

The Residential Care Decision

When others
can help...



A resource for Carers
prepared by Carers of
Southern Fleurieu
Carer Support Centre

Dear Carer

As you will be aware, there are many stages of caring when you're supporting someone with a disability or chronic physical or mental illness. Taking steps to move a family member or friend into a residential facility can be a particularly painful and stressful time for Carers. For instance, it's a time when the topic of dying may arise; a very sensitive area for discussion, and one which is often avoided.

Understanding your responsibilities and what is likely to occur at these times will alleviate some of the pressure and stress, and ensure that everything goes as smoothly as possible.

The following notes were prepared for you by Carers in the 'Still Caring Group' at the Southern Fleurieu Carer Support Centre, based at Victor Harbor. Members of the group hope that you will find help and comfort in learning from their personal experiences, and the experience of other Carers over many years.

Please be gentle with yourself

Carers from the Still Caring Group

This information was prepared by the Still Caring Carer Group, 2010. Some members of the group are caring for a person who is resident in a nursing home whilst others have experienced the death of the person they cared for.

Making the decision to move the person you care for into residential care

Why is moving so hard?

Emotions:

- a) loving someone and/or sharing their life for many years makes separation very difficult.
- b) you may experience feelings of failure e.g. 'I haven't tried hard enough'. 'Did I tell her/him often enough how much I care?'
- c) you may be fearful of living alone.

Relationship Commitment:

You may feel that you're violating wedding/commitment vows by moving your partner into long term care. Ask yourself how your partner would deal with this decision if faced with a similar situation. Everyone has different coping abilities.

'My mother cared for me, now it's my turn to care for her':

Caring for a parent who has dementia or severe disability is very different to raising children, even though the tasks may be similar.

Honouring old promises:

We sometimes make promises that cannot be kept: we cannot predict the future.

Moving symbolises decline:

Moving into residential care can be a powerful symbol of the fact that:

- a) a disease is progressing; or
- b) the person is slipping away.

Family and friends who criticise:

Sometimes those around us reinforce the guilt and pain with careless comments or their beliefs. They may not be aware of the pressure you are experiencing as the Carer.

The Media:

The media gives extensive coverage to negative stories in residential care but rarely reports on positive caring stories and happy situations.

Some important points to keep in mind

You are not alone

Many have been challenged with this decision.

There are no 'right' or 'wrong' decisions

It's just a difficult decision to make, and one you may discover has no positive options - even after careful consideration.

It may be useful to ask for help

Take the time to discuss your situation and feelings with someone not personally involved e.g. contact South Coast Carer Support and chat with a Carer Support Worker.

The person you care for may take months to adjust to the new situation

Your family, friends and relatives may also have difficulty coping with the changes.

'No one can care for him/her as well as I can'

This is true as residential care cannot provide one-to-one care. However it is likely that your health and well-being will improve, and time spent with the person you care for may be more enjoyable.

Am I still a carer?

- You are still a Carer although the tasks will be different.
- Keep in mind that your caring does not cease at the door of an aged care facility.

How do I tell the person I care for?

- It's important to prepare them, but keep in mind their unique needs and capacity to understand.
- It can be quite difficult to talk about the approaching move.

Questions to consider

- How and when should you bring the up the question of moving?
- Who should tell the person you care for that he or she is moving?
 - a) you may wish to tell them yourself; or
 - b) it could be a family member, friend or health professional - someone who knows the person concerned.
- What should you say?

Plan what is to be said ahead of time. Write it down. Think about the person's reaction and plan your responses.
- Who should be present and involved in the discussion?
 - a) it may be useful to have more than one person present (a family member or friend); or
 - b) you may feel that the person you care for will respond better to just one person.
- How will you deal with your feelings about this decision?

What sort of reactions might be expected?
(e.g. changes in mood or behaviour)
- What if the person you care for asks questions about the move?

Keep the discussion short, simple and consistent: this is usually the best option. Consider...

 - a) how much information is appropriate; and
 - b) that details can be confusing for some people.
- How will you deal with the feelings of the person you are caring for?

Acknowledge their feelings. Listen and offer reassurance. They may be angry, sad, resistant: don't discount their feelings.
- Be aware that you may behave, or talk differently:

This is a life-changing situation. Even when you're trying not to show your feelings, it's likely that you'll be exhibiting tension, guilt or anxiety and that they'll react to these changes.

Visiting facilities before the move

Preparing yourself for the visit:

It's not unusual to feel overwhelmed when visiting facilities. Be aware that the experience will generate a range of feelings. It may be your first time inside this type of facility; or it may trigger past memories. The visit may also confirm that it's time for this move, which may be difficult to cope with.

Some things to keep in mind during your visit

Expect to feel a range of emotions:

It is not unusual to feel emotions such as relief, sadness, shock, guilt etc. It may be beneficial to have another person with you to offer emotional support and to share reactions.

Residents with a range of abilities and needs:

You will see residents who are more confused or physically frail than your relative, and others who may appear less impaired.

Disruptions and unpredictable situations can occur:

Residential facilities can appear at times, bewildering and unpredictable places. For instance, staff may be called away at a moment's notice to cater to resident's needs, or to an emergency. Remember too, that even the best places have bad days. If you are unsure or uncomfortable about what you are seeing, you may want to ask questions or arrange to visit again.

Before visiting, make a list:

- a) you may wish to visit more than one facility.
- b) it may be helpful to write down some questions before you visit and ask each facility you visit the same questions.
- c) don't be afraid to jot down some notes while you are looking around.

After your visit

Take a few minutes to reflect on your visit

Make some additional notes.

Ask yourself how you feel

Jot down some words to describe how you felt being there: comfortable or uncomfortable, welcomed or neglected (keep in mind, it may be difficult to separate out your feelings about having to move your relative versus how you feel about the residence).

Did you get all the information you wanted?

You may need to make another phone call if there are still some unanswered questions.

Talk about your visit with other family members and friends

Be kind to yourself

This is understandably a very emotional time - give yourself permission to do whatever you need to do to get through this period.

Where possible it is sometimes helpful for the person you care for to have respite in your chosen facility.

Moving Day making the transition from home to residential care

- What can the Carer do to minimise the stress? Plan ahead. Divide the task into three areas, before, during and after the move.
- Plan what possessions you will move. What items are special and familiar to your relative or friend?
- Choose items such as a favourite chair, bed cover, books, photographs, cosmetics etc. Check with the staff to ensure that there is adequate space for the chosen items.
- Query with the facility to see if you can decorate the room to suit your family member or friend before they arrive. This way it will be welcoming and have some familiar items displayed.
- Prepare a 'personal profile' about your relative or friend covering their interests, likes and dislikes. Provide information that will assist the staff to provide quality and comfortable care.

- Put together a photograph album of important people, pets and places. Providing topics for conversation and happy memories for your relative or friend.
- Seek assistance from family and friends with the practical tasks.
- Seek assistance from a staff member at the facility to help you prioritise what needs to be done before the move and what can be left until the new resident has moved in.
- Do as much of the paperwork as you can before moving day which will enable you to be with your relative or friend as he or she moves and is introduced to staff and new surroundings.
- Seek help and support from a trusted person to accompany you on moving day. It will be comforting for you and the person you care for to have a familiar person with you. If you are required to complete the moving in tasks they can give their attention to the person you care for.
- Consider how you might assist your family member or friend to feel more relaxed about moving day. It may help to maintain their regular routine or it may be better to do something special.
- Check with the facility to determine their preferred time of arrival. Try to coordinate with them to ensure that it is also a good time for your relative or friend.
 - a) when are they most rested?
 - b) when are they at their physical best?
 - c) is there a time when they are in a better mood?
- Dedicate the whole day to the move remembering that you will be emotionally and mentally fatigued. Once the move is complete use the remainder of the day to care for you.
- Plan what you will do when you leave the facility. You may like to have some quiet time for yourself or you may choose to debrief with a friend.
- Be aware that you may experience mood swings from relief to doubt about your decision once the move is completed. You may also be more fatigued than usual. These are very normal feelings.

- Be aware that you may be quite exhausted having spent time and energy in caring for your relative or friend and undertaking the move. It is emotionally draining; allow yourself some 'healing time'.

When someone dies in a residential care facility

It is always difficult to discuss the issue of dying. However, being well-informed and establishing good communication between family members will help all parties to cope better.

Once a resident has died there is very little time before their room needs to be vacated. There are always others awaiting placement in an Aged Care Facility.

Funeral parlours have a booklet which provides a guide for planning a funeral. Completion of this booklet can save time and anguish at the time of death.

Once the Death Certificate is obtained the family can notify relevant organisations and businesses e.g. banks who will require a copy of the Death Certificate.

Where does the funeral director meet with the family if a person dies in a nursing home?

The Funeral Director will meet with the family in their home. It is important for this meeting to be held in a quiet place where the family feel comfortable.

What happens if you wish to hold the funeral in another town or state?

Your local Funeral Director can arrange this; however it will add a significant amount to the total cost.

Funeral arrangements

When the person you care for enters a residential care facility, it is usually a requirement that you nominate a Funeral Director.

It is wise to speak with various funeral directors to satisfy the requirements of both the person you care for and family members.

Issues to be considered when discussing a funeral:

- a) Will the person be buried or cremated?
- b) Will the funeral be private or public?
- c) Will there be flowers or donations?
- d) What clothing and cosmetics will the person wear?
- e) Does the person wear glasses and/or false teeth?
- f) What music will be played?
- g) What will be the content of the ceremony?
- h) Will it be religious or civil?
- i) Where will it be held?
- j) Who will be involved?

*It is usually possible to tell how much time is left when death is approaching,
consider whether you wish to be present at the death*

