



Alzheimer Scotland
Action on Dementia

Letting Go Without Giving Up



Continuing to Care
for the Person
with Dementia



Alzheimer Scotland

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Dementia is a blanket term used to describe various disorders of the brain, all of which result in impairment of intellect, memory and personality. This is usually accompanied by changes in behaviour and the gradual loss of the skills required to cope with the activities of daily living.

This booklet is aimed at those who have been caring at home for a family member, partner or friend who is now in the later stages of dementia and where a decision has been made to transfer the person to a care home setting. It does not cover the process of making the decision about or arranging long-stay care nor how you go about choosing a care home. These themes are covered in another Alzheimer Scotland publication, *A Positive Choice: choosing long-stay care for a person with dementia* (2003). Instead, it looks at the impact of the move on the carer and the person with dementia.

The booklet aims to help carers establish new caring roles for themselves through visiting and working as partners with care home staff to help them understand the person with dementia and provide the best possible care in what is likely to be the person's final home.

Letting Go
Without Giving Up:
Continuing to Care
for the Person with Dementia

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Contents

Section One. Introduction	7
Section Two. Emotions	8
Section Three. The Impact of the Move on the Person with Dementia	12
Section Four. Don't Leave It Until the Funeral	13
Section Five. Practical Ways to Stay Involved	15
Section Six. Understanding Behaviour	17
Section Seven. Visiting	19
Section Eight. Communication	23
Section Nine. End Stage Dementia	25
Section Ten. Preparing for the End of Life	26
Section Eleven. Conclusion	28
Section Twelve. Further Reading and Sources of Information	29

Section One

Introduction

The idea for *Letting Go Without Giving Up* grew from concerns expressed by carers who felt they were no longer allowed to have a role in caring for the person they had looked after at home after the person entered long-stay care. This booklet is aimed at carers who want to continue their involvement in the lives of the people they have cared for, even if they are no longer responsible for their day-to-day physical care needs.

The booklet will also be of value to care home staff as it explains the benefits and ways of involving relatives and friends in the continuing care of the person with dementia. If you work in a long-stay care setting, you may also want to read *Working with Dementia: a handbook for care staff* (MacKinlay, 2004). This short booklet, written by a carer, describes how dementia affects the individual with the illness and asks care staff to try to understand how the new resident and the carer/relative might be feeling around the time the resident is admitted. It also describes the behavioural and communication difficulties that may occur and how staff can develop strategies to deal with these issues.

Some readers will want to read *Letting Go* from cover-to-cover while others may want to refer to particular sections as issues arise. We have tried to include as many practical tips and suggestions as possible, based on the

experiences of current and former carers.

When a person with dementia goes into a residential setting, he or she is entering a different stage of the illness which will mean changes for both the person with dementia and the carer. While dementia is a terminal illness, it is an unpredictable condition and there is no fixed pattern as to how the illness will progress. However, although no-one has the same journey or path through dementia, there are common features to the journey which it may help carers to understand and prepare for. These are set out in later sections. Anyone wanting to know more about how the illness may progress in their relative should consult the person's GP in the first instance.

The booklet also looks at: the emotional impact on the carer of making the decision to place the person in a care home; the effect of the move on the person with dementia; helping care home staff to understand the person; making visiting more pleasurable; communicating, both with the person and care home staff; coping with difficult behaviour; and preparing for the end of the person's life.

Even if the illness cannot be cured, we can still aim to provide the best quality of life for the person throughout this last phase of the disease. That aim underpins the following sections of this booklet.

Section Two

Emotions

Deciding that someone should move into long-stay care can be a very difficult decision to take. In many cases, this decision is made after a period of reflection and investigating choices of care home. You have made a choice based on balancing what is best for everyone involved. In other cases, a crisis of some sort may lead to your relative being admitted to a care home very quickly, without giving everyone time to prepare properly. Whatever the circumstances, you are likely to feel that you are riding on an emotional rollercoaster. This section explores the common range of emotions felt by carers and suggests some strategies for coping.

Guilt

You may feel guilty that you have not been able to keep your relative at home for longer even though you know that you have done everything you could and that the decision is the best for all concerned. Feelings of guilt may be particularly strong if you have promised your relative, a now-deceased parent or a friend that you would never put them in a care home.

If the person has problems settling in to the home, this will add to your own distress and feelings of guilt. You may wonder if you have made the right decision? In time, the person may become unable to communicate with you or respond to you, and may even be unable to recognise you. This can be the most distressing experience of all.

Feeling guilty for not feeling guilty

It can be difficult for carers to be honest about their feelings when their relative enters a care home. If you believe you are expected to feel guilty and to admit to anything else would seem wrong, then you may not be willing to say you feel relieved. There are no right or wrong feelings. Some people feel guilty, some don't. Some may have guilt put upon them by others.

Possible reasons for guilt and suggestions for coping:

- You may have had unrealistic expectations of your ability to cope or the toll that caring would have on you
- You may feel guilty because you sometimes wanted to walk away from your responsibilities to the person and now you have done so
- You might feel guilty that you never liked the person and they now seem so helpless; maybe I could have tried harder to like them?
- Maybe the person who has dementia used to criticise you in the past or always made you feel inadequate, so even now nothing you do can seem right
- You may have promised the person in the past that you would always look after them at home. Now you have been forced to break that promise.

Most carers have experienced similar thoughts and feelings and, in the circumstances, they are quite normal. It may help you to talk them through with someone who understands – this could be a professional, member of a carers support group or a good friend.

Anger

You may find that you feel anger towards the person with dementia for leaving you to cope on your own, even if you have had to take most of the responsibility for the day-to-day running of the home, the family finances, home repairs, and so on, for some time.

“You are now responsible for everything in the house – it’s down to you – finances, repairs, decisions. Even if you’ve been doing all these things for years you still realise you’re on your own now that your relative is in a care home.”

The anger you feel may be directed towards care home staff – if you can no longer care for the person, you are going to make sure that the home gets it right.

People need to be allowed to be angry – find someone you can safely express that anger to; or go somewhere where you can shout or "throw stones in the sea".

Grief, Loss, Loneliness & Bereavement

You may feel grief at yet another change in your relationship with the person. Rather than feeling that the burden of care has been lifted you may feel emptiness – even if your relative has changed through the course of the illness, you will still miss their presence in your life.

Sense of loss

A sense of loss is one of the most powerful feelings that carers experience. Depending on your relationship with the person and your individual circumstances you may grieve for the loss of:

- the person you once knew
- the future you had planned together
- the relationship you once enjoyed
- their companionship, support or special understanding
- your own freedom to work or to pursue other activities
- finances or a lifestyle which you once took for granted.

Loneliness

You may also feel a strong sense of loneliness caused by:

- going home to sit on your own
- having no one to talk to
- seeing other couples
- missing the person
- feeling on your own

It is important to acknowledge these feelings and not to feel the only one who may feel like it.

Bereavement

Even though your relative is still alive, you may feel a sense of bereavement at the loss of the person they once were and the loss of your relationship with the

person, yet feel unable to mourn properly. There have probably been several stages during the course of your relative's illness when you have experienced feelings of loss and the period when your relative enters a care home will mark another type of loss. This sense of loss may be lessened by care home staff recognising you as the expert in the person's care and involving you in the planning and delivery of care to your relative.

Assumptions about different types of carers

After a person with dementia enters a care home, relatives commonly struggle to adjust to changes in their relationship with the person, changes in their role and changes in the pattern of their day. The impact of these changes will differ from person to person. Some might assume that the impact would be greatest on husbands, wives or long-term partners but adult children, particularly those who have continued to live with their parent, can also feel a great sense of loss.

Not all caring relationships are loving ones. You may have had a difficult relationship with your relative before he or she became ill; the illness and the need for you to take on the caring role may have meant that a lot of issues have never been resolved. You may need help to work through your feelings through counselling or therapy – see Section 12 for sources of further support.

When the person goes into long-term care you may grieve at another change in your relationship. The relief which you might feel initially may be replaced by feelings of loss and grief, mixed up with guilt, which can last for a surprisingly long time. You may miss the person's presence and may experience feelings of emptiness. You may feel very tired, both physically and emotionally.

What might help

- Try to take it easy until you feel your energy levels rise again.
- Give a structure to your day which may help you get through the difficult early months.
- Not everyone is the same, but don't fall into the trap of building your life around visiting the person in their new home. You need to build a new life for yourself which includes these visits.
- Talk about your feelings to an understanding professional, to other carers, to a trusted friend or to supportive members of your family. Don't bottle your feelings up.
- Call the Dementia Helpline at any time to speak, in confidence, about how you are feeling (0808 808 3000)
- Speak to staff at your local Alzheimer Scotland service
- Try to persuade friends to drop in for a chat or to phone you regularly

On the day of the move

The move may be difficult for both you and the person you care for. The person is likely to feel upset at being left and you may find this experience very harrowing. Many carers feel that they have lost their role in the person's life, as though they have been deprived of caring. You may feel that the person's move leaves a huge gap in your own life.

"I was too wrapped up in concern and planning for her to be OK to think about how it would be for me. I had no idea what it was going to do to me – it was awful to be reduced from daughter and primary carer to visitor. It took a few months to come to terms with it"

Daughter

Get someone to go with you if you can, to support you and for you to spend time with when you leave.

Comments from carers about how they were affected

"Sending back his driving licence, throwing out his library card – it's as if he's died but he hasn't"

"I didn't think I would grieve – I thought I'd lost him years ago – but now I'm grieving for this other person"

"Depends on what kind of relationship you had with the person before – if only I'd"

"Emotions change from day to day or hour to hour."

"I feel deep sorrow for the person and what they've lost."

"Now my husband is in care, everyone asks how he is not how I am."

"You need to forgive yourself"

Carers find different ways of coping. Some find carers' support groups particularly helpful since it is possible to speak to members about things you might not want to discuss with your children or other members of the family; however, where the group includes some carers who are still looking after their relatives at home, it can make you feel inadequate – why couldn't I cope if they can?

Does it get any easier to cope? For some, not others.

Looking on the bright side

You may find that there are positive aspects to your changed circumstances. Your life will no longer be centred round the practical tasks or caring or organising help. You may feel less stress. You may feel that you now have the freedom to do things for yourself, or to go out when you want to. You may get more sleep. The lessening of your responsibilities may come as a relief especially if you or the person you care for is ill, even with a minor illness. You may also find that your time with your relative can be more relaxed and enjoyable if you no longer have to deal

with many of the practical caring tasks now carried out by the care home staff.

Establishing a relationship with care home staff

Quite often, carers are asked to stay away for the first week or so to allow the person to settle. This is generally not held to be good practice – it is important for the carer to maintain contact, the carer knows the person best. It's a traumatic enough time without feeling excluded. If the home suggests staying away, discuss it with them and go with what feels right. Alternatively, you could stay away but phone in regularly to check.

Some carers find that being asked to stay away for a few days sends a message that they are no longer expected to play a significant role in their relative's life.

"We'll take over now – you have a rest"

This may be well-meaning, but can establish a role for the relative which is hard to adjust at a later date.

Often staff-relative relationships are established very early on. The initial welcome when the person with dementia moves in can make all the difference for future relationships. Being met at the door, shown to the person's room, introduced to staff and other residents, and being given a cup of tea can all be important in reassuring you that you have made the right choice.

You may feel all sorts of conflicting emotions, alternating between feeling reassurance that your relative will receive appropriate care and despair that you are no longer able to provide that care. The focus on your relative may leave your feelings rather neglected.

"They were lovely and that made me feel better. Because it is an emotional experience. I've been responsible for him for the last six years and to suddenly let go and hand him over to somebody else. I shed quite a few tears over it."

Daughter

Other relatives may find that their feelings are not acknowledged.

"I think there's a lot that someone could have said. 'How are you feeling about this?' 'How is it affecting you?' 'Are you coming to terms with it?'"

Son

An alien environment?

The difficulties experienced by relatives in making decisions about placing the person in a care home do not necessarily end when you find a suitable home. A care home is generally an unfamiliar environment for both the person with dementia and the carer - the people and the surroundings are strange and no-one is quite sure where they fit in or what the rules are.

It is important to try and make the new setting as familiar as possible to the new resident and relatives, at the same time establishing new relationships with staff and helping staff become familiar with the needs of the person and the family. Taking familiar pieces of furniture for the person's room, putting up familiar pictures, ornaments or other memorabilia and favourite music can all help make the new home less unsettling. Ensuring the family are given time to help settle the person is also important.

Section Three

The Impact of the Move on the Person with Dementia

The person with dementia may have had little input into the decision to place him or her in a care home and the experience of being moved from familiar surroundings and familiar faces can be extremely unsettling. This can result in challenging behaviour or a deterioration in the person's condition but steps can be taken which may help the person adjust and settle more quickly.

Even if the person cannot express feelings and wishes verbally, he or she may still be upset at leaving home. Try to understand and accept those feelings. Try reassuring the person that you will be visiting regularly, taking him or her on outings, and so on.

Talk to staff at the home – they may have ideas on how to help you and the person adjust to the change. The person may be very low in spirits for the first few weeks but some people settle in very quickly. Be prepared, though, for the person to feel very unsettled. Often someone with dementia asks to go home. Sometimes, the person will say this to relatives and care home staff alike, sometimes he/she may only say this to the family either because he or she doesn't want to confide in strangers or because it seems impolite. You may want to discuss with other family members and staff how you will respond if the person asks to go home – it can help if you are all consistent and help you feel more prepared for what one carer described as 'an emotional body blow'.

Ask staff how your relative seems when you are not there; it may be that he or she remembers what has changed more when familiar people visit and is settling in quite well the rest of the time.

On being admitted to the care home, the person with dementia may experience a range of difficulties, including disorientation, deterioration and frustration.

Disorientation

Leaving a familiar environment where you feel safe and comfortable to move to a place where all the faces, smells, sounds and colours are unfamiliar can

be really frightening and confusing.

"We took some things in to try to make her feel more secure in the first few days. For example, her unwashed pillow slip and nightie, for a familiar smell, and her old sofa because she was used to it and sat there all the time. Smell is especially important to my mother because she's blind."

Daughter

Deterioration

Deterioration of the person's condition may or may not have prompted the admission to long-stay care; however, it is not unusual for a person's condition to get worse on admission to a care home. The unfamiliarity of the surroundings can mean, for example, that the person can no longer find his or her way to the toilet, which can cause him or her to become incontinent. The person will also not be receiving the one-to-one care that he or she received at home.

Frustration

The person may have great difficulty in getting unfamiliar care home staff to understand his or her wants and needs, which can lead to anger or aggression. The person may also be used to having more freedom of movement than the home may be used to providing.

The person is undergoing huge changes in his/her life and there are bound to be changes in behaviour and even deterioration in the condition. Often, homes will suggest that a carer stays away for a few days to allow the person to settle in. This is no longer seen as good practice and carers should decide what is in the best interests of the person with dementia and themselves.

On the day of the move, try to make sure that when you leave, the person is occupied with something positive, such as a meal and thus distracted from the fact that you are leaving.

We took Mum's favourite music with us and made sure it was on when she arrived.

Section Four

Don't Leave it Until the Funeral

How many of us have attended a funeral service and discovered all sorts of interesting things we never knew about the person whose life we are celebrating? This section stresses the importance of letting care home staff know about the person they are caring for, what has made the person; holding on to the person's identity. As the person's memory and ability to communicate verbally get worse, family and friends may be the only ones who can keep alive the knowledge of the person – their likes and dislikes, their memories, their history.

In the past, there was a strong tradition in professional health and social care services to "take over" the complete care of the person going into long-stay care in hospitals and care homes, with family members being viewed as no longer directly concerned with the care of the person. More recently, there has been a move away from this 'paternalistic' approach but this sort of cultural change takes time to develop. Professionals may still be inclined to take over, even in a very well-meaning way, and relatives and friends expect to let them, even if they are reluctant to do so. Relatives may think "They know best" and care home staff may encourage that view, however subtly.

"Don't worry, we'll look after him now"

On the one hand, this may sound reassuring; on the other hand it may be giving relatives the message that their services are no longer required. More will be said about how such messages can be misunderstood in Section 8 on Communication.

Person-centred care

With the gradual shift away from the paternalistic approach has come the concept of person-centred care. Person-centred care stresses the importance of letting people know about the person; what has made the person; holding on to identity/ sense of self.

In particular, it is:

1. Care that is centred on :
 - the whole person not the diseased brain;

- remaining abilities, emotions and cognitive abilities –not the losses;
 - the person within the context of family, marriage, culture, ethnicity, and gender.
2. Care that is centred within a wide society and its values.

How can you as a carer contribute to person-centred care?

Let people know about the person you have cared for; what has made and continues to make the person; how to hold on to the person's identity. Don't leave it until the funeral to tell people about the person's life, achievements, interests, fears and passions. By giving the home as much information as possible, you will help staff understand the person and provide the best quality of care and understanding as possible.

The Care Commission, the organisation in Scotland which registers care homes and oversees standards of care, sets out requirements for the sorts of information that homes should collect about a resident; however, you cannot provide too much detail about the person.

Some of his or her likes and dislikes may seem insignificant but knowing about them could make all the difference to a staff member trying to understand why a resident is reacting in a particular way. This sort of information, together with details of the person's life history and significant relationships, personality, attitudes and values, personal preferences and routines can all be gathered together to form a **personal profile** which is unique to that person.

Putting together the profile – handy hints

- What was the normal pattern of the person's day before entering the home or further back in their younger days?
- If you send in photographs, write on the back who they are and what is their connection with the person with dementia

- Remember to record information about children and pets
- A loose-leaf binder helps you to add new sections easily
- Consider working with other family members and friends on drawing up the profile – they may be able to contribute additional information from their own relationship with the person.

Drawing up a life history

Methods for doing this varies. Some homes might involve the person's key worker in working with the resident and his or her family and friends to put together an actual life story book. (see Section 7 for more on life story books). In others, the details about the person's life and history are recorded simply as part of the process of "care planning".

Section Five

Practical Ways to Stay Involved

Preparing for the period after the person has settled in is just as important as preparing for the move. It can be an emotional time with mixed feelings such as relief, guilt and grief at the separation. Your daily activities suddenly change.

Many people believe that full time residential care will remove them from the caring role. The fact is you are still caring. 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 your role as a carer. You are the 'expert' when it comes to caring for your relative.

Your role now is to work with care home staff to inform, advise, recommend, make decisions and encourage the best possible quality of care for your relative. You can also continue to contribute to the physical care of your relative if you want and to the extent that you want.

The care home should involve you in caring for your relative by:

- asking you for information about your relative's family background, past employment, activities and hobbies, likes and dislikes, language, religion, culture, etc.
- encouraging you to make your relative's room as home-like as possible
- working with you to develop a care plan for your relative which sets out his or her care needs, goals, strategies and actions to ensure those needs are being met
- reviewing the care plan with you regularly
- informing and consulting you about management of your relative's condition
- consulting you about issues such as the time your relative likes to get up and go to bed, bathing times, what they wear, what they eat, when they have their meals, and so on. These preferences should be accommodated as much as possible within the home's routines
- encouraging you to read your relative's day to day notes or

communication book

- greeting you on arrival and saying goodbye
- inviting you to attend relatives' meetings where the day to day running of the home is discussed, although not all homes have such meetings
- informing you about the person, not just when they are ill but about good things such as achievements, outings they have been on, how they relate to other residents and staff, and so on.

If the home does not actively promote involvement from relatives you should speak to the manager or person in charge about how you wish to be involved and ways they can help you to do this.

Relatives should be seen as an asset

Some relatives report that they feel resented when they try to continue aspects of day to day caring such as helping with meals, taking the person to the toilet or taking the person outside for a walk in the garden. Staff may feel that it is an implied criticism of them while the relative may see it as simply carrying on doing something they have always done.

One argument against relatives getting involved with personal care is that they may not be covered by insurance if any accident took place. It might be possible for homes to offer appropriate training or the home could ask the relative to sign a disclaimer against them sustaining an injury.

Pressure on staff may mean that some tasks like cutting finger nails, applying make up or sewing on buttons are hard to fit in to the daily schedule. These are tasks that relatives may be delighted to help with, to the benefit of all concerned.

In other cases, staff may have difficulties persuading the person to maintain adequate levels of hygiene. A relative might be able to persuade the person by helping with bathing.

Care planning

The care plan should be a detailed document setting out an individual's care needs, considering the person as a whole rather than a set of symptoms or problems. The plan should be updated and reviewed regularly, to reflect the person's current situation. Relatives have a significant role to play in giving information about the person's social, emotional, spiritual and cultural needs as well as their likes and dislikes and preferences. If you have been caring at home for some time, you can also contribute valuable information about the person's medical and nursing needs, although this contribution may lessen as time goes by and the person's condition changes.

Monitoring Personal Expenditure

In calculating the amount to be contributed by an individual towards their care home fees, the local authority has to allow the resident to retain a Personal Expenses Allowance (PEA) of (currently) £18.80 per week. Residents should not be asked to put their PEA towards meeting the basic cost of their care but carers should

check with the home what services are included in the fee charged – will the resident be expected to pay for items such as hairdressing or outings, for example? The PEA is intended to buy items such as personal toiletries, small gifts and clothes but carers may wish to add to this sum to enable residents (or care home staff on their behalf) to buy extras such as food treats.

A carer may already have been involved in recording the person's preferences for things like toiletries and food in the personal profile which will help care staff to know what items should be purchased on a regular basis. But carers may want to be consulted about larger items of expenditure on, for example, clothing and may want to keep track of any accounts set up for the resident's personal expenses.

One carer was very upset to learn that a sum of money had been taken from her husband's account to buy him a new shirt since it was in a colour that she would never have chosen for her husband and which he would not have wanted to wear.

Section Six

Understanding Behaviour

Relatives may make the difficult decision to place the person with dementia in a care home because their behaviour has become too hard for the carer to cope with. But even where behaviour has not been a particular problem in the past, the move to a care home is highly likely to cause changes in the behaviour of the person and even deterioration. This section looks at some of the changes that may occur, the importance of understanding behaviours, and strategies for coping with difficult or challenging behaviour.

Regardless of a diagnosis of dementia, behaviour is an essential part of being a human being. You may have found when you were caring for your relative at home that he/she had certain behaviours that you found difficult to understand or cope with; for example 'wandering' (now more accurately described as 'walking'), or perhaps he/she became very withdrawn and difficult to communicate with or did not want to get washed or dressed.

When someone moves to a care home, these behaviours will continue and, because of the unfamiliar faces and surroundings, may be more difficult for care home staff to deal with. Alternatively, after admission your relative may start to show types of behaviour that are a challenge either to staff or to other residents.

It is important that you do not feel responsible or guilty if there are problems with your relative's behaviour. You can, however, make an important contribution to helping the care home staff to manage any challenging behaviours by:

- understanding that behaviours for someone with dementia are a way of communicating, when speech is difficult and the dementia is clouding how the person thinks – exhibiting a behaviour is a way of being heard
- providing the home with as much background information as possible – it may give the key to the behaviour
- encouraging the staff to look at the behaviour and make an informed decision as to whether they need to

try to change or control the behaviour – it may not be necessary

- remembering that some behaviours caused by the disease process may never be understood or modified but how the illness affects the person will eventually change and, with it, the person's behaviour.

Remember that care home staff go home at the end of the day and there is a team of people involved which makes it easier for them to keep on caring, even when they are faced with challenging behaviour.

"There's a whole team here – you had to do it on your own."

Understanding

Understanding the person with dementia and adapting the environment or care practice is needed to better meet the individual's needs rather than using restraint or medication to control the behaviour.

A good balance needs to be struck between protecting residents and the gains in quality of life that can be achieved by taking some risks for example in relation to walking

Factors to consider:

- environment - is it too noisy, too hot, too cold?
- physical - can he/she see and hear OK? Does he/she need to go to the toilet?
- physical illness - is the person in pain but unable to tell you? Does he/she have an infection?
- depression will affect behaviour, particularly if the person is grieving at the loss of his or her former home and way of life
- medication – this usually takes the form of some kind of sedative but should only be considered as a last resort.

Relatives can be a valuable resource in understanding the behaviour of the

person with dementia. Your experience and knowledge of the person may help explain why the person seems anxious or has reacted badly to a particular situation. People who constantly try to leave the home or get agitated at particular times of the day may be recalling something from their earlier life when they went to work at a particular time or left home to collect the children from school.

People whose first language was not English may revert to their first language as their dementia develops. Where staff are unable to communicate, relatives may be able to talk to the person on the phone to determine what is causing a problem. People who are resistant to eating may be persuaded to eat when helped by a relative they know and trust.

Care home staff should consider using the equivalent of a "pain ladder" in determining what steps should be taken in managing challenging behaviour and investigate what is the appropriate response and tactics to use **before** trying medication?

ANTI-PSYCHOTICS
ANTI-DEPRESSANTS
COMFORT
ENVIRONMENTAL

Section Seven

Visiting

Visiting is the main way in which you can maintain close contact with your relative, yet visiting can cause all sorts of difficulties which need to be treated with sensitivity. You have been living with or caring for the person for many years, in some cases for a lifetime, so the concept of visiting is unfamiliar. You have to rely more on talking to the person, whereas before you would have done things together. You are uncertain about what to expect in the new surroundings of the care home. You want to do the right thing and not cause any upset to the staff, while at the same time making sure that your relative receives the standard of care he or she needs. This section considers how often you should visit, offers suggestions for activities during visits, including during the later stages of the illness, and how to manage leaving.

Making the decision to find residential care for the person with dementia may be one of the most difficult decisions you have to make. You may feel guilty about not having been able to care for them right to the end at home and feel that you are abandoning them. However, it is important to bear in mind that what you are doing is in the best interests of everyone concerned. Although, it may be difficult to handle at first, the person will benefit from full time professional care.

You can still visit regularly and may even find that as time goes on, your relationship improves, as you are no longer under such strain. You might find it difficult to see the person with dementia being cared for by other people and feel somewhat excluded. This is why it is important to visit regularly and if possible to remain actively involved in the person's care. You could, for example, assist at meal times, comb the person's hair, give them something to drink and help to make them comfortable. In this way you will be helping the staff as well as carrying on caring for the person with dementia.

At first, you might find visiting difficult but it generally becomes easier after a while so try to persist. Many people find that their relationship with the person

they have cared for improves after he or she enters a home. With the pressure off, you may be able to bring back the outward signs of loving and affection which may have been suppressed by the stress of day-to-day caring.

"I visited any time. I could go in and give him his lunch and tea"
Wife

Life Story Books

A life story book can combine photos with notes about the person's parents, brothers and sisters, children, work, places he or she has visited or lived in, favourite holidays, friends, hobbies, favourite foods, least favourite foods, colours, favourite films, music, likes and dislikes. Photos, post cards, scraps of material from old clothes or bedcovers and other memorabilia can be added to the story book.

Handy hint

It helps to use poly pockets or plastic covering for life story book pages – they will get handled a lot.

Don't feel you **must** do anything beyond what you would like to do, but if you feel you want to, some possibilities are:

- visiting the person – but don't feel you must visit every day or even every few days, if that isn't right for you
- keeping the person involved about family news
- helping the person reminisce, perhaps with photographs or a life story book of reminders of significant events and people in his or her life
- going on outings – to shops, to tea or to visit old friends, or a run in the car
- choosing new clothes and personal items
- helping in the home with some of the person's day-to-day care or at mealtimes
- bring newspapers and magazines to look at together
- play games that the person has enjoyed in the past
- help decorate and tidy the person's room

- bring others to visit
- bring pets, if allowed by the care home
- take in things that the person likes such as chocolate, crisps, or even a little alcohol if that does not conflict with any medication the person is receiving.

Handy hint

If the person likes to listen to music, try to find a waterproof personal stereo/CD player in case of spillages

Think about what you would like to do and what you would rather not do and don't worry if your feelings about this change over time – this is normal. You can become more or less involved as you wish, secure in the knowledge that your relative is safe and cared for.

Difficult visits

Sometimes visits can be hard to cope with emotionally if the person is, for example, weepy or angry. If this happens:

- talk to the staff and find out how the person is at other times
- try varying the times you visit – the person may feel better in the mornings when he or she is less tired
- visit just before a meal so the person has something to do after you leave.

Visiting in the later stages

Many people find visits difficult when the abilities of the person with dementia decline and he or she is no longer able to join in conversation. Where this is the case, some ideas for making visits enjoyable for both of you include:

- looking at old photographs or mementos together to remind the person of his or her life
- massaging hands and perhaps feet with scented creams or oils can be relaxing and comforting. The scent of perfumes and flowers can also be enjoyed
- listening to some familiar music together
- having a cuddle or simply holding hands; a smile, a comforting gaze or a look of affection can often provide reassurance to the person with dementia

- visits from friends and relatives, even though they may not be recognised or remembered, can provide stimulation and comfort
- a stroll around the grounds, even if in a wheelchair, can be enjoyable for both of you
- keeping your visits short – 10 minutes may be enough for both of you
- taking things to hold and touch.

Don't get despondent when visiting - take pleasure in the small things - a smile, a laugh, a joke, a cuddle, a glimpse of recognition.

Don't stop visiting because you think there is no point because your relative doesn't appear to recognise you. Each day is different and it is difficult to tell what the person is feeling but care staff say people always appreciate seeing visitors. Live for the moment - it does not matter that the person won't remember your visit - you will have hopefully brought pleasure and happiness whilst you were there.

Activities

Consider things like massage, life story books, photos, objects, sensory material – fabrics, smells, textures, music, going outside to the garden.

Personal grooming – styling hair, giving a manicure, putting on nail polish

Resource boxes: as well as individual's life story books, some care homes may consider making use of resource boxes which can be filled with items that can be used during visits to trigger off conversations or ease communication between residents and visitors. This could include books with photographs, postcards of tourist attractions, music tapes or CDs, videos of particular events, and even things like handcreams or other sensory material like fabrics. These can be inexpensive to put together and could encourage visitors to get involved.

Don't feel you can't try something different or introduce your own activities just because "the staff might not like it".

Frequency of visits

There is no correct number of times that the carer should visit, or amount of time they should stay. The important thing is to make each visit as rewarding as possible and to do whatever you can manage and what feels right. Some people visit every day, particularly husbands and wives. But you should do what feels right for you – if visiting every day is stressful for you and upsets the person, then don't do it.

You might consider sharing the visits with other relatives and friends. Don't feel you can't take a holiday either because you would miss some visits or because you feel guilty when the person cannot do the same.

Leaving

Leaving after a visit can be a difficult time particularly if the person becomes distressed.

You might want to try:

- telling staff when you plan to leave so they can be there to help
- making your departure coincide with an activity or a meal
- keeping your goodbyes short and leaving straight away.

If the person wants to leave with you or gets upset when you leave try different tactics – vary the time of day you visit; vary the length of visit; maybe coincide your visit with just before a meal or when the person has something else to focus on.

Wanting to go home

A common phrase heard from people with dementia in care homes is "I want to go home" or "I don't like it here".

This can be especially hard for carers who already feel guilty or upset about placing the person in a care home. Wanting to go home may be caused by feelings of insecurity, depression or fear. It may be that the "home" the person is talking about no longer exists. Instead, it may describe memories of a time or place that was comfortable and secure such as the person's childhood.

You might want to try:

- understanding and acknowledging the feelings behind the wish to go home
- reassuring with touching and holding and telling the person that they will be safe
- looking at photographs or talking about childhood and family
- distracting the person with food or other activities such as a walk
- not disagreeing with the person or trying to reason with them about wanting to go home.

"The most awful part of the whole thing was dealing with John saying I'm coming home or leaving here next week"

Where to conduct the visit

You may feel more comfortable visiting the person in his/her own room rather than a communal lounge. Visiting in a public place can cause a strain, particularly where the person may be hard of hearing or where other residents are receiving visitors. You may feel very inhibited about engaging in conversation in a residents' lounge. On the other hand, you might prefer to have the distraction of other people if your relative does not communicate.

You may feel reluctant to suggest that you move your relative to a more private area for your visit especially if you need assistance from staff to move the person. It helps if there are seating arrangements in the home to suit varying needs of residents and visitors. Some visitors might want to share a meal or a snack with the person which may require a small table to be set aside. Visitors may wish to come along at mealtimes – if arranged in advance and paid for if required, this may encourage the resident to eat more.

Home visits

Should you take the person home for a visit? There are problems with caring for the person although organisations like Crossroads may be able to provide support for a short visit. However, you do not want the person upset or disorientated by moving them around too much.

The person may get a feeling of comfort and pleasure from experiencing home,

the garden, and familiar smells. Even if he or she doesn't remember the event, the good feeling may stay with him or her or they will at least enjoy it at the time.

"I don't think I could cope with my husband coming home – it would be cruel for both of us, but it depends on those involved."

Visiting policies

If there are rules about visiting, relatives and friends need to know what they are. Are there certain times of day which must be avoided? Can you bring along a pet or small children? It could be frightening for children but many older people get great pleasure from seeing young children. You would have to gauge this for yourself – if the person gets pleasure from seeing the children, and the children are happy, then there should be no reason why they should

not be involved.

Is there somewhere where visitors can make a cup of tea? If you have been told to treat the home just as you would if it was your mother's own home, then get ticked off for going to the kitchen to make a hot drink, how would you feel?

How you are received when you visit can make a big difference. If you ring the doorbell and it takes ages for someone to answer, then the person answering can't even exchange a few words with you, it can make you feel like you are intruding and less inclined to visit as regularly or for as long. Being greeted by a familiar, friendly face can make all the difference.

Section Eight Communication

In this section we consider communicating with your relative and communication between care home staff and relatives and friends.

Communicating with the person with dementia

Only 7% of communication is via the spoken word. The remaining 93% is non-verbal, so even if the person can no longer speak, this still leaves quite a lot to work with. As the dementia worsens, the person will have increasing difficulty in understanding what is said or what is going on around them. They may gradually lose their speech, or repeat a few words or cry out from time to time.

Ten things to do to improve communication

- Believe that communication with the person is possible
- Try to focus on the nonverbal signs as well as what is said
- Avoid making assumptions: check things out with the person
- Make your communication a two way process that engages the person with dementia
- Avoid the use of jargon or complicated explanation. Keep your conversation as simple as possible without being patronising or sounding childish
- Do not ask questions which have 'why' in them. The person with dementia may find the reasoning involved in giving an answer difficult and become annoyed with themselves
- Be a good listener. Give the person your full attention and resist the temptation to finish their sentences and talk at the person
- Talk at a slower pace so that the person has an opportunity to grasp what is being said
- Maintain a calm and unhurried approach
- Discover the best time of day to spend time talking with the person

Having focused on how we can improve our communication, there is also a need to acknowledge that the living environment can play a part in helping

communication. A quiet area where carers and residents can sit together away from the distraction of other people and the television can be more conducive to good communication. Visitors may prefer to go to the person's room rather than sit in communal areas.

Where the person can no longer communicate verbally, consider using other methods. One way to let the person with dementia know that you care and that they are not alone is through touch. You could simply take hold of their hand gently without saying anything or gently put your arm around their shoulders. The physical contact might provide reassurance. Listening to music together or using items in resource boxes involving scent or texture can all give a sense of togetherness even if no words are exchanged.

Some relatives get upset when they see the person showing affection towards care staff but it should be seen as the person communicating in the best way they can. If the person is happy with the care staff that is a good reflection on the care being given and the family should be comforted by that thought.

Communication with staff

Sometimes the most innocent remark can be misinterpreted and cause considerable upset. Sometimes staff can answer a relative's question in a way that they think will be the least upsetting – with the opposite effect.

For example, if one of the reasons you decided to place your family member in a care home was that you could no longer cope with his or her challenging behaviour, it will not necessarily help you to hear that he or she is "no bother" or "no trouble at all". A statement like that is likely to make you feel guilty or that you have somehow let the person down. The staff may have been facing the same problems but just do not want to worry you.

Relatives and staff need to know what their respective roles are in the care of the person with dementia. It is not a criticism of staff that you want to carry

on doing things for your family member – it is a way of you feeling involved and of maintaining your connection with the person.

Sometimes relatives ask the person in charge of the home if it is all right for them to get involved in a particular way. This agreement needs to be passed on to all the staff involved.

Some carers may live too far away to visit regularly but can still be kept informed by telephone or in writing about how their relative is getting on. As well as regular news, there may be special situations which relatives need to be told about such as changes in the person's health or changes to their medication. Some homes make a point of telling relatives about medical appointments to give them a chance to attend with the person.

Keeping relatives informed can be haphazard if there are not proper mechanisms in place to do so. A key worker or named nurse can be the main point of contact for relatives but there needs to be a back-up mechanism for occasions when that worker is not on shift.

Make sure you know and are told about:

- who the key worker is for the person
- what the doctor said if called
- any reviews of how the person is doing
- how you should approach care staff if your relative is dissatisfied but afraid to complain.

Some care homes keep a communication book in a resident's room where relatives and other visitors can pass on information and raise queries. Some carers may want to have a visitors book so they can see who has been to visit their relative, who might otherwise forget or be unable to explain who has visited. Staff can also get involved in filling in pieces of news and information about what the resident has been doing since the previous visit.

Some home managers say their door is always open to relatives and other visitors. Even if this is the case, relatives may prefer to make a set appointment to ensure that sufficient time is set aside for the meeting.

Other sources of information and support

Some homes set up meetings for relatives where pieces of news about the home can be passed on and to allow questions to be asked; meetings can also include talks from invited speakers as well as a chance for relatives to get together to discuss issues collectively.

Newsletters and notice boards are other communication methods which could be used.

"The staff at the home were always very proactive in telling me about any problems Mum had and what they had done about them. I think it's important to share information. I also tried to make sure that I told the staff about any changes I noticed in Mum or any concerns I had as soon as possible."

Daughter

Complaints

Each care home will have a complaints policy and procedure which should be explained to relatives and residents but often a problem can be dealt with informally before it reaches the stage of a formal complaint.

Frequently, the problem lies with the first person that the complaint goes to – the simplest thing can get blown out of all proportion just because it was handled badly in the first instance by a member of staff reacting defensively. A situation can be defused and the relative's anger deflected by the willingness of the staff member to listen and investigate.

"I wasn't here when that happened but let's look at what's recorded."

Section Nine

End Stage Dementia

There are around 63,000 people with dementia in Scotland, of whom 28% are thought to be in the end stage of the illness.

What do we mean by end stage dementia?

The length of time the person may experience in the end stage of the illness can still be many years; it is impossible to determine how long.

End stage dementia is the last part of the long journey that somebody with dementia has to make. While each person's experience is different, by this stage of the illness the person is likely to exhibit severe memory disturbances and the physical side of the disease becomes more obvious. Particular symptoms include:

- severe fragmented memory
- limited verbal skills
- orientation only to self
- inability to make judgements
- inability to problem solve
- no independent function
- a need for help with personal care and continence management.

Later still, the person may enter a stage of total dependence and inactivity where he/she may have difficulty eating and walking, may fail to recognise relatives, friends and familiar objects, have difficulty understanding and interpreting events, may suffer bladder and bowel incontinence, and be confined to a wheelchair or bed. The latter can make the person especially vulnerable to infections such as pneumonia, which can be fatal.

People with dementia differ in the speed with which their abilities deteriorate but deteriorate they will. While dementia is a terminal illness, death often occurs as a result of complications arising from the effects of the disease rather than the disease itself. So, an inability to swallow can increase the risk of food and drink entering the lungs rather than the stomach which in turn can lead to pneumonia. In addition, many older people with dementia have other conditions that tend to increase in incidence with age, such as heart

disease, diabetes and cancer. These conditions can also contribute to the person's decline and eventual death.

Towards the end of the disease, treatment focuses on relieving symptoms rather than curing the problem but this can be challenging for those caring for someone who is increasingly unable to report or describe their pain or discomfort.

As a long-term carer, you are likely to have spent years developing vital knowledge and caring strategies to help you meet the unique needs of the person you care for. Your awareness and sensitivity to the, often, subtle changes in your relative's behaviour, facial expression and body language that can indicate pain or distress make you ideally placed to help care home staff provide appropriate care.

Carers also carry knowledge about the person with dementia's past beliefs, wishes and preferences about specific types of medical treatments or interventions. More will be said on this issue in Section 10.

Section Ten

Preparing for the End of Life

Towards the later stages of the journey through dementia, carers and relatives may be faced with a number of difficult and emotionally-charged decisions. For example, in a medical crisis, questions about the use of resuscitation or various treatment options like artificial feeding or antibiotics can be very challenging for relatives and medical staff to resolve. This section looks at how you can plan ahead for some of these difficult decisions.

Dementia is an unpredictable illness – we can't talk about specific timescales but it will shorten life.

What do you want for the person? And what would they want for themselves?

Many people have very strong views and preferences about the ways in which they would want to be treated in the event of them suffering from a life-threatening illness. Your relative may in the past have expressed wishes and preferences about his or her future care and medical treatment which, because of the progression of the illness, he or she may be unable to communicate later on. A growing number of people are setting down these preferences in the form of advance statements (often called living wills) which state what types of treatment they would or would not want to receive if they were unable to give or refuse consent.

As long as your relative is capable of understanding what proposed medical treatment involves, his or her consent is necessary. It is important to remember that capacity to give informed consent must be assumed, unless there is evidence to suggest otherwise.

If a doctor believes that a treatment will benefit a patient with dementia who is incapable of consenting, the doctor should sign a certificate of incapacity which gives him or her authority to treat the person. Before doing so, the doctor should consult with the carer and anyone else closely involved with the person, to get their views on the person's ability to give consent. Where there is a legally appointed proxy or substitute decision maker, such as a

welfare attorney or a welfare guardian with medical decision making powers, the doctor must seek a decision from that person, where it is reasonable and practicable to do so.

The doctor's authority to treat can cover any procedure or treatment designed to safeguard or promote the person's physical or mental health. Treatment without consent can still be given in an emergency without the need for a certificate of incapacity, in order to preserve life or prevent serious deterioration.

The Adults with Incapacity (Scotland) Act 2000, however, says nothing about the withdrawal and withholding of treatment, although it would be considered good practice for the doctor to consult.

The Care Commission stipulates that, on admission to a care home, the family are asked what they want to do about funeral arrangements, resuscitation, etc. This can be distressing at a time when people are already feeling upset but it helps to be forewarned.

Information about the person's past and present wishes and views should be recorded in the personal profile where possible. Recording information about views and preferences about resuscitation and funeral arrangements may seem premature but it can save distress at a later date.

When your relative has died

After the person's death, you are likely to pass through various stages. Although death has to be expected, and you have already experienced a lot of grieving and loss throughout the course of your relative's illness, you may well feel shock when the time comes and may feel numb. Later, you may become preoccupied with thoughts of your relative and feel unable to accept what has happened to him/her. Many people say that they still expect the person to reappear.

At first you may feel relieved that the person is dead. You may then feel ashamed that you have felt this but

relief is a normal reaction. You may also feel angry or guilty or depressed, alone and exhausted. These are normal feelings under the circumstances and you need to give yourself time to get back on your feet.

Following your initial reaction and response to the death of your relative, your emotions may change. You may start to experience feelings of guilt, anger, isolation and depression and may feel unable to accept and come to terms with the person's death, even if at the beginning you seemed to be coping well on the surface. The intensity of these emotions can leave you emotionally drained. It is therefore important not to ignore them, but rather to acknowledge them and let them pass. In this way, you will be able to grieve their loss and carry on with your life, knowing that you did your best.

Looking after yourself

To survive the grieving process you need to look after yourself. Even when you are coping well, there may still be times when you feel upset and depressed, even for months or years afterwards. Talk about your feelings to an understanding professional, to other carers, to a trusted friend or to members of your family. Don't bottle your feelings up.

Try to persuade friends to drop in for a chat or to phone you regularly. You should avoid making any important decisions at this time when you are likely to be feeling shocked and vulnerable.

Accept that you will have good days and bad days, and the bad days may well outnumber the good days. Special dates such as anniversaries and birthdays can be particularly hard to cope with – try to arrange something positive to do on those dates.

Pay attention to your physical and mental condition. During the grieving process, people have a higher risk of becoming ill or depressed. It is therefore important that you look after your health and that you contact a doctor should you feel ill or depressed.

Keep in contact with family, friends and other carers. Speaking to people who know and understand you will help prevent you from churning over depressive thoughts and doubts. For example, you may start to ask yourself if you could have done more for the person and think about times when you might have shouted or got angry with the person. By talking with others who understand, you may be able to release some of the tension you are feeling which may have built up over the years and start to see things more in perspective, remembering the good times rather than blaming yourself.

Once some time has passed the memories of the impact of the disease will become less vivid and you may find that you are able to remember the person as he or she once was before the illness set in – even if this seems unlikely immediately following his or her death.

“When my mother died after ten years of Alzheimer’s disease, she was very different from her real self. In a way, I felt I started to lose her long before she actually passed on. But she still left a huge gap in my life. It’s now two years since her death, and I have managed to pick up the pieces of my own life again. Even though I will always miss her, the worst feelings are past now and I find I can remember her as she used to be before she got ill”

Staying in touch with the care home

Where you have played an active role in the care of your relative while he or she was in the care home, you may find it hard to adjust to no longer visiting the home. You may have developed relationships with members of staff and other residents. It may be possible for you to stay in touch through attending a carers' group where you can share your loss with other carers; or you may be able to participate by becoming a volunteer or helper or a fundraiser.

Section Eleven

Conclusion

'You never get used to it, it does not get any better but stay involved at what ever level you feel comfortable with - you have a unique contribution to make to the remaining life and eventual death of your loved one'

Carer

You have given all the direct care and support you've been able to over the years. Visiting and staying involved is part of continuing that care and support. If you have been providing care to someone with dementia for a number of years, you are the expert in that person's care and have a great deal still to contribute, especially in the early stages of the person's stay in the care home when staff need to get to know and understand the person.

Why is it so hard to let go?

Caring for someone with dementia has been likened to working a 36-hour day so it stands to reason that removing that workload will leave a huge gap in a carer's life. You will have to contend with a range of emotions resulting from the decision for the person to move to a care home, particularly if it takes the person some time to get used to his or her new surroundings. Because the caring relationship has changed, the person you love may start to become more of a stranger to you; as their condition worsens, you may feel that you now have to do all the giving, as they can no longer share their emotions and feelings with you in a meaningful way and it becomes difficult for them to focus on anyone apart from themselves. It is the very essence of the illness that robs you of the person they were but does not rob you of your memories nor of the desire to keep caring for the person.

How do you cope?

Each person copes in different ways and no-one should feel pressurised into acting or reacting in a particular way. You should do what feels comfortable and right for you. Some people want to visit every day; others find that they feel happy visiting less often, particularly as the person settles in. Talking through your feelings with family and friends may help, or you may prefer to talk to other carers who have shared similar experiences. It may help simply to remember what a special person he or she is and that he or she still needs your love and support in what may be their final journey.

Who is there to support you?

Ask family and friends for help, explaining how you are feeling; share your feelings if possible with the staff in the care home or with members of a local carers' support group; contact the Dementia Helpline on freephone 0808 808 3000; talk to health and social care professionals.

What services would be useful?

Some carers have spoken about the support which they received from social work and health care staff while the person with dementia was still at home, but this support vanished once the person entered a care home. While it may not be possible for these professionals to continue to offer the same level of support to someone no longer providing direct care, they may still be willing to offer support, perhaps over the phone, or may be able to put you in touch with other sources of support such as your local Alzheimer Scotland service. For example, in Dumfriesshire, Alzheimer Scotland has a Carer Liaison Officer whose role is to support bereaved carers or carers whose relative has moved to a care home. There are similar posts in other parts of the country.

There may be courses in your area aimed at former carers involving learning a new activity, social and cultural events, reviving old interests. Younger carers who have perhaps given up work to care for a parent may wish to return to the workplace but may need some support in order to be able to do so. You can find out what services are available in your area by contacting Carers Scotland or the Princess Royal Trust for Carers – see Section 12.

Getting back on your feet

Although you may feel very tired after someone dies or goes into long-term care, the time will come when you are ready to re-establish your own life and move forward. You may feel very unconfident at first and find it difficult to take decisions, make polite conversation or cope with social gatherings. But don't give up. Your confidence will gradually return. Take things slowly and try to ensure that you have plenty of support from family and friends, professionals and other former carers. Keep interests/hobbies/friendships going if you can. You can use these to help you adjust to when you are no longer providing day-to-day care.

Section Twelve

Further Reading and Sources of Information

Further Reading

Alzheimer Scotland.

A Positive Choice: choosing long-stay care for a person with dementia.

Edinburgh: Alzheimer Scotland, 2003.

ISBN 0 948897 39 2

For a copy, contact the 24-hour Dementia Helpline on Freephone 0808 808 3000. A single copy is free to people with dementia and carers in Scotland; others pay £2.00 per copy (post & packing free)

MacKinlay, M.

Working with Dementia: a handbook for care staff.

Edinburgh: Alzheimer Scotland, 2004.

ISBN 0 948897 42 2

Single copies are free to care staff. Contact the Dementia Helpline, as above.

Sources of Information and Support

Alzheimer Scotland

22 Drumsheugh Gardens,
Edinburgh EH3 7RN

office: 0131 242 1453

Website: www.alzscot.org

e-mail: alzheimers@alzscot.org

24 hour Dementia Helpline

0808 808 3000

Alzheimer Scotland is Scotland's leading dementia charity. We provide services and campaign actively to help people with dementia and their families and carers. We aim to be the national and local voice of and for people with dementia and their carers in Scotland; to improve public policies for the benefit of people with dementia and their carers; and to provide and to secure the provision of high quality services for people with dementia and their carers.

Care Commission

Headquarters,
Compass House,
11 Riverside Drive,
Dundee DD1 4NY
Tel: 01382 207100
or lo-call 0845 603 0890

Website: www.carecommission.com

The Care Commission regulates and inspects all care services in Scotland, including care homes, using the National Care Standards to ensure that service users receive the same standard of care wherever they live in Scotland.

Carers Scotland

91 Mitchell Street,
Glasgow G1 3LN
Tel: 0141 221 9141

Website: www.carerscotland.org

e-mail: info@carerscotland.org

Carers Scotland is the Scottish national office of Carers UK. It campaigns for a better understanding of the issues affecting and services needed for carers under three themes: equality, empowerment; and partnership.

Cruse Bereavement Care Scotland

Riverview House,
Friarton Road,
Perth PH2 8DF
Tel: 01738 444 178;
fax: 01738 444 807

E-mail: info@crusescotland.org.uk

Offers free information and advice to anyone who has been affected by a death; provides support and counselling one to one and in groups; offers education, support, information and publications to anyone supporting bereaved people.

Princess Royal Trust for Carers

Campbell House,
215 West Campbell Street,
Glasgow G2 4TT
Tel: 0141 221 5066

Website: www.carers.org

email: infoscotland@carers.org

The Princess Royal Trust for Carers was formed in 1991 at the initiative of Her Royal Highness The Princess Royal. The Trust provides training and support for 29 Carers Centres across Scotland, as well as raising funds for development work.

Relatives & Residents Association

24 The Ivories,
6-18 Northampton Street,
London N1 2HY
Tel: 020 7359 8136 (Advice Line)
fax: 020 7226 6603

Website: www.relres.org.uk

The Association aims: to offer support and information to families, friends and residents about issues affecting care homes or nursing homes; to further an active partnership between relatives and care homes; and to spread good practice in residential and nursing care and influence policy and standards. The advice line is best contacted between 9.30 and 4.30, Monday-Friday. Remember that there are differences between Scotland and England in legislation and regulations if you are seeking information about legal and financial aspects of care home provision.



www.alzscot.org

This booklet is aimed at those who have been caring for a family member, partner or friend who is now in the later stages of dementia and where a decision has been made to transfer the person to a care home setting. It particularly looks at:

- The emotional impact on the carer
- The impact of the move on the person with dementia
- The role of the carer in helping staff understand the person
- Practical ways to stay involved
- Making visits more enjoyable
- Preparing for the end of the person's life
- Coping with bereavement

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