

Caring Partnerships

This help sheet provides information for families and carers of people with dementia who have recently moved into residential care. It emphasises the value of a caring partnership with residential staff.

About your new role

Preparing for the period after settling into residential care is just as important as preparing for the move. The time of separation can be emotional with a variety of mixed feelings. These might include feelings of relief, guilt or grief. Certainly your daily activities will suddenly change.

Many people believe that full time residential care will remove them from the caring role. However you don't stop caring just because you no longer do the physical tasks of caring. Allowing others to take responsibility for the practical caring tasks does not lessen the importance of your role as a carer. In fact, you are the "expert" when it comes to caring for the person with dementia.

Your role with professional care workers is to inform, advise, recommend, make decisions and encourage the best possible quality of care for the new resident. You can also continue to contribute to the physical care if you wish.

There is no rule to say how much you should be involved. It is your choice. Remember that you must also respond to your own needs as well as feel comfortable about your level of involvement in the care of the person with dementia.

Support groups can continue to be helpful after the move to residential care. Many facilities also run relatives' groups because they acknowledge the difficulties experienced by many relatives once the move has occurred.

Dementia Australia also run local groups that provide support to carers of people with dementia in residential care, as well as providing counselling and a range of information.

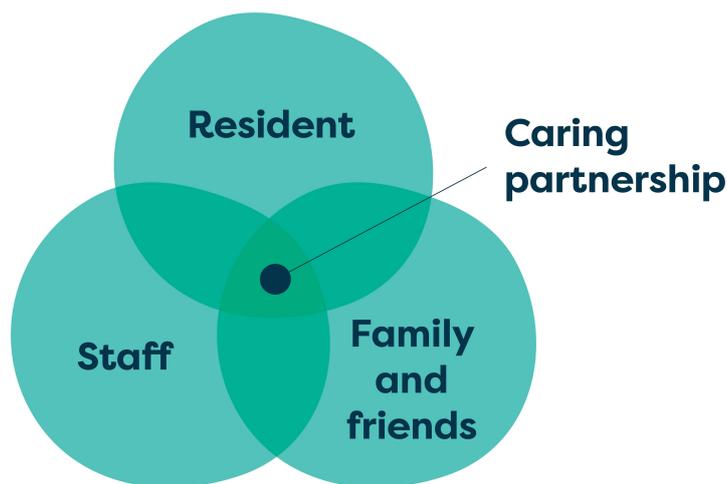
How you can continue to care

The care a person with dementia receives is best if it is seen as a partnership between you and the residential care home.

A caring partnership means that:

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

You can visualise this partnership as three circles joining together:



Your involvement should be welcomed and encouraged. You may feel completely exhausted in the early days after the move and want to take time out from the caring role. The door however should always be left open for you to get involved in whatever way you wish. This may be anything from sharing a meal together, assisting with showering to receiving regular information about the residential care home.

The home should involve you in caring by:

- 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 which sets out the resident's needs, goals, strategies and actions to ensure that their needs are being met
- Reviewing the care plan with you regularly
- Nominating a relative or advocate who is regularly informed about general care issues
- Consulting you regarding management of the resident's confusion, changes in mood or restlessness
- Inviting you to help out with activities, including outings or events at the home
- 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 home is discussed, and encouraging your feedback on things like meal times, menus, activities, communication and accreditation
- Clarifying the resident's wishes regarding future health care, as this can provide much-needed guidance when they are no longer capable of expressing an opinion
- Consult with you regarding any proposed changes in the medical care of the resident, such as changes in medicines or medical treatments

If the residential aged care home does not actively promote the involvement of families and friends you can speak to the manager about how you wish to be involved and ways that they can help you to do this.

Should you feel that the aged care home is not receptive to your involvement then you may need to get information and support from:

- The advocacy service for residents of aged care homes is the Aged Care Complaints Commissioner:
Online: agedcarecomplaints.gov.au
Phone: **1800 550 552**
In writing, address your written complaint to:
Aged Care Complaints Commissioner
GPO Box 9848
(Your capital city and state or territory)
- The **National Dementia Helpline** on **1800 100 500**

How to get the care you want

Communicate your 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.”

Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**