



Alzheimer Scotland
Action on Dementia

A positive choice

- choosing **long-stay care** for a person with dementia





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To the best of our knowledge and belief, the information in this booklet is correct. However, it is not a definitive statement of the law. If you are in doubt, check with a solicitor.

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Contents

PART 1 - Making the decision	2
Introduction	2
Reasons for considering long-stay care	2
A difficult decision	3
Involving the person with dementia	4
What if the person does not want to move?	4
Getting help with your decision	5
PART 2 - How to arrange long-stay care	7
Introduction	7
Community care assessment	7
NHS care	8
Free personal and nursing care	9
Financial assessment	10
Problems with financial assessments	11
Income	11
Savings and property	11
Joint capital	12
The house	12
Financial responsibilities of the spouse or civil partner	14
Deprivation of assets	14
Extra expenses	15
Financial advice	15
PART 3 - Choosing a home	16
The right to choice	16
'Topping up' the fees	16
If you disagree	17
Information about homes	17
Standards and inspection	18
People under 65	18
Couples	18
What to look for	19
Choosing a home - checklist	20
The contract with the home	25
Checking the contract	25
Legal arrangements	26
PART 4 - Managing the move	27
Practicalities	27
The transition	27
Your own feelings	28
The feelings of the person with dementia	28
Settling in	29
Care plan	30
Staying involved	31
Difficult visits	31
At the end	32
What happen if the home is not satisfactory?	33
Further information	34
Acknowledgements	37

Part 1 - Making the decision

Introduction

If you care for a person with dementia, there may come a point when you have to think about long-stay care. Perhaps it will be because of a crisis. Or perhaps you are starting to plan ahead. Either way, it can be a difficult and painful decision.

However, choosing long stay care is not normally a decision you will have to make alone. The social work department will help, by providing a community care assessment. They will look at the needs of the person with dementia and his or her carer. They will help you, and the person with dementia where possible, to consider whether long stay care is the right choice or whether other arrangements for extra support could help the person stay at home for longer.

Long-stay care is care somewhere other than at home. This booklet is mainly about choosing a care home. Sometimes people with dementia with complex needs will go into long term NHS care, but this is not very common these days.

Page 2

Reasons for considering long-stay care

There are many possible reasons for considering long-stay care. The person you care for may want to go into long-stay care, perhaps because he or she is not coping, or for the company. Perhaps the person's condition has recently worsened and long-stay care now seems best. Maybe you feel that you are no longer able to improve the quality of the person's life. Perhaps he or she now needs more care than you can manage. Or perhaps the person has been in hospital, and when he or she is discharged you are now unable to take him or her back.

Ideally, you should think about the move to long stay care well in advance. That way, you have plenty of time to discuss it with the person with dementia and the rest of the family, and to choose the right home - and if a crisis does happen, you will already have thought through the options. But don't be hard on yourself if that's not the way it happens. Sometimes a move has to happen quickly, for example because of a change in the person's health - or the carer's health. And many people find it too difficult emotionally to think about long stay care, until they have to. Many people have found that it can take weeks, months or even years to face up to and make the decision.

“We'd never discussed it - we thought, it happens to other people, not to us.”

Wife

A difficult decision

“I know I wasn’t caring for her out of love any more - it was more because I felt it was my duty.”

Husband

Very often, carers and families find deciding on long-stay care one of the hardest decisions they have to make. They may feel guilty at no longer being able to go on providing care. Sometimes people feel that they are failing in their duty, or breaking a promise not to let the person go into a care home. Carers may feel grief and frustration at not managing to go on caring for as long as they wish they could. But for most people with dementia, there comes a time when they need more care than can be managed at home, even with support services.

“I couldn’t take any more, I was just exhausted myself.”

Wife

You, and your family if you have one, are important too. You must take into account your own health, both physical and mental. You can be a better support to someone if you have not yourself ‘gone under’ with the strain. Consider:

- Would you want someone else to go on caring for you even if it was seriously affecting their life?
- Would the person you care for have wanted you to keep caring past the point where you can manage?

“We knew in our hearts that she’d never have wanted us to sacrifice our own lives and careers for her.”

Daughter

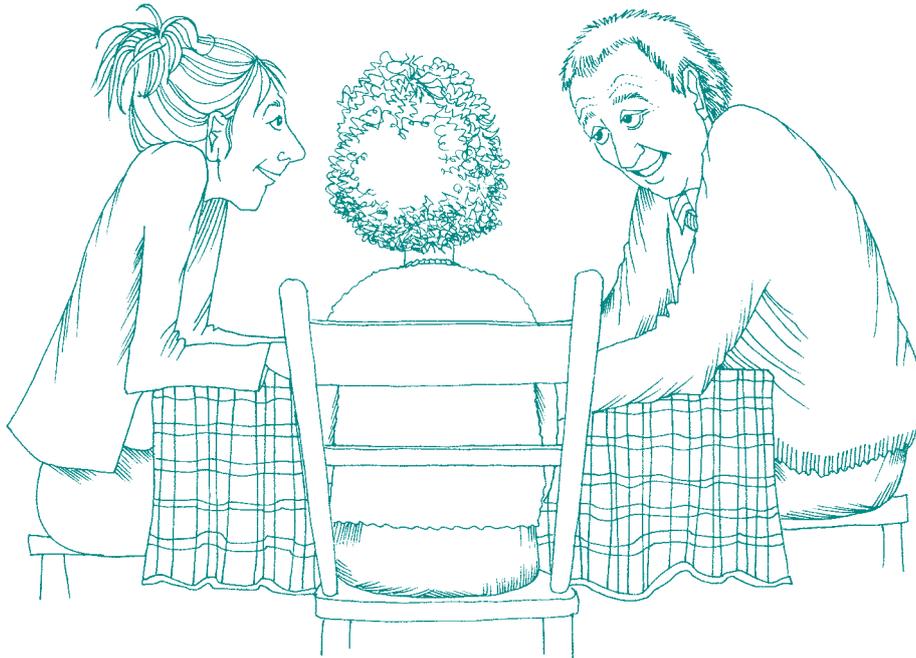
If you are worn down by trying to manage day-to-day caring, perhaps letting someone else take on the practical caring could mean that the time you spend with the person is more enjoyable for both of you.

In some cases the person with dementia actively wants to enter a care home, perhaps for the company or because he or she doesn’t want to be a burden on those they love. For some people this can make the decision easier, but it can be painful for others.

“I was really hurt when she decided to go into a home, after all the years looking after her.”

Daughter-in-law

Involving the person with dementia



Page 4

If you can, talk to the person with dementia about the options

If you can, talk to the person with dementia about the options. Try to involve him or her in the decision as much as is practical. It is important that any decision is either a joint one, where that is possible, or made with full consideration of the person's feelings. The person may already have told you his or her wishes. Take them into account if you can. But remember, the situation may have changed. Sometimes a promise not to let someone go into a home might have to be reconsidered, or broken, in the best interests of everyone involved.

Advocacy can help to make sure that the views and wishes of the person with dementia are heard and respected, and represented to others where the person is unable to do this by him or herself. Advocacy aims to promote maximum involvement in decision making. Sometimes a friend or family member may advocate for the person, or call the Dementia Helpline on 0808 808 3000 to find out about independent advocacy services in your area.

What if the person does not want to move?

“I told him I just could not cope any longer, and the home could look after him 24 hours a day”

Carer

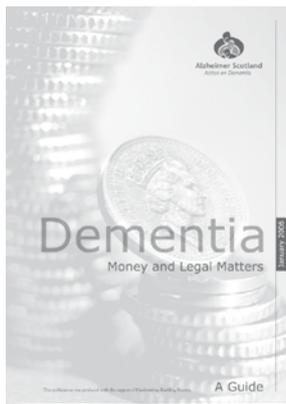
“I told her, ‘I’m frightened, anything could happen to you if I’m not here.’”

Carer

People with dementia may lack insight into their situation. Sometimes someone with dementia will not understand why he or she should move into a home. Try talking to the person about why you think he or she would be better to move. Focus on the positive aspects. Try taking him or her to visit the home you have in mind, or suggest a trial stay.

There may be other options. Perhaps he or she could stay at home for a little longer, with extra support? Ask the social work department if there is any more support available to help with keeping the person at home.

However, it may simply not be possible for the person to stay at home, perhaps for his or her safety or health, or perhaps for the safety or health of the carer or others.



If the person will not agree to move, someone else may have to make the decision on his or her behalf. This might be someone with a welfare power of attorney for the person - that is, someone that he or she appointed, when still well, to take such decisions. Or it may be necessary to ask the court to appoint someone to make the decision for him or her. This could be an 'intervener', who would be able to take just this one-off decision, or a 'guardian', who would stay involved long-term, and might have powers to take welfare and financial decisions. See the booklet *Dementia - Money and Legal Matters* (see **Further reading**) for more information.

Getting help with your decision

Don't feel that you have to make this decision by yourself. It is important to talk through your feelings about your decision with other people.



It is important to talk through your feelings about your decision with other people

Try to involve the rest of the family in the decision too. But if you disagree, don't let them pressure you into doing something you feel uncomfortable about.

Other people who can help are:

- family doctor (GP) or consultant
- community psychiatric nurse or mental health nurse
- social worker or care manager
- staff at any day centre or hospital that the person you care for attends
- priest, minister, rabbi, imam or other religious leader
- your local Alzheimer Scotland service, carers' centre or advocacy service
- other carers who have had to make a similar decision.

You can also ring the Dementia Helpline free on 0808 808 3000 at any time, day or night. They can give you information and support, send you a list of homes, put you in touch with local services or a carers' support group or just help you to think things through.



It can also help to speak to other carers who have had to make the same decision

It is quite natural to feel guilty about the decision. These feelings are nothing unusual. But remember, it is not a selfish decision. It may help to remind yourself that you are taking the best interests of the person you care for into account at every step along the way.

“There are four of us, and we all visited homes and made joint decisions. My sister said, ‘We have to share the guilt.’”

Daughter

Of course, the success will also be shared. You will probably also worry about how the person you care for will react. It will naturally be difficult for him or her at first. But experience shows that often the person with dementia adapts to the situation faster than the carer. You may well find that your relationship with the person improves in the long run. We will look at ways for making this adaptation easier for both of you later in the booklet.

Part 2 - How to arrange long-stay care

Introduction

Once you have decided to find out about long-stay care, you will want to start thinking about how to arrange it and how to pay for it. This section covers community care assessment, free personal and nursing care arrangements and financial assessment.

Community care assessment

Everyone who needs care is legally entitled to a community care assessment. The assessment will show what kind of care would best meet the person's needs. Carers also have the right to ask for an assessment of their own. This will look at how you are coping with caring for the person with dementia, and how able you are to go on caring. You may need extra resources to help you in your caring role, and the person with dementia may need other services. The assessment may result in more services, to help you go on caring at home, or it may show that a care home is now the best way forward.

It is a good idea to ask for a community care assessment if you are considering long-stay care, even if the person may not yet need help to pay the care home's fees. Although it is possible to choose and pay for a home privately, Alzheimer Scotland strongly advises people to involve the social work department and get an assessment to make sure that the person gets the right care. The Scottish Executive says that social work departments should advise people on the right care and on what is available, even if they will be paying privately.

An assessment is not just advisable but necessary for the person to be able to claim his or her free personal or nursing care allowance. It is also essential for people who may need help paying fees now or in the future. Most people with dementia will not be able to pay all of their care home fees, unless they have a substantial income. Fees are usually several hundred pounds a week. If the social work department does not agree to the person's placement, they may not top up the fees in the future, and the person may have to move. So it is better to have an assessment right at the start.

The social work department will arrange a community care assessment. There may be a waiting list so the person may not be assessed right away. However, the social work department has a legal duty to assess someone within a 'reasonable' time. What is reasonable will be different in each case. If you feel the person needs long-stay care urgently, perhaps because of a change in circumstances, make this clear to the social work department. It is best to do this in writing. If the waiting time does not seem reasonable, seek legal advice. You may be able to take legal action.



Everyone who needs care is entitled to a community care assessment from the social work department

A community care assessment simply involves talking to a social worker, care manager or another professional authorised to do assessments. He or she will ask about the needs of the person that you care for. He or she will also talk to others involved with the person's care, such as doctors, nurses or occupational therapists. It is a good idea before the assessment to write down any problems and any help that you think is needed. Have your notes with you to make sure you don't forget anything - but if you do, write to or phone the assessor to get it added in.

It is important to make sure that the views and wishes of the person with dementia are fully taken into account in the assessment. Often people with dementia need someone to advocate for them; this could be a member of the family or an independent advocate from an advocacy service (call the Dementia Helpline to find out about advocacy services).

If the person is assessed as needing long stay care, the local authority may make the arrangements, or you can do it yourself. The local authority must make the arrangements if there is no-one else who can do it. Guidance from the Scottish Executive says that the local authority should also be prepared to make the arrangements for someone who is taking up free personal or nursing care payments or who is making an arrangement to defer payment so that their home does not need to be sold. They can also make the arrangements in other circumstances if they choose to.

NHS care

Where someone is in hospital, he or she should only be discharged if the services the person needs have been assessed and arranged. Some people will be able to return to their own home, with whatever support services are necessary. Scottish Executive guidance says that the social work department should provide aftercare services to people with dementia leaving hospital. Up to one month's care in the person's own

home is free. Some people will be discharged to care homes paid for from their own resources, with means-tested help from the local authority as described below. Some people, who have particularly complex needs, will be assessed as needing NHS continuing health care. The decision is made by the person's consultant.

If the person is assessed as needing NHS continuing care, the care may be provided within the NHS, or they may place the person in a care home. In this case, the NHS will pay for the person's care.

If the person is to be discharged from hospital care and you feel he or she should not be discharged, you can ask for a review of this decision from the Director of Public Health of the local NHS Board. The hospital must tell you how to do this. You must ask for the review within 10 working days of when the person was told of the decision. The review should be completed within 14 days of you making the request.

If you are still not satisfied, you can request a second opinion from an independent consultant from another NHS Board area. You must ask for this within 10 days of receiving the result of the first review. The nominated consultant will review the clinical decision to discharge the person and will report his or her opinion within 25 days. This second opinion will be final, unless the person's care needs have changed significantly.

Free personal and nursing care

Free personal and nursing care arrangements in Scotland came into effect in July 2002 under the Community Care and Health (Scotland) Act 2002. The arrangements apply to anyone paying all or part of his or her own fees.

Personal care in care homes is free to people over 65, provided they are assessed as needing it. Nursing care is free for people of any age living in care homes, provided they are assessed as needing it.

The local authority will pay any contribution for personal or nursing care direct to the care home, not to the resident.

- People over 65 who pay all their own fees and need personal care will get £145 per week, plus if they need nursing care an extra £65, making a total of £210 per week. If they are under 65 and need nursing care they will get £65 per week.
- People who pay some of their own fees will get a top up from the council towards their fees of at least these amounts.

Everyone paying all or some of their own fees will continue to pay the rest of their fees, covering accommodation etc.

People who get the payment for free personal care cannot continue to be paid Attendance Allowance or the care component of Disability Living Allowance after the first four weeks of their stay in the home. People who get the payment for free nursing care but *not* free personal care can still get Disability Living Allowance if they are paying all their own fees. The mobility component of Disability Living Allowance is not affected.

If you are told by your local authority that they have a waiting list and they will not pay the free personal or nursing care payment from the date the person moves into the care home, seek advice about how to challenge that decision. Your local Citizens Advice Bureau may help (address in the phone book); you may also use the local authority's own complaints procedure.

Financial assessment

Local authorities are required, each year, to set maximum standard rates that they will pay towards care home fees. The local authority will carry out a financial assessment, or means test, to work out how much the local authority pays and how much the person with dementia pays towards these fees. The assessment is based only on the income and capital of the person going into the home, and his or her share in any joint resources. If you disagree with this assessment, you can make a complaint.

There is further detail on financial assessments in Age Concern Scotland's Factsheet 10s: *Local authority charging procedures for care homes*. Call the Dementia Helpline on 0808 808 3000 or Age Concern on 0800 00 99 66 for a free copy. If you call Age Concern, make sure you ask for the Scottish version.

The purpose of the financial assessment is to see how much income and capital (savings and property) the person has. Income and capital will either: count in full, be partially disregarded, or completely disregarded. Once the local authority have worked out which parts of the person's income and capital count, they will calculate the person's contribution. The person must always be left with a personal expenses allowance. From April 2006 this is £19.60 a week. People over 65 receiving the savings credit of Pension Credit, or who have qualifying income above certain levels, will keep up to an extra £5.05 on top of this. This is in order to make sure people benefit if they have saved for their old age.

In some cases, for example where the person has a dependent left at home, the local authority may agree to leave the person a larger allowance.

The financial assessment looks at the income and at the savings and property of the person with dementia. If the person has more than the 'upper limit' (currently £20,000) in savings and property (see page 14), he or she will have to pay all the home fees until the savings come down to this level. If the person has between the upper limit and the 'lower limit' (currently £12,250), he or she will get some help towards the fees from the local authority. Below this level the person will get the full shortfall between his or her income and the fees paid by the local authority.

If the financial circumstances of the person with dementia change, the amount that he or she pays towards the cost of care may also need to change. Most local authorities will do an annual review. If you feel the person's financial circumstances have changed, you can ask for a review of the financial assessment at any time. It is especially important to do this if the person's savings have reduced to the upper limit, where he or she would qualify for help with the fees for the first time (£20,000) or when the person is between the upper limit and the lower limit (£12,250), where the person's contribution should be reviewed every time there is a change of £250 in his or her capital.

Problems with financial assessments

In most places the system works fine, but in some areas, there can be difficulties. For example, in some local authorities there are long delays getting the bill, leaving people not knowing how much to pay toward the care home fees. If this happens, keep pushing the local authority. Ask the professionals involved, and the home, for advice on how much to pay or put aside in the meantime, so as not to get left with arrears that are hard to pay off.

If you think the person's financial assessment is wrong, speak to the social work department to see if you can get it changed. If that doesn't work, you can make a complaint to the social work department. They have a legal duty to have a complaints procedure and to tell you how to use it.

Income

People often become entitled to benefits when they move to a care home so it is a good idea to ask for a benefits check. This is especially true for someone with a spouse or partner. The local authority expects the person you care for to receive all the social security benefits he or she is entitled to, such as state retirement pension and Pension Credit. The booklet *Dementia - Money and Legal matters* (see **Further reading**) has more information on benefits.

They will also count private pensions, and certain other money received, as income. Some kinds of income are partly disregarded. For example, if the person going into long-stay care has an occupational pension, private pension or a retirement annuity contract, his or her spouse or civil partner (but not an unmarried partner) is entitled to keep half the amount. Where a partner who is not a spouse or a civil partner remains at home, the local authority can use their discretion to allow the person an increased personal expenses allowance so that he or she can support the partner remaining at home.

£10 a week of a War Widow's or War Disablement Pension and £20 of certain charitable and voluntary payments - but no more than £20 of the two together - are disregarded. Some income is disregarded entirely, including Disability Living Allowance mobility component, the Christmas bonus, War Widow's Special Payments and some charitable and voluntary payments.

If the person has savings or property valued between £12,250 and £20,000, the local authority will assume a standard amount of income from this, instead of the actual interest he or she gets.

Savings and property

The person's capital is his or her savings, plus the value of property such as buildings or land, premium bonds and stocks and shares. The local authority will not take into account the value of personal possessions, the surrender value of a life insurance policy or certain other items.

If the person you care for has more than the upper limit (£20,000) in capital he or she will be treated as self funding and will pay the full fees less any free personal or nursing care payments they are entitled to. Once the capital is reduced below £20,000, the person should be entitled to help with the fees from the local authority. Tell the local authority some months before the capital reaches £20,000 to give them time to calculate any contribution they should be making once the capital reaches that level.

If the person has between £12,250 and £20,000, the local authority will treat them as having an extra £1 a week income for every £250 or part of £250 between £12,250 and £20,000. Savings of below £12,250 are not counted at all. Ask for a review of the financial assessment each time the person's savings reduce to the next £250. He or she may be entitled to more financial support.

Joint capital

The person is counted as owning an equal part of any joint capital - see below for how a house is treated. Because it is always half the amount of a bank account that is counted, it may be sensible to divide it equally into two separate accounts. That way, if the savings of the person in the care home decrease faster than the other person's, he or she will get the full extra support.

The house



If the person owns a house, its value can only be counted by the council if the stay in the care home is seen as permanent. If it is, the value of the house is then disregarded for the first 12 weeks of the person's residence. You can ask the local authority to do this at any time up to 12 weeks after the person becomes a permanent resident. If the house is on the market, its value can also be disregarded for up to 26 weeks for Income Support or Pension Credit purposes.

If the person with dementia lived alone and owned his or her house before entering the care home, the value of the house will be counted as capital, less any mortgage and 10% of the value to cover the cost of selling it. If losing the house is a concern, the local authority can agree a 'deferred payment', where the council pays all or part of the person's share of the care home fees until the person dies, and then reclaims the money from his or her estate. This is a legal agreement, which includes a 'standard security' over the home (just as when a mortgage company lends money) to cover the deferred amount. It is interest free until 56 days after the person dies.

Someone is only eligible for deferred payment if he or she:

- has been assessed as needing care in a care home
- has capital at or below £12,250, not counting his or her home

- would not normally have his or her home disregarded (see next section)
- does not wish to sell the property or is unable to sell it quickly enough to pay the care fees
- can grant the local authority a standard security against his or her home.

It is likely that a person with dementia will lack the capacity to enter into such an agreement; however, someone with an appropriate power of attorney, or who has the relevant authority through a guardianship or intervention order, could enter the agreement on the person's behalf.

The council can't force the person to sell the house. But if it doesn't agree a deferred payment, it can put a 'charging order' on the house, which means whenever the house is sold, the council will get repaid. Seek legal advice if this happens.

When the value of the house is not counted

The value of the house *must* not be counted if someone is still living there who is:

- the spouse, civil partner or cohabiting partner of either sex of the person with dementia, or
- a relative who is aged 60 or over, or
- a relative who is disabled or incapacitated, or
- a relative who is under 16 and is a child whom the person in care is liable to maintain.

If someone else still lives there, the local authority has discretionary powers to ignore the value of the house if they think it is reasonable to do so. For example, this could apply to a carer or relative who does not come under one of the categories above. In practice, this varies between local authorities. Some are much more strict about taking the value of the person's home into account than others. The local authority will have a general policy. Ask to see it. However, they must treat each case on its merits. If they do not, court action may be possible. If you are living in the home of the person with dementia whom you have been caring for and you are not over 60, or incapacitated or his or her spouse or partner, get advice from the Citizens Advice Bureau, the Dementia Helpline or a solicitor.

If the person owns a part share in the house, this should be counted at the market value if sold on its own, not as a share of the value of the whole house. The only realistic market for a part share in a house is likely to be the other joint owner or owners. If they are unable or unwilling to buy the person's share then the market value could be nil. For example, if a person jointly owns a house with someone else then they are regarded as owning half the house. The assessment should be based on how much might be raised by putting half of a house on the market - it should not be based on the value of the house divided by two.

If the house needs to be sold

If the house needs to be sold (perhaps because it is lying empty) but the person is not mentally capable of agreeing, no-one has financial power of attorney and there is no financial guardian or intervener, then no one has the power to sell it. In this case, if no one else is applying, the local authority has a duty to apply to court for an intervention order or to get a financial guardian appointed. If they do not do this, seek legal advice.

Renting out the house

It may be possible to rent out the person's home and use the income toward the care home fees. Seek legal advice if you are considering this. If the person's home is subject to a deferred payment agreement, any income they receive from renting it out will count in full as income in the financial assessment.

Tenants

If the person was a tenant, the rights of someone else who lives in the house depend on how closely he or she is related to the person, how long he or she lived in the home and whether it is rented from a public or private landlord. You should get advice if you want to carry on living in the home and the landlord is not willing to let you do so.

Financial responsibilities of the spouse or civil partner

When doing the means test, the local authority can only assess the person with dementia. They cannot consider joint resources if that person is married or has a civil or cohabiting partner.

However, married couples and civil partners (but not cohabiting couples) have a legal duty to maintain each other. This is known as being a 'liable relative'. This means that where a local authority is contributing to a person's care home costs, they could ask the spouse or civil partner to pay all or part of the local authority's contribution. The Scottish Executive has announced that it intends to repeal the 'liable relatives' rule and has made provisions in the Adult Support and Protection Bill which is expected to become law late in 2007. In the meantime the Scottish Executive has asked local authorities to exercise discretion not to apply this rule. Until the rules change some local authorities may still ask to look at the finances of the spouse or civil partner.

If you do give the local authority information on your finances, they will then decide if it is reasonable to ask you to contribute towards the cost of your husband's, wife's or civil partner's care. They may ask you to agree an amount you can afford. There are no rules about how much this should be or how much they should leave a spouse or civil partner to live on. However, government guidance says that they should not necessarily expect a spouse or civil partner to live at income support level.

However, the local authority does not have a right to look at the spouse's or civil partner's finances. If you are the spouse or civil partner of someone going into long-stay care, you can refuse to give any details of your own finances. The local authority would then have to consider going to court to ask for an amount of maintenance to be set. If they do, you should seek legal advice.

Deprivation of assets

If the local authority believes that the person with dementia has given away his or her house, savings or other property, excluding personal possessions, so as not to pay so much for long-stay care, they may treat the person as still being in possession of the value of the capital; this is known as "notional capital". Even if avoiding fees was not the only reason, the local authority can still count the value. They can

decide to do this even if it was given away more than six months ago; there is no set time limit. Local authorities have different policies on how far back they look to see if someone has given away property or savings.

If the local authority decides that the person is in possession of notional capital, he or she may not have sufficient funds to pay the care home fees. If this is the case, local authorities have a legal responsibility to provide the care that they have assessed the person as needing.

In one House of Lords judgement, a Scottish local authority decided it did not have a duty to provide accommodation in a care home to a woman who, they decided, had intentionally deprived herself of capital by transferring ownership of her house to her sons, and was therefore in possession of notional capital of over the capital limit. The House of Lords decided that was wrong and that local authorities must provide the care they have assessed the person as requiring and that the provision of the services is not related to the person's ability to pay.

If the person gave the money or property away in the last six months before moving into a care home, the local authority can treat the person who received it as liable to pay towards the care home fees. They can recover the difference between what the care home resident can now pay and what he or she is assessed to pay counting the capital that was transferred, up to the total value of the transfer or gift. However, if the transfer took place more than six months before the person moved to the care home, the local authority has no power to treat the person who received the asset as liable to contribute to the fees. Seek advice if the local authority tells you otherwise.

The Department for Work and Pensions will also consider whether someone has deprived him or herself of assets in order to decide if they qualify for benefits.

Extra expenses

When you visit homes, check whether there are extra costs not included in the fee quoted to the local authority. These may include things like hairdressing. The person shouldn't be expected to pay for incontinence supplies or any other medical needs. These should be provided by the NHS to the home or through the person's GP. Chiropody is also available free from the NHS if the person needs it.

If extras are not included then the person with dementia may be expected to pay for them so it is worth checking this in advance.

Financial advice

There are a number of companies offering financial advice on planning for care home fees. They advise on, or sell, long stay care insurance and other financial products. If you decide to use a company to help you plan, make sure:

- you take expert independent financial advice
- you understand what the company is offering and what their fee is before signing up
- the company is properly registered with a regulatory body.

Part 3 - Choosing a home

The right to choice

When the social work department agrees that long-stay care is appropriate, they will then decide on the amount of money they are willing to pay for a place in a home. Each local authority has a maximum amount it normally pays, although in some cases where the person has special needs (for example, to be near relatives or cultural needs) you could ask for a higher amount, and if necessary use the complaints procedure to argue for it to be paid.

They should offer the person a place in a suitable home. However, there is often a waiting list for places in homes and it may be several months before they are able to offer a place. Or they may ask you to choose from a list of suitable homes, because you know the person and his or her preferences best. The social work department should help you and the person with dementia with the decision.

Whether or not you want to select a home yourself, it is a good idea for you, and if possible the person you care for, to visit a few homes. This will give you an idea of what facilities are available. If the local authority then suggests a home, you will have a better idea if you like it. You may then feel less worried afterwards about having made the right decision. See page 20 for what to look for when you visit a home.

Don't feel pressurised into accepting the first place offered by the local authority. You have the right to wait for another place or to suggest a home of your own choice. This can be anywhere in the UK. The council must arrange a place there, provided:

- it is suitable for the assessed needs of the person you care for
- a place is available
- the home is willing to deal with the local authority on the authority's terms and conditions
- it does not cost more than the authority would normally pay.

Involving an independent advocate, who will represent the wishes of the person with dementia without being emotionally involved, can be helpful in choosing a home.

'Topping up' the fees

If you choose a home that costs more than the local authority would usually pay, they must still arrange a place there if someone is willing and able to pay the difference. The local authority is responsible for ensuring that any arrangement to pay a top up fee is sustainable; the person paying the extra will need to show that he or she can keep up the payments for as long as the person is in the home. If he or she stops paying, the local authority may well not pay the extra and the person would have to move.

The person going into the home could pay the extra him or herself only if he or she is getting free personal or nursing care payments but not other help towards the fees, or if the council agrees to a deferred payment (see page 12).

If you disagree

You will probably reach an agreement with the social worker about the way ahead. If not, or if you are unhappy about any part of the assessment, you have the right to complain. Each local authority has a complaints procedure. Ring up the social work department for a copy of the procedure if you want to complain; it will tell you what steps to take.

Information about homes

All care homes in Scotland are registered with the Care Commission (see Further information). The Dementia Helpline can send you a list of care homes which cater for people with dementia in any area of the UK, or you can get a list from the local Care Commission office.

You are unlikely to get opinions about specific homes from any of the above sources. It can be helpful if you know someone who has a relative in care and knows about homes in your area. He or she may be able to advise you based on personal experience. Ask at your carers' support group. The Dementia Helpline can tell you how to contact groups in your area. But remember, these are only individual opinions.

Once you have a list of homes, make a shortlist and ask for brochures and information about vacancies. Make sure that you state the level and kind of care that the person you care for will need. Tell them that the person has dementia.

Try to visit as many homes as possible before making a decision, so that you can compare the facilities and care being offered. Some brochures may give a slightly misleading impression. So when you get there spend time looking around and talking to staff and residents. Don't be afraid to ask questions and keep your eyes and ears open. It will help if you have a checklist of things to look out for and to ask about. A trial stay can be helpful if this is possible.



Try to visit as many homes as possible before making a decision

Standards and inspection

All care homes are inspected by the Care Commission twice a year, including an unannounced visit. Ask to see the inspection reports for the homes you are interested in. You can get these from the homes themselves, the Care Commission, or in some areas they are available in public libraries. The Care Commission website will also have inspection reports for selected homes (see Further information).

All care homes have to meet the National Care Standards for care homes for older people. These have been produced by the government to allow people to see what standards people who live in care homes should be able to expect. The Care Commission take these standards into account when regulating services. You can get a copy of the National Care Standards for care homes for older people free from the Scottish Executive website (www.scotland.gov.uk/Topics/Health/care/17652/9328) or from Blackwell's Bookshop, 53 South Bridge, Edinburgh EH1 1YS (0131 622 8283). The Standards are also available through your public library.

People under 65

Because there are fewer people under 65 with dementia, it can be hard to find a suitable home. While some people will be happy in a home where most residents are a lot older, others may feel out of place, and activities may be unsuitable.

People arranging care for people with dementia under 65 often find that they are forced to compromise - perhaps the home isn't quite right but is near enough for friends and family to visit often. Or perhaps there is a suitable place but it's further away and harder to visit.

There is no easy solution to this, but it may be helpful, if possible, to organise trial stays before a permanent move, to see what works best. It may be possible to agree special arrangements with the social work department, such as someone to take the person out. If there is an activities co-ordinator at a home, he or she may be able to arrange activities suited to the individual; try to find out from the home how they plan an individual's care.

Couples

Sometimes couples will want to move into a care home together. In order to get help with paying the fees, each of the couple must be assessed as needing to be in the care home. If this is the case, the couple's income and capital would be assessed separately by the local authority as though they were two single people (even though they might be sharing a room). So if the couple has less than £20,000 each in capital, they could qualify for help with the fees. In contrast, in some cases the Department for Work and Pensions (DWP) assesses couples together and so they may qualify for less benefit. If this happens, seek advice, as most couples should be treated as two individuals by the DWP even if they share a room.

What to look for

Over the next few pages are some suggestions for your checklist. **Don't worry if you can't get answers to all of these questions.** They are only a guideline to give you an idea of what to look out for. Some of them may not be important to you.

You may like to photocopy the checklist to take to different homes. You can tick the boxes, give the home marks out of five for each item or tick items when you have found out the information you need. This will give you a way of comparing different homes.

Once you have found somewhere you think is suitable then it is a good idea to visit it again with the person you care for so that you can see how he or she reacts and how he or she might settle in. Perhaps you could also bring a supportive friend or relative for another opinion.



It's important to find a home that is as suitable as possible so that, hopefully, the person with dementia should not have to move again.

It's important to find a home that is as suitable as you can because, if possible, the person with dementia should not have to move again. A second move can be very difficult for everyone concerned. Sometimes a change in circumstances will mean there is no other option but, where possible, the person should be able to expect to stay in the home for the rest of his or her life.

Choosing a home - checklist

Location and setting

- Is the home convenient to visit?
- If the person enjoys going out, are there shops, a park or a pub nearby?
- If the person is religious, is there a suitable place of worship nearby?
- Is there a view from the lounge or dining room when residents are sitting? If so, can the residents see trees, plants and sky; or people, traffic and activities? Some people might prefer one type of view over another.
- Are there any trees close to the windows where residents can watch birds or even squirrels?
- Are there any windows open when you visit? Can you smell or feel fresh air in the public rooms?

Outdoor space

- Is there a safe attractive outdoor area? Ask if it is regularly used.
- Is the door kept locked or can residents easily go out for fresh air?
- Is the setting pleasant, with hanging baskets and a variety of colourful and scented plants? Is there a greenhouse or potting shed that residents can use to grow their own plants and seedlings?
- Is there level access (no steps) to an outside sitting area? Is there outdoor furniture such as tables, chairs and benches for residents to use. Is it sturdy, clean and well maintained?
- Is there any equipment for outdoor activities like bowls?

First impressions

- What size is the home? Many people feel that a smaller home is better for people with dementia. However some larger homes have smaller dementia units.
- Is the atmosphere friendly, welcoming and homely?
- What is the lighting like? Dim light can make it harder to see and too much glare from waxed floors or windows can add to confusion.
- Is the home clean without being too tidy and is it pleasantly furnished and decorated?
- Do you notice any unpleasant smells?

Access

- Are the corridors wide enough for a walking frame or wheelchair?
- Are baths and toilets suitably adapted?
- Is there a ramp or lift?

Bedrooms and personal possessions

- Can the person have a single room? This is important in retaining dignity and privacy.
- Can residents bring some of their own furniture and possessions? This can be very important in helping the person to settle in and feel at home.
- Is there room for an armchair in the room?
- Is there enough storage space?
- Can residents go to their room when they want to be alone and do staff respect the need for privacy and always knock on bedroom doors?

- Does the laundry system make sure that clothes don't get lost or returned to the wrong person? How does the home make sure no-one ends up wearing someone else's clothes?
- Are there ensuite facilities?
- Can the bed be placed so that the person can get out on his or her usual side?
- Is there natural light or will the light always have to be on?
- Is there a view?
- Is there noise or disturbance from other nearby rooms?

Money

- How does the home look after residents' personal money?
- Is cash kept in a secure place?
- Are clear accounts kept?
- How is residents' money spent?
- Are residents helped to buy small items? It can be important for people to have some money to hand to keep some sense of control.

Toilets and continence

- Are there enough toilets in easy reach of the bedroom and living area?
- Are they large enough for a member of staff to help a resident and keep the door closed at the same time?
- Do staff work out an individual toilet programme for each of the residents based on his or her needs or do they depend on batch toileting and the use of incontinence pads and catheters?
- Are staff tactful about incontinence? If you notice unpleasant smells or residents with skin sores, this can be an indication that something is wrong.

Living areas

- Is there more than one room where residents can sit?
- Is the television always on or are there quiet areas too? People with dementia can find constant background noise confusing.
- Is there a designated smoking room for residents?
- Are chairs arranged to encourage talking and activity or are they just placed around the room?
- Are there any live or artificial plants or flowers indoors? Do the live plants look healthy and watered?

Meals

- Does the home cater for special diets and do they take into account residents' likes and dislikes?
- Is there any choice at meal times?
- Can residents choose to eat at different times or in their rooms?
- Are there any catering facilities for the residents where they or their visitors can make a snack or a hot drink?
- Do residents enjoy their meals?

Health

- What happens if the person is unwell?
- Which doctor will the person see?
- What arrangements are made about medication?

- What arrangements are made about regular dental care?
- What arrangements are there for eye tests and hearing tests to ensure that spectacles and hearing aids are to the correct prescription?
- Do staff try to ensure residents use their spectacles and hearing aids?

Visitors

- Are visitors welcome at any time?
- Can they join the resident for a meal or make snacks?
- Are children welcome in the home?
- Are visitors able to take the resident out if they want to?
- Are there any regulations on the number of visitors?
- Can animals/pets come to visit residents? Does the home or unit allow residents to keep pets or are there any resident pets owned by the home?

Transfers

- What will happen if the person's condition worsens?
- Is the home able to cope with more severe levels of dementia or will the person have to move if he or she develops problems such as incontinence or challenging behaviour? Further moves may be unsettling for someone with dementia.

Residents

- What type of residents does the home take? The type of company around the person you care for can make a difference. If the other residents are much more advanced in dementia, then you may find that the person goes downhill quickly. Equally, if there are few other people with dementia the person may feel excluded or unwelcome. The mix of residents may also affect the amount of time and attention they get from the staff.
- Do the residents seem to be involved in activities and chatting or are they just sitting around doing nothing?
- Do they seem alert and interested?
- Are they nicely dressed and groomed?
- Do they seem content?
- Can some of the residents tell you what they think of the home and staff?
- Do residents seem panicky, in pain or vacant?

Activities

- Are activities arranged for each day or are residents just left in front of the television?
- Are there games and activities designed for people with dementia?
- Are outings and outdoor activities planned?
- Are birthdays and special events celebrated?
- Do people come in from the community to visit, to help with activities or entertain?
- Are residents encouraged to get involved with day-to-day life in the home, for example, with household chores or meal preparation?
- Are residents encouraged to do as much for themselves as they can?
- Does the level of activity appear to be too stimulating or too boring for your family member?
- Would he or she enjoy the activities offered?
- Is there familiar old music to listen to?

- Is there a record of residents' meetings?
- Is there a noticeboard for events? Try to see the programme of events for the last month too, to see how much variety there is.

Cultural

- If the person you care for comes from a different background or culture to most of the other residents, will his or her particular needs be catered for in an understanding and sensitive manner?
- Do staff seem interested in and respectful of differences such as diet, religious observance, hygiene practices, clothing and ways of relating to other people?

Staff

- How many staff are there compared to the number of residents?
- Are they full-time or part-time?
- How often does the home use agency staff? A lot of new faces can be difficult for residents, and agency staff will not get to know them. Sometimes agency staff may have less training.
- Is there much staff turnover? Ask a few individuals how long they have been there and how happy they are in their jobs.
- Do staff have experience of dementia?
- What opportunities do they get for training?
- Are staff qualified or are they untrained care assistants?
- How many staff are on duty during the day and at night?
- Do the staff seem friendly and caring?
- How do staff respond to residents? Do they treat them with dignity, humour and affection or do they talk down to them, bully or ignore them?
- Do staff treat residents as individuals and know about their backgrounds and interests?
- Do they seem to enjoy their work and are they warm and approachable?
- Are they willing to tell you what they think of the home?

Management

- Does the manager have a special knowledge of dementia?
- Does the manager own the home or is he or she appointed?
- If the manager is appointed, what input does the owner have in the day-to-day running of the home?
- Does the manager seem over-concerned with rules and regulations or does he or she treat the home as belonging to the residents?
- Does the manager seem tolerant and caring as well as efficient and capable and is he or she friendly and considerate to staff and residents?
- Does the manager openly answer your questions and does he or she understand your worries?
- Can he or she deal with special problems such as unpredictable behaviour in sympathetic way?
- Is he or she interested in the residents as individuals and does he or she try to meet their particular needs?
- Does the home have a carers' group or regular relatives' meeting with senior staff? This is a sign that the management is prepared to listen to suggestions or complaints.

Admission

- What kind of admissions procedure does a home carry out before admitting residents?
- Do they offer to compile a detailed list of the person's habits and preferences or will you have to insist on this yourself? (You may of course prefer to do it yourself).
- Will there be a member of staff who is particularly responsible for the person?
- Does each resident have a personal care plan? Each resident should have their care plan reviewed annually and it is good practice to review it 4-6 weeks after admission.
- How does the home welcome new residents and help them settle in?
- Do you think that you will be able to talk to staff about your own feelings and anxieties?
- Does the home offer day care or temporary stays so that the person can get used to the home before moving in?
- Is there a waiting list?
- Is there a review of the placement after the first few weeks so that everyone can discuss how the person with dementia has settled in, what has been achieved and what problems have arisen?
- Does the home actively encourage you to be involved?

The contract with the home

There are three kinds of contract that may be made with the care home:

1. For people not eligible for or not claiming free personal or nursing care - a 'Route 1' contract arranged privately and independently between the care home and the resident.
2. For people getting free personal or nursing care payments - a 'Route 2' contract, where both the council and the resident have their separate contracts with the home. The local authority pays the care home directly for the free personal or nursing care while the resident pays directly for the rest, covering the accommodation and living costs. This route may be chosen because the resident (or his or her representative) wants to negotiate and pay for a place in a particular care home or wants to specify a particular type of care without involving the local authority in their private agreement.
3. Alternatively, for people getting free personal or nursing care payments - a 'Route 3' contract, where the council manages the contractual arrangements with the home on behalf of the resident. The council also contracts with the resident to reclaim the part of the fees the resident is due to pay. It is also possible, if all three parties agree, for the person to pay the home directly.

Checking the contract

If you are setting up a Route 1 or Route 2 contract it is important to read it through and check the terms and conditions before you sign it. You may wish to take legal advice first. If you are arranging a care home place on behalf of someone with dementia, you need to have the appropriate legal authority to be able to sign on his or her behalf (see Legal arrangements section below).

Care and services

The contract should include information about the care and services the person with dementia will receive, including arrangements for meals, drinks and laundry services. It should also state how the home will meet any special requirements such as dietary and spiritual needs. Does it say how any changes to the person's care needs will be managed? Can the home make any significant changes to the service it provides without consultation?

Fees and payments

You should make sure that the contract is clear about the fees that have to be paid, how they are calculated, how often they should be paid and who is responsible for paying them. Are there any 'extras' to be paid for? As fees are likely to rise over time, how much notice will you get of an increase? What happens if the person has to go into hospital or dies - how long would fees be payable? How much notice does the home require if a resident moves out?

Accommodation

The contract should also give information about the room the person will occupy - can the care home move the person to a different room without consulting you, for example?

Insurance and liability

The contract should state how residents' money, valuables or other property will be kept safely and also who is responsible for insuring any property, particularly if the resident has brought any possessions from home such as furniture or a TV. You should check to see what the contract says about liability insurance and whether the home excludes itself from responsibility for damage to a resident's property or injury to any resident.

Even if the council arranges the contract with the care home, you should still ask to see it to make sure it includes any special requirements set out in the care plan produced as a result of the person's community care assessment. You should also check if there are any extra charges which would not be covered by the contract such as the cost of hairdressing or outings.

Legal arrangements

Very often when someone with dementia is going into a care home, he or she is no longer fully mentally capable of making decisions, providing financial information or signing contracts. If someone has power of attorney for the person, he or she is legally entitled to act on the person's behalf. There are two kinds of power of attorney in Scotland:

- **continuing (also called financial) power of attorney**, which gives the power to manage the person's financial affairs, such as entering into contracts and paying bills
- **welfare power of attorney**, which gives the power to take welfare decisions, such as where the person should live, on his or her behalf.

Some care homes ask relatives to sign contracts, which include a clause establishing liability, as a guarantor, for the relative to pay fees in the event the person in care is unable to do so. Seek advice before signing any agreement of this kind. In some cases, relatives are asked to sign contracts even though they don't have the legal authority to do so. If no-one has a power of attorney with the right powers, it may be necessary to apply to the court to give someone the power to take the decision on where the person should live or to sign the contract if he or she can't. This might be an 'intervener', with just these powers, or a 'guardian', who could look after the person's affairs long-term. You could do this yourself, or the local authority could do it - and they must do it if a guardianship or intervention is needed and no-one else is applying. See *Dementia - money & legal matters - a guide* for more information - you can get a copy from the Dementia Helpline, or see www.alzscot.org.

The person with dementia must always be consulted as fully as possible about what he or she wants, and his or her past wishes must also be taken into account.

Where a person has no-one else to look after his or her money, most care homes can now manage finances for their residents, usually up to £10,000. There are careful safeguards, and homes are supervised by the Care Commission (see Further information).

Part 4 - Managing the move

Practicalities

Among the practical issues you will need to arrange are:

- packing
- moving furniture if the person is taking it
- putting name labels on clothes
- compiling information to help care staff - for example, photographs and notes of who's who in the family and information on the person's needs, likes and dislikes, such as food preferences, dressing habits and daily routine
- arranging extra security if the house is left empty, and organising insurance (most home insurance is invalid if a house is not occupied, so talk to the insurance company about special arrangements).



Compile information to help care staff

The transition

Unless it is an emergency admission, it is a good idea to visit the home you have chosen before the move. For example, visit for tea a few times if you can.

On the day of the move, try to make sure that when you leave, the person is occupied in something positive, such as a meal.

“We took her favourite music with us and made sure it was on when she arrived”

Daughter

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

Your own feelings

“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

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 harrowing. Many carers feel that they have lost their role in the person's life, as though they have been deprived of caring. They may feel that the person's move leaves a huge gap in their own life.

“We've been married 54 years - even ten months later, I still feel as though he's in the house if I hear a noise.”

Wife

The person's children may feel loss too in seeing their childhood home sold. Many carers feel guilt - perhaps because they feel they ought to still be caring, or as though they have betrayed the person.

You may continue to wonder if you have done the right thing. Deciding that someone should move into long-term care can be a very difficult decision. You have made a choice based on balancing what is best for everyone involved. Don't keep your feelings to yourself. Talk to friends or relatives, speak to other carers in a support group, speak to staff at your local Alzheimer Scotland service or call the Dementia Helpline at any time to talk confidentially.

There are positive effects too. Your life will no longer be centred around the practical tasks of caring or organising help. You may feel less stress. You may feel that you have the freedom to do things for yourself, or go out when you want. You may be more able to sleep. You may find the lessening of your responsibilities a relief - especially if you or the person with dementia is ill, even with a minor ailment. When most of the practical caring tasks are being looked after by the staff, you may find that your time with the person can be more relaxed and enjoyable, especially as time goes on.

The feelings of the person with dementia

Even if the person can't express feelings and wishes verbally, he or she may still be upset at leaving home. Try to understand and accept his or her feelings. Give the

person a chance to say goodbye to his or her old home if you can. 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 and other professionals who know the person. They may have ideas on how to help both you and the person get used to the change. Sometimes the home may be familiar to the person from respite breaks, which can help him or her to feel more settled.

Once in the home, the person may take some time to adjust. Don't be surprised if he or she seems very down for the first few weeks. But some people settle in quite quickly.

“The home’s very good, very caring and homely. He’s a Gaelic speaker and in this area everyone knows everyone else. Though he doesn’t realise where he is, he says, ‘this is a good place,’ every time I go up.”

Wife

At first, you may find visiting difficult. It does become easier after a while, so try to persist. In fact, many people find that their relationship with the person that they have cared for improves after he or she goes into a home. With the pressure off, you may be able to bring back the outward signs of loving and affection which may have been covered up by the stress of day-to-day caring.

Ask staff how the person seems when you're 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.

Settling in

There are some ways of making it easier for the person to settle in.

“We took transitional objects to try to help 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

Try to involve the person in the move if you can and it isn't too distressing for him or her. Help him or her to choose familiar things to take along. These might be small items such as photographs or ornaments, or larger things such as favourite pieces of furniture.



Help the person to choose familiar things to take along

Be prepared, however, for the person to feel very unsettled. Often someone with dementia asks to go home. Sometimes he or she will make this wish clear to family and staff alike, and sometimes it may only be the family who hear it, because the person doesn't want to confide in strangers or seem impolite to them. It is a good idea to discuss with other family members how you will respond if the person asks to go home. It can help you be consistent, and to feel a bit more prepared for what one carer called 'an emotional body blow'.

“If she asks to go home, we’ve all agreed to remind her of the decision that was made, that we’re worried about her safety, and that she has friends of her own age there. But in self-protection, often we side-step the question, ending visits by saying, ‘We’re just going to visit so-and-so,’ so that she won’t ask.”

Daughter

Care plan

The home should draw up a care plan. This plan will cater specifically for the needs of the individual person. The care plan also gives you the chance to say how much you want to be involved in the person's care. If the local authority is involved it is a good idea to involve the person's social worker in the preparation of this plan and in monitoring it to ensure that it is being properly followed. The plan should also be reviewed from time to time, as the needs of the person are constantly changing as his or her condition changes.

You can help the home by providing them with as much information as you can about the person you care for, including a potted history of their life and information about any habits or preferences which they might not otherwise know about. With this information the home is much better equipped to treat the person with dementia as an individual.

Staying involved

Many people find that once the person they care for goes into long-stay care, the quality of the relationship improves. There are many opportunities to stay involved with caring for the person, yet you no longer have to look after every little task.

“I visited any time, I could go in and give him his lunch and tea.”

Wife

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 what's right for you
- keeping the person informed about family news
- helping him or her reminisce, perhaps with photographs or a 'life history book' of reminders of important events in his or her life
- outings - to shops, to tea or to visit friends, for example
- helping in the home with some of the person's day-to-day care or at mealtimes
- choosing new clothes and personal items.

“I try to arrange that he goes in to hear the church service - he still loves the singing.”

Wife

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

“It's a while ago but I still go to the Alzheimer Scotland meetings and I still visit the home where he died once a week, as a volunteer - they looked after my husband and I want to do something for them. You can blether about anything and I enjoy it! I think it's good for me too.”

Wife

Another Alzheimer Scotland booklet, *Letting go without giving up: continuing to care for the person with dementia*, considers the impact of the move to a care home on both the person with dementia and his or her carer. It suggests ways that carers can establish new caring roles for themselves through visiting and working as partners with care home staff. For a copy, contact the Dementia Helpline on 0808 808 3000 or visit www.alzscot.org.

Difficult visits

Many people find visits difficult when the person with dementia is no longer able to join in conversation. Some ideas for making your visit enjoyable for both of you are:

- try looking at old photographs and mementos together, to remind the person of his or her life - he or she may have a life story book which you can use for this (but this may not always go on being suitable)
- hand massages can be relaxing and comforting
- the person may appreciate physical contact such as cuddles
- try putting on some familiar music to share together
- try keeping your visits short - 10 minutes may be enough for both you and the person with dementia.



The person may appreciate physical contact such as cuddles

Sometimes, visits can be very difficult to cope with emotionally - if the person with dementia is weeping or angry, for example. If this happens:

- talk to the staff and find out how the person is at other times
- try varying your visit times - for example, perhaps the person may feel better in the mornings when he or she is not as tired
- visit just before a meal so that the person has something to go on to.

Sometimes staying involved can be difficult - for example if the person is always distressed when you see him or her. One carer said it felt harder than coping with a bereavement. Don't blame yourself if you find this hard - it's a normal reaction. Seek support, from other carers through a support group, the Dementia Helpline, your local Alzheimer Scotland service or friends.

At the end

At the end of his or her life, the person should be kept comfortable and not in pain. If the person had any beliefs or preferences about dying, talk to the home to make sure they are aware of this. The person may even have put in writing the types of treatment he or she would or wouldn't want to receive. This is called an advance directive (or sometimes a living will).

Seek support for yourself - from friends, family, support organisations such as Cruse (See Further information), your minister, priest, rabbi, imam or other religious leader or teacher and the Dementia Helpline.

What happens if the home is not satisfactory?

The first thing to do is to speak to the management of the home itself. It may just be a case of adjusting the person's care plan or something equally simple. Don't feel afraid to express your views. After all, the home is being paid to look after the person, who is entitled to receive the best care possible. Every registered home must have a complaints procedure which you can follow if the problem is not sorted out.

If you are still not satisfied, you can complain to the Care Commission. A leaflet called 'How to use the Care Commission Complaints Procedure' is available from the Care Commission to advise you how to make a complaint. Ring the Dementia Helpline to talk over the problem and for information on how to complain.

Normally, you should use the care home's complaints procedure first, and if you are not satisfied with the outcome, complain to the Care Commission. However, if you feel particularly vulnerable you can complain directly to the Commission, anonymously if you wish, without having to use the home's procedure.

If the local authority organised the placement, you can also speak to the social work department. They have a complaints procedure which you can follow. The social work department may be better able to discuss the problem direct with the home. If the problem is due to the condition of the person with dementia changing then you can arrange for a new community care assessment to see if the person's needs have changed.

Some people are anxious that if they complain, the person with dementia may suffer. If this worries you, call the Dementia Helpline or someone you trust to talk things over before you decide what to do. Maybe you would prefer to complain to the Care Commission rather than the home itself.

Finally, it is important to remember that no home is going to be perfect. But if you satisfy all your worries before the person enters the home then you will be able to relax and concentrate on enjoying your relationship.

Further information

Alzheimer Scotland

22 Drumsheugh Gardens, Edinburgh EH3 7RN; office: 0131 243 1453

Website: www.alzscot.org; email: alzheimer@alzscot.org

24 hour Dementia Helpline 0808 808 3000

Provides specialist information and support for people with dementia and their carers in Scotland and works on their behalf to improve public policies and services. There are local support groups throughout the country. The charity also runs the 24 hour Dementia Helpline and provides services around Scotland offering day and evening care, home care and other services including information and assistance with claiming benefits and local authority financial assessments. Publications list available. Information pack available free to carers, from the Dementia Helpline. Calls to the Dementia Helpline are free (except calls from certain mobile phone networks). Useful publications include:

Dementia - money and legal matters: a guide for carers, £5.00 (single copies free to carers and people with dementia in Scotland).

Letting go without giving up: continuing to care for the person with dementia, £2.00 (single copies free to carers and people with dementia in Scotland).

Alzheimer's Society

Gordon House, 10 Greencoat Place, London SW1P 1PH; office: 020 7306 0606.

Helpline: **0845 300 0336** 8.30 - 6.30, calls charged at local rate.

Website: www.alzheimers.org.uk; email: info@alzheimers.org.uk

Provides information and support for people with dementia and their carers in England, Wales and Northern Ireland. Publications list available.

Age Concern Scotland

Causewayside House, 160 Causewayside, Edinburgh EH9 1PR

Office: **0845 833 0200**.

Website: www.ageconcernscotland.org.uk; email: enquiries@acscot.org.uk

Age Concern Scotland aims to improve services for all older people and campaigns on their behalf, and supports local groups which run practical services including day centres, visiting schemes and information. They also manage the Scottish Helpline for Older People (SHOP) **0845 125 9732** (10-4 Mon-Fri)

Factsheets available online or from the SHOP information line include:

Factsheet 10s - *Local authority charging procedures for care homes*

Factsheet 29 - *Finding care home accommodation*

Factsheet 38s - *Treatment of the former home as capital for people in care homes*

Factsheet 39 - *Paying for care in a care home if you have a partner*

Factsheet 40 - *Transfer of assets and paying for care in a care home*

Care Commission

Compass House, Discovery Quay, 11 Riverside Drive, Dundee DD1 4NY

01382 207100 or lo-call 0845 60 30 890

Website: www.carecommission.com;

Email: Communications.Team@carecommission.com

The Care Commission regulates care services and oversees standards of care. It registers all care homes. Contact headquarters for details of your local Care Commission office, which can supply lists of care homes and copies of inspection reports.

Citizens Advice Bureau

Address in your local phone book, or from Citizen's Advice Scotland, 0131 550 1000, or locate your nearest bureau on the CAS website **www.cas.org.uk**

CABx can advise you on welfare benefits and help with application forms. They can also help you find specialist help such as a solicitor.

Cruse Bereavement Care Scotland

Riverview House, Friarton Road, Perth PH2 8DF

Tel: 01738 444 178

Email: **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.

Department for Work and Pensions

Your local office will be listed in the phone book. Look for the display advertisement in the business numbers section.

Benefit Enquiry Line for People with Disabilities: 0800 88 22 00 or, for textphone users only, 0800 24 33 55. Calls are free except from certain mobile phone networks. Disability Living Allowance Helpline: 0845 712 3456 - advice on existing claims. Pension Credit Claim Line: 0800 99 1234 - to find out if you are eligible and to make a claim. Website: **www.dwp.gov.uk/lifeevent/benefits/index.htm**

Legal Services Agency

Operates two Mental Health Legal Representation Projects, one in Glasgow and one in Edinburgh. Their qualified solicitors give confidential advice on all aspects of the law relating to mental illness, brain injury and dementia. Initial advice is free. This service is open to all residents of Argyll & Bute, East Ayrshire, East Dunbartonshire, East Renfrewshire, City of Glasgow, Inverclyde, North Ayrshire, North Lanarkshire, Renfrewshire, South Ayrshire, South Lanarkshire, West Dunbartonshire, East Lothian, City of Edinburgh, Midlothian and West Lothian Councils.

3rd Floor Fleming House, 134 Renfrew Street, Glasgow G3 6ST; 0141 353 3354

Tuesday mornings 11.00 am to 1.00 pm or phone for an appointment.

and

3rd Floor Princes House, 5 Shandwick Place, Edinburgh EH2 4RG; 0131 228 9993

Website: **www.lsa.org.uk**

Public Guardian

Hadrian House, Callendar Business Park, Callendar Road, Falkirk FK1 1XR; 01324 678300; Fax: 01324 678301.

Website: **www.publicguardian-scotland.gov.uk**; email **opg@scotcourts.gov.uk**

The Public Guardian registers continuing and welfare powers of attorney, authorisations to access funds, guardianship orders and intervention orders pronounced in terms of the Adults with Incapacity Act. He or she supervises guardians and people granted an intervention order and will investigate any

complaints regarding the exercise of functions relating to the property or financial affairs of an adult relating to any of these, or any circumstances in which the property or financial affairs of an adult appear to be at risk.

Scottish Executive

For community care guidance.

Health Department, Community Care Division, St Andrew's House, Regent Road, Edinburgh EH1 3DG

www.show.scot.nhs.uk/sehd/ccd.asp

Scottish Independent Advocacy Alliance

Melrose House, 69a George Street, Edinburgh EH2 2JG

Telephone: 0131 260 5380

Website: **www.siaa.org.uk**; Email: **enquiry@siaa.org.uk**

An alliance of independent advocacy organisations - can advise on finding a local advocacy group.

Seniorline

0808 800 6565, 9am - 4pm Monday - Friday - calls are free except from certain mobile phone networks.

Welfare rights advice and information line run by Help the Aged.

Social Work Department

This is the part of your local authority, or council, which deals with community care services, assessing the need for guardianship and other legal provisions. In some councils, it may be called something else, such as the Community Services Department. The address is in your phone book under the local authority. For England and Wales the local authority Social Services Department is the equivalent body.

Solicitors

Many solicitors offer a free first interview service. A charge will be made for any further advice or work. Legal Aid may be available depending on the circumstances. The Dementia Helpline (**0808 808 3000**) can send you a list of solicitors in your area who have an interest in mental health matters.

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www.alzscot.org

This booklet is for carers and relatives of people with dementia. Thinking about long-stay care can be difficult and sometimes painful. This booklet is based on the experiences of carers. It will give you and the person with dementia practical information about long-stay care. It will also help you deal with the emotional aspects of choosing long-stay care. Some questions the booklet looks at include:

- How do I find out if moving into a care home is the right thing for the person I care for?
- Who can I talk to about my feelings?
- What should I look for when choosing a care home?
- What help can the person with dementia get with care home fees?
- How can I stay involved?

April 2007

£3 (post & packing free)

Single copies free to people with dementia and carers in Scotland

ISBN 978 0 948897 49 8

This information is available in large print on our website www.alzscot.org or from the Dementia Helpline.