 Arawa
Road, Whakatane
Postal address: PO Box 13, Whakatane
Phone: (07) 308 0525
Fax: (07) 308 0526
Email: whakatane@alzheimers.org.nz

Choosing a Home

Residential Care Line	(09) 375 4395 or 0800 725463	www.adhb.govt.nz/rcline
Seniorlink website		www.seniorlink.co.nz
Eldernet website		www.eldernet.co.nz
A Question of Care – published by Care Publications	(03) 326 6291	
The New Zealand Retirement Guide – published by Full Moon Guides	0800 738473	www.fullmoon.co.nz
HealthCare Providers New Zealand	(04) 499 4156	www.healthcareproviders.org.nz

Financial and Legal Issues

Work and Income – Residential Care Subsidy	0800 999727	www.workandincome.govt.nz
Long Term Residential Care in a Rest Home or Continuing Care Hospital – What you need to know booklet		www.moh.govt.nz/olderpeople
Information on asset testing		www.moh.govt.nz/assettesting
Age Concern New Zealand	(04) 801 9338	www.ageconcern.org.nz

Managing Concerns

Health and Disability Commissioners Office	0800 112233	www.hdc.org.nz
Advocacy services:		
Health Advocates Trust – for Upper North Island	(09) 525 2700 or 0800 555050	
Advocacy Network Services Trust – for Hamilton to Wellington	(06) 348 0074 or 0800 423638	
Advocacy Services South Island – for all South Island	(03) 377 7501 or 0800 377766	



Your Notes



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Alzheimers New Zealand

Alzheimers New Zealand
PO Box 3643, Wellington
Ph (04) 381 2362
Fax (04) 381 2365
Email nationaloffice@alzheimers.org.nz
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Making life better for all people affected by dementia
Kia piki te ora mo ngā tāngata mate pōrewarewa



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