



Supporting
families and
friends of older
people living
in residential
aged care

The Australian Centre for
Evidence Based Aged Care
(ACEBAC)

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AIPCA

Australian Institute
for Primary Care & Ageing


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If you are considering moving, or have already moved, a family member or friend into a residential aged care facility the following information may be helpful. The Australian Centre for Evidence Based Aged Care (ACEBAC) has searched for the best and most current information that will give some insight into how to relate to the people involved in the care program offered by the facility.

The words 'family', 'family member' and 'relative' are used throughout this booklet to refer to anyone who has been involved, and wants to remain involved, with the person who is living, or will be living, in residential aged care. This includes friends even though they may not always be specifically referred to by name in this booklet. The word 'resident' is used to refer to the person living in the residential aged care facility.


Older people need to maintain contact with their family and friends. Family members and friends may want to continue to provide some of the care required by the older person when they move into residential care. Aged care facilities have an obligation to consult with family members. However, sometimes there can be misunderstandings on the part of both parties that can lead to frustration and impinge on the relationship between families and care staff. A collaborative approach from both families and staff benefits all concerned.

The information in this brochure is designed to examine the caring relationship from the point of view of all parties: the family or friends; the care staff; and the facility management. We hope this will clarify some issues and help you to seek further information from the facility, or other sources if required.

Involvement in Care



If you have been involved in caring for a spouse or family member for some time you will know this person very well. You may have been involved in providing intimate personal care. You may have been under pressure yourself to maintain a balance in your own life, as constant care is tiring and can be demanding on family members. The feeling of 'giving up' and relinquishing care to someone else may be both a relief and a frightening prospect. It is therefore very important you maintain your involvement in care in ways that are best for you and your relative. This will mean forming relationships with others that are involved in the care and sharing information about your relative to make the care meaningful for all



Summary



The following points are a summary of ACEBAC's review of the information about family and staff relationships in residential aged care:

- Collaborative team care between family members and care staff is the best model for delivering care.
- Family members need to understand how the facility works, whether teamwork models are really working and how they can contribute to care delivery.
- Communication avenues should be established from the time when the older person is planning the move into residential care.
- Care planning and monitoring is a team effort and changes to care are best achieved through team decisions.
- Family members need to be aware that their relative may prefer to make some decision about their own care without the family's involvement.
- Positive relationships are essential for quality of life of people living in residential care.
- When there are disagreements within families the staff can receive mixed messages which can have a negative effect on their relationship with the family.
- Mutual trust, respect, empathy and understanding and familiarity are important building blocks for positive relationships between staff and families.

The summary provided on the previous page is now explained in more detail.

My family member is an individual

- Of course they are! They can never be replaced. Relationships formed over years are the basis for human well being, although they may vary and some are stronger than others. We must respect the fact that others may not see our relationships the way we do, but nevertheless they are expected to come to an understanding about how we feel.
- Care staff are taught to respect the individuality of each resident and to encourage the expression of this in the life of the person. We all express our individuality in our own way and our needs may change over time. It can be hard for care staff to meet all these needs especially when they are caring for several people at the same time. Talking to the family to find out how needs can be met is very important for all staff members involved in care. To provide the best individualised care, it's important that care staff are aware of those things that make your relative unique such as their: interests; likes and dislikes; personality; life history; and the things they value and are important to them.
- You may find some staff are better than others at finding ways to preserve your relative's individuality. You may think that your relationships with these staff are stronger than with others. Appreciation of the care offered by these staff can be expressed in many ways but it is preferable not to seem to favour one staff member over another. Care is delivered over a 24-hour period and therefore many different staff members will relate to the residents in different personal ways.



Family members have needs as well

- Moving a relative into residential aged care has often been described by families as 'the hardest thing we ever did' – it is common to feel guilty.
- Sometimes family members feel the strain of visiting their relative and not being able to share in the care experience in the same way as they did at home. The reason for moving into a care facility may also be a factor in determining how families relate to caregivers. A diagnosis of dementia may be devastating for families and any terminal illness will bring grief and feelings of helplessness.
- It is important you make your feelings known to staff and ask about any aspects of care you are uncertain about. Staff need to know your thoughts about involvement in care and how much you would like to participate in the day to day life of your relative and the facility.
- Support for families is important and may be found through external agencies as well, such as Alzheimer's Australia, Carers Australia or other organisations concerned with long term illness.
- You may need more information about the facility's provision of health care and what your responsibilities are as a family member. For example, maintaining suitable clothing, shoes, outings and special treats are things you can provide. Your relative may have attended special health professionals such as the dentist, podiatrist or gone to a hairdresser over many years and you may wish to maintain this relationship and service while they are living in an aged care facility. You can discuss this with the facility manager.
- Further information about other medical issues or diagnoses can be obtained by arranging a meeting with the doctor, reading about the problems, finding out through chronic care associations, using the internet, and asking questions of senior care staff.

Maintaining communication

- You have known your relative for a long time; the staff for only a short time. Providing information about the care needs of your relative will help in developing positive relationships between you and the care staff. Often family members feel that staff are reluctant to take notice of information you may have provided. This may be due to the fact that staff feel that the resident's needs, as expressed by their family, cannot be realistically met. A discussion about the roles of the staff and the input from you as a carer, based on the resident's care plan is one way to establish good communication. If a particular staff member seems unapproachable you can discuss this with the facility manager. Resolution of any concerns you may have is best achieved through discussion and clear communication.
- It is important to share clear information. You have a right to receive correct information about care issues. Being honest and talking openly about your expectations should make it easier for staff to know what you require and whether they can meet your needs and those of your relative.
- We all want the best for our relatives but we also need to be aware of the constraints of living in a community environment with many other people. It is often impossible to concentrate solely on one person when there are ten others waiting. Balancing time and complex priorities in care is difficult for staff, but they should still listen to your concerns and talk about how a compromise can be reached.
- Communication is a vital ingredient for shared care in a true partnership model between the care staff and you as a relative. Keeping the lines of communication open requires an effort from both partners. The quality of life for the older person living in the aged care facility should be the common focus for all discussion.




Controlling what happens in care

- Sometimes family members feel they are just bystanders in care delivery and that they can only monitor what happens and report what they see as below standard care. This approach causes friction between care staff and the family as the staff feel they are being watched and reported to management for poor work. It is better to work with staff to achieve the goals set initially and to share concerns with the staff member directly. If there are ongoing issues, or staff are inappropriate in their response to your concerns, then management should be informed.
- Information and knowledge is power and can be used to maintain control over situations by some staff who feel they cannot let family members be involved in aspects of care.
- Getting to know the staff and allowing the staff to get to know you, can help to create a more comfortable and welcoming environment for families. A positive relationship is more likely to develop when staff and family treat each other with courtesy and respect. Establishing trust takes time, tolerance and an understanding of reasonable expectations in long term care settings. It is important to remember that no person can know everything at once or be expected to react to demands immediately unless they are life threatening.
- It is important to recognise that older people in care may still be able to make meaningful decisions about their lives and we need to respect these choices. There may be times when your relative wants to make decisions about care, or other aspects of their life in the facility, without your knowledge or approval. Sometimes residents may want to keep aspects of their life private and not involve the family.

Management issues



- The way in which care facilities are managed may affect the relationships between staff and families. Staff workloads, level of training, and care models can work against collaborative care. Families complain about not enough staff, too many fixed routines, staff not having enough time to talk to relatives and poor communication.
 - All facilities work to a budget and all are required to meet Australian government standards for accreditation. If you understand these obligations you will see how staff have to operate and this may affect your involvement in care. If you have concerns about poor organisation you should raise this with the management, not the direct care staff. Often there may be friction between staff and management and involving families in these matters may only increase the tension in the facility.
 - Quality of care issues that relate to poor management are best dealt with by direct discussion with facility management first. There are avenues for families to raise concerns with the Department of Health and Ageing, or to seek advice from advocacy or consumer groups if the problems cannot be solved with the facility management. If you believe work practices are impeding quality care, then you should raise your concerns and seek answers. Organisations provide care for many older people and most try to do their best with the resources available, so it is essential you get the facts right before taking matters further.
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Collaborative care




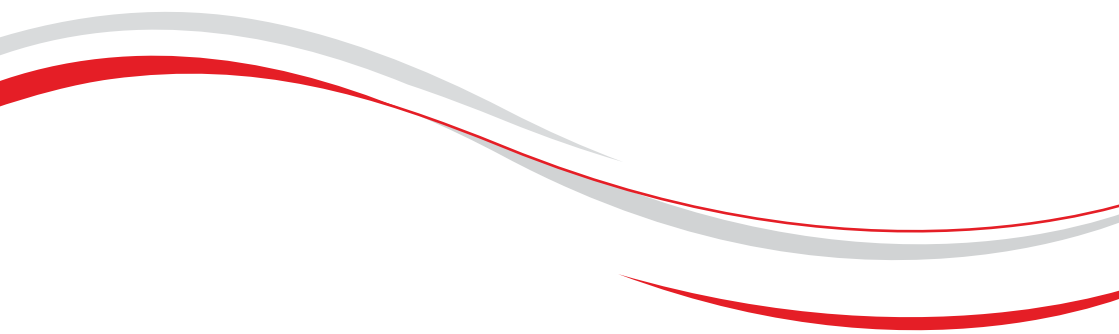
To collaborate means to 'work with'.

- Working with others to achieve a result is teamwork. Staff engaged in care and family members should ideally work as a team, share information and support each other in making decisions about care, while always ensuring that the older person is involved where possible. How staff are prepared and supported by the organisation will also determine how they are able to function as a team member. You should also expect the staff team members to consult with you before taking action in care matters.
- If team members do not communicate, the result can be competition, not collaboration. The older person receiving care becomes 'owned' by the factions that develop and a tug of war ensues that can only be detrimental. Strong personalities should not be allowed to overcome teamwork and disrupt care. Open communication is the way to avoid this problem.
- Teamwork is the only way to deliver care to improve the quality of life for the resident. Care staff cannot provide total care without the input from family members and family members cannot undertake all the care that a skilled caregiver can provide.
- Sometimes there can be tensions within families. When families cannot come to an understanding about decisions affecting their relative, it can also become more difficult for the staff who may be receiving mixed messages.

Care interventions



- The most important part of care delivery is the first meeting between the family members and the care staff to discuss the care plan. Team meetings are a very good way of getting information and discussing expectations with the 'new' care team. Staff perceive family members in a more positive manner if there is a shared model of care from the start.
 - The roles of each team member should be clear and the implementation of care strategies should be shared. Lines of communication should be made clear and avenues for family members to be included in decisions outlined.
 - Care staff require management support and guidelines to help develop the team approach.
 - Sometimes care interventions undertaken by staff may cause you concern in relation to dementia care, resident safety and behaviour. Team discussions should take place before any decisions are made about altering care e.g. increasing medication, changing rooms etc. These agreed changes should be written up in the care plan.
 - In emergency situations decisions may have to be made quickly, but family members should expect to be contacted as soon as practicable.
 - Again team meetings are the best way to discuss future options for care and any changes that may be seen to be required
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We would like to acknowledge and respect your continued involvement in the care of your relative while they live in a residential aged care facility. Some useful contact numbers and websites are provided below.

Useful contacts:

Alzheimer's Australia

– there are State offices but the contact number of the National Office is (02) 6254 4233 <http://www.alzheimers.org.au>

The Alzheimers Australia National Dementia Helpline is 1800 100 500

Carers Australia

– there are State offices but the general contact number is 1800 242 636 <http://www.carersaustralia.com.au/>

Aged Care Complaints Investigation Scheme

1800 550 552

Elder Rights Advocacy (Victoria)

1800 700 600 or 9602 3066

