Dementia - residential care

Summary

- Making the decision to find alternative care for a person with dementia can be one of the most difficult decisions a carer will make.
- There are different types of residential care available and it may help to have some practical advice before making the move.
- Careful planning and support from family, friends or carer support services can help make the move less stressful.
- A carer’s role will change once a person with dementia is in residential care – there may be new issues to cope with.
- Visiting is important for the person with dementia and their carers, but it can sometimes be difficult.

Making the decision to find an alternative to caring for a person at home can be one of the most difficult decisions a carer will make, particularly if the person with dementia has been a long-time companion.

Being prepared can help to make this decision less stressful. Knowing about the services, government policies and costs of residential care beforehand can help carers to make the best choice, even if the decision has to be made quickly.

Finding information about residential care

Some people and organisations you could talk to include:

- your doctor
- Dementia Australia
- other families and carers
- My aged care – gives support and assistance with queries about access to home and community care, respite fees, and bonds and charges
- Commonwealth Respite and Carelink Centres – provide information about the range of community-care programs and services available to help people stay in their own homes
- Carers Victoria.

Types of residential facilities

Facilities that provide long-term residential care are usually grouped into two categories, being those providing high-level care and those providing low-level care. Specific dementia units are also available for some people.

Low-level care residential facilities

Low-level care residential facilities are funded by the Australian Government and are suitable for people who are mobile, but need some assistance. They may need support with personal care, laundry, cooking, shopping or the supervision of their medication. Accommodation is usually in bed-sitting rooms with private or shared bathroom facilities.

High-level care residential facilities

High-level care residential facilities provide 24-hour nursing care for residents, and are staffed by nurses and personal care assistants. Generally, these facilities are most suitable for a person in the later stages of dementia, or those with other medical conditions. The Australian Government funds all high-level care residential facilities.

Ageing in place

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Many aged care facilities provide ‘ageing in place’. This means that the person can stay in the same room, even if their care needs, services and funding changes, for example, from low care to high care.

**Specific dementia units**

These are units designed specifically for people with dementia and can be classified either as high- or low-level care. Not all people with dementia require a specific dementia unit. People with special care needs, such as those who may not be safely accommodated in general residential facilities, are best suited to these units.

**Assessment for residential care**

The Aged Care Assessment Team (ACAT) will determine the level of care needed by the person with dementia. The team will recommend appropriate types of residential care and provide details of facilities that may be suitable. Any concerns or issues that the family or the person with dementia may have, can be discussed with the team.

As applications will usually have to be made to several facilities, it may be necessary to visit a number of places. Try to work through the list of facilities in an organised way, taking notes as you go. If possible, take a friend or family member on the visits. Trust your intuition and common sense when assessing accommodation for a person with dementia.

**Residential care decision-making checklist**

All residents should have access to the quality of care and the services that they need. The Australian Government monitors care and accommodation standards in residential aged care services.

When you are looking at a residential facility, some things to consider include:

- Does it feel like a friendly, welcoming place?
- Are surroundings – such as buildings, grounds and individual rooms – suitable?
- Is there somewhere to sit privately?
- Is the security satisfactory? Is there freedom to move around?
- Can the family come and help the person eat and shower?
- Are day-to-day care issues – such as food, access to the bathroom and temperature control – satisfactory?
- Are there procedures in place in case of a fire?
- Is there at least one person on duty at all times?
- Has the fee structure been fully explained? Are there extra costs?
- What are the resident's rights regarding such issues as their own belongings, pets, mail and religious beliefs?
- What is the attitude of managers and workers – do they listen to carers and ask for information?
- What training have the staff members had? Do staff members have dementia-specific training?
- What is the staff-to-resident ratio?
- Is the range of activities and choices for recreation satisfactory?
- Are visiting times and access for family members satisfactory?
- Can outings, overnight stays and holidays with family members be easily arranged?
- Do other residents appear well cared for?
- Can residents have their own doctor?
- What is the medication policy?
- What are the arrangements for giving medication?
- Are the medical services and specialist services satisfactory?
- Does anyone speak the language of the person with dementia?
- Are other services, such as hairdressing and massage, provided?
- Is there any assistance in making the move from the home to the facility?
- Can increased needs be catered for?
- Are carers asked for suggestions and comments?
- Is there a complaints policy?
- Can carers join a residents and relatives committee?

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Planning for the move into residential care

Once a place becomes available in a residential facility, you may need to make a decision very quickly, so it is helpful for you to plan the move in advance.

People with dementia can be disturbed by change. Explain simply and gently where and why they are moving. Emphasise the positive aspects, such as new friends and enjoyable activities.

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

Some tips that may help with the change include:

- Ensure that the person’s room has as many familiar items as possible. Family photos, familiar prints or paintings on the wall, and familiar bed coverings can make the new room look a little more like their own bedroom at home.
- Label all personal items with large and easy-to-read identification. Check if the facility provides a labelling service, as this may save you some time.
- Be aware that, during this initial moving stage, it will take time for both the person with dementia and the carer to adjust to the new situation. Expect a period of adjustment. People do settle. Many people with dementia actually do better in a structured environment, because they may feel more secure and get more stimulation.
- There is no right number of times that the carer should visit, or a right amount of time they should stay. Many carers will wish to visit frequently during this time. Others will want to rest and recover from the strain of caregiving. The important thing is to make each visit as rewarding as possible.

Visiting someone in residential care

When a person with dementia moves into residential care, the role of families and carers does not usually come to an end. Many people may choose to stay involved with practical caring tasks such as assisting at mealtimes. Others become involved in the social activities of the facility. The level of involvement will vary with each person.

Visiting is important for both resident and carer

Visiting is usually very important to both the resident and their family and carers. It is often the main way that families and carers stay connected with people they have cared for, even though they may no longer provide the day-to-day caregiving.

The person with dementia may enjoy seeing other members of the family or old friends. Encourage grandchildren to visit. If the children are young, prepare a visiting bag that contains treats and activities to keep them entertained. If allowed by the facility, bring in a pet.

Making visits more enjoyable

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

Some suggestions include:

- Bring newspapers and magazines to look at together.
- Read mail together.
- Play games that have been enjoyed in the past.
- Listen to a tape of music or a story, or watch a well-loved video.
- Look at photo albums together.
- Help decorate and tidy the room.
- Help with personal grooming – washing or brushing hair, painting nails.
- Assist with writing to friends and relatives.
- Bring others to visit.

Outings can be enjoyable

Some suggestions for outings include:
• a short drive in the car, perhaps stopping for afternoon tea
• a visit to another person in the facility
• a stroll or wheel around the facility garden.

**Visiting in the later stages of dementia**

Find an activity that will stimulate as many of the senses as possible – sight, taste, smell, hearing and touch.

Suggestions for activities include:

- A gentle kiss or holding hands can be reassuring.
- Massaging legs, hands and feet with scented creams or oils may be enjoyable for some people. The scent of perfumes and flowers can also be enjoyed.
- A smile, a comforting gaze or a look of affection can often provide reassurance to a person with dementia.
- For many people, music can provide comfort and familiarity.
- Visits from friends and relatives, even though they may not be recognised or remembered, can provide stimulation and comfort.
- Listening to a reading from a favourite book or poems can provide enjoyment.
- A stroll around the grounds, even if in a wheelchair, may be enjoyable for both the resident and visitor.

There is no correct number of times to visit or a particular amount of time to stay. The important thing is to make each visit as rewarding as possible.

**Leaving after a visit**

Leaving after a visit can be a difficult time for both the person with dementia and their visitors. Things you can try to make parting less stressful include:

- Take an activity to do with the person. Once you have finished the activity, it is time to go.
- Ask the staff to divert the resident, or time your leaving for when a meal is about to be served, so that there will be something else for the person to do.
- Let 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’.
- Keep farewells brief and leave straight away. Lingering, apologising or staying a little longer can make future farewells harder.

**Wanting to go home**

A common phrase heard from people with dementia in residential care is ‘I want to go home’. This can be especially upsetting for families and carers.

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. The term ‘home’ may bring up memories of childhood or of a home or friends who no longer exist.

Some things you can do to help include:

- Try to understand and acknowledge the feelings behind the wish to go home.
- Reassure the person that they will be safe. Touching and holding can be reassuring.
- Reminisce 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 with the person or try to reason with them about wanting to go home.

**Aged Care Complaints Scheme**

If you have a concern about the care you or someone else is receiving, it is important that you talk about it. Complaints can help aged care providers improve the services and quality of care they provide to you or your loved one. One complaint from you can also help other people.

For complaints about residential facilities and Community Aged Care Packages, call the Aged Care Complaints

Support groups for families and carers of people with dementia

Alzheimer’s Australia coordinates a large number of support groups throughout Australia. Support groups bring together carers, relatives and friends of people with dementia under the guidance of a group facilitator, usually a healthcare professional or someone with first-hand experience of caring for a family member.

Families and carers may be looking after a person with dementia at home or in residential care. Many people find enormous comfort and practical assistance from attending support meetings with others who know what it is like to care for a person with dementia. Many residential facilities run relatives’ groups, because they acknowledge the difficulties expressed by many families once their loved one has moved.

Where to get help

- Your doctor
- National Dementia Helpline – Dementia Australia Tel. 1800 100 500
- Aged Care Assessment Services Tel. 1300 135 090
- My aged care Tel. 1800 200 422
- Carers Victoria Tel. 1800 242 636
- Commonwealth Respite and Carelink Centres Tel 1800 052 222
- Aged Care Complaints Investigation Scheme Tel. 1800 550 552

This page has been produced in consultation with and approved by:

Dementia Australia