

Dementia in Detail

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Dementia in Detail

There may come a time when it is not possible to go on caring at home, however in making a decision, it is important to involve the person with dementia as much as you can and involve other people, to share responsibility for the decision.

Eventually, you may not be able to go on looking after the person with dementia at home. Perhaps they have become so ill they need a team of people to care for them. Or perhaps your own health has changed. Not everyone can be a carer and not everyone can go on caring as long as they wish they could. It is important to understand and accept what you can and can't do. Most people with dementia are likely to need to move into long-stay care in the later stages of their illness.

Try not to take this difficult decision on your own. Involve the person as much as you can, and take into account any wishes she may have expressed in the past. But remember that things change, and sometimes it may be in the person's best interest to move into a care home, even if that isn't what she would have hoped for. Involve other family members too if you can. But if they disagree, remember that as the carer, you know the person and the situation best. Professionals such as the social worker, doctor, nurse or staff at services the person uses can help you. It may help to also talk to other carers who have had to make a decision about long-stay care.

Arranging Long-Stay Care

Get a community care assessment to see what sort of care the person needs, and get a carer's assessment for yourself, also.

The best way to arrange long-stay care is to ask the social work department for a community care assessment. An assessment will make sure the person gets the right kind of care to meet their needs. A community care assessment is essential for the person to be able to get the free personal or nursing care allowance towards the care home fees. It is important to have an assessment if the person needs help paying the fees now, or might need help in the future.

You have a right to a carer's assessment for yourself, too. This will look at how you are coping, and how able you are to go on caring. To do the assessments, a social worker, care manager or another professional will talk to you and to others involved in the person's care. The assessment may show that moving into a care home is the best option for the person. Or sometimes it may be that there are other services which could help you cope at home for longer, if you want to.

If the person is assessed as needing long-stay care, the local authority can arrange it, or you can choose to arrange it yourself.

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Choosing a Home

The Care Inspectorate registers and inspects care homes and can give you information about them. You should visit several care homes before you make a choice.

You can choose a home in another part of the UK and a more expensive home than the local authority will pay for, if someone can top up the fees.

An independent advocate may be helpful.

Most people with dementia who need long-stay care will move into a care home. Care homes may be run by private companies, the social work department or voluntary organisations. Care homes provide different levels of care – for example, some provide nursing care and others residential care. All care homes have to meet National Care Standards.

All care homes in Scotland are registered and inspected by the Care Inspectorate who can give you a list of homes in any area. Copies of inspection reports for care homes you are considering are available from their website: www.careinspectorate.co.uk.

The local authority has a maximum amount they will normally pay for care home fees. They should offer the person a place in a home that is suitable and may provide a list of homes for you to choose from. You can also choose a different home, anywhere in the UK, as long as it is suitable for the person's needs and doesn't cost more than the local authority normally pays. Or, if it costs more, you or someone else can agree to pay the extra, bearing in mind that, if you stop paying for any reason, the person may have to move.

It may be helpful to involve an independent advocate when you are making these decisions. The advocate can represent the wishes of the person with dementia without being emotionally involved.

Call the Dementia Helpline or the Scottish Independent Advocacy Alliance to find out more.

A few people with dementia who have very complex needs may need NHS continuing care. This decision is up to the person's NHS consultant.

Paying the Home Fees

- **People over 65 paying all or part of their own fees can get free personal care.**
- **People of any age paying all or part of their own fees can get free nursing care.**
- **The value of the person's house will be counted in some circumstances but not in others.**

As long as the person has been assessed by the Social Work Department (SWD) as needing personal or nursing care then this portion of the fees will be met by the Local Authority.

The local authority pays the allowance for free personal care or free nursing care, or both, direct to the care home.

The person then pays the rest of the fees, which are for food, accommodation and so on.

The amount for personal care is £163 per week, and for nursing care it is £237 per week.

Other Help Towards the Fees

Care home fees can be hundreds of pounds a week. Many people will need some help with paying.

The SWD will give the person a financial assessment and will look at the person's income and capital.

The person's income will be used to pay the care home fees.

The person should always be left with a weekly personal allowance (at least £21.15 from April 2012, plus up to £6.45 more for some people over 65 receiving Pension Credit, depending on savings and income).

If the person's income is not enough to pay the full fees, the local authority may help to pay the amount over the income.

If the person has savings or property worth more than the 'upper limit' (£23,250 from April 2012), the person will have to pay the home fees until the amount reduces to this level.

If the person has an amount between the upper limit and the 'lower limit' (£14,250 from April 2012), then the person will have to pay part of the fees and the local authority will pay part.

If the person has less than the lower limit, the SWD will pay up to their maximum amount only.

The House

If the person owns a property the SWD will normally count it as part of the person's capital if moving into a care home permanently. The SWD can count the property value, less any mortgage and less 10% of the property value to cover selling costs. But they must ignore the value of the house for the first 12 weeks of the person's stay in the care home.

However, the SWD must ignore the value of the property completely if one of these people still lives there such as the person's husband or wife, or opposite sex partner, a relative who is over 60 or a relative who is disabled or incapacitated.

The SWD can also decide to ignore the value of the property if someone else still lives there, such as a carer or a same-sex partner. Seek advice from the Dementia Helpline or a solicitor if you live with the person with dementia and the SWD say they will take the property into account.

The Move and After

Plan the move. Personalise the person's room with familiar things. Talk to the care home about how the person is settling in, and about the care plan. Give it time – both you and the person with dementia will need time to adjust.

If you're not happy about the person's care, talk to the care home first, and make a complaint if you are still not satisfied.

Spending time planning before the person moves can help to make it easier for both of you. You will have to cope with practical issues as well as with your emotions.

Most people find that the person settles in with time, and visiting gets more enjoyable. Your relationship may even improve now that you don't have to deal with day-to-day caring.

The care home will put together a care plan for the person with dementia. You can give them important information about the person's needs and likes and dislikes. If the person has a "life story book" make sure the person takes it to the care home, so that staff can learn about the person's life. You can also say if you would like to be involved with ongoing care; but don't feel that you 'ought' to do anything more than what you would like to do.

The booklets "Letting go without giving up" and "Continuing to care for the person with dementia" are available from the Dementia Helpline and are for carers who want to continue to be involved in the life of the person they have cared for. It looks at the impact of the move on the carer and on the person, and practical ways of staying involved and making visits more enjoyable.

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Coping with Your Feelings

It is normal to have difficult feelings such as guilt. Talk to someone about how you are feeling.

It may be very hard for you to accept that you can no longer provide care for the person with dementia. You may feel guilty or think that other people will disapprove. It may be hard to know what you will do with all the spare time you suddenly have. You may feel lonely without the person you were looking after and feel a sense of loss. It is probably impossible to avoid difficult and painful feelings. It may help to talk to friends or professionals about how you feel, or to call the Dementia Helpline. It can also be helpful to talk to other carers at a carers' support group.

In time you will probably realise that your decision is for the best. It can be a comfort to see the person settle in and enjoy your visits. Although the care home will cope with the day-to-day caring, you can still be involved. Taking the person out for a walk, a run in the car or a day at home may still be possible. You may also be able to help with personal care, if you want to.

Publications

Alzheimer Scotland Booklets

All available in full text online at:

www.alzscot.org or free to carers in print or on tape from the Dementia Helpline on 0808 808 3000.

Activities:

A guide for carers of people with dementia

For carers who look after someone who has moderate to severe dementia and need help with planning daily activities.

Dementia:

Money and legal matters – a guide for carers

A comprehensive guide to planning for the future, benefits, community care rights and financial assessments.

Don't make the Journey Alone

Written by three people with dementia, this booklet offers personal thoughts, support and practical advice to people with a recent diagnosis.

Getting help from your Doctor:

A guide for people worried about their memory, people with dementia and carers

Looks at how dementia is diagnosed, treatments, getting help and support, keeping well and when the person with dementia should see the doctor again.

I'll get by with a little help from my Friends:

Information for friends of people with dementia

Written by carers, this booklet gives practical advice to help friends stay involved with both the person with dementia and the carer.

Letting Go Without Giving Up:

Continuing to care for the person with dementia

For people who have been caring at home for a family member, partner or friend who is going into a care home. Aims to help carers establish new caring roles for themselves through visiting and through working as partners with care home staff.

Looking after Yourself

Produced with the help of carers in Scotland, this booklet encourages carers to look after themselves as well as looking after the person with dementia.

A Positive Choice:

Choosing long-stay care for a person with dementia

Based on the experiences of carers, this booklet gives practical information on long stay care and help to deal with the emotional aspects. Includes information on help with care home fees and a checklist of what to look for when choosing a care home.

Information Sheets

Alzheimer Scotland also publishes a range of information sheets on topics including:

Alzheimer's disease, vascular dementia, Lewy body dementia, alcohol-related brain damage, drug treatments for dementia, travel and holidays, continence management, sexuality, driving and dementia, when people with dementia walk, plus local dementia service guides for many areas of Scotland.

Age Concern Factsheets

Wide range of fact sheets available online at:

www.ageconcernscotland.org.uk or from the Age Concern Information Line on 0800 00 99 66 (ask for the Scottish versions). Titles include:

Factsheet 10 – Local authority charging procedures for care homes(including free personal care)

Factsheet 29 – Finding care home accommodation

Factsheet 38 – 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

Factsheet 41 – Local authority assessment for community care services

Factsheet 46 – Paying for care and support at home

Health Scotland Booklets:

Available free to carers from the Dementia Helpline and local health promotion departments.

Worried about your Memory?

This booklet looks at what can cause forgetfulness and when to see the doctor if you are worried.

Facing Dementia

Information for people with early dementia and their carers, looking at practical arrangements and coping with feelings.

Keeping Safe:

A guide to safety when someone with dementia lives alone

Also useful for carers of people with dementia who do not live alone, this booklet looks at how to assess what is a risk, balancing risks and independence for people with dementia and practical steps you can take to help someone be safer.

Understanding Dementia:

A guide for young carers

A colourful booklet for 12 to 18-year-olds who are close to someone who has dementia. It explains dementia and looks at how to cope with its effects, encouraging young carers to look after themselves and to blame the illness, not the person with dementia or themselves.

Scottish Government Guidance

Guardianship and intervention orders - Making an application:

A guide for carers

Available on the Scottish Government website at www.scotland.gov.uk/publications

or free from:

Blackwell's Bookshop, 53-62 South Bridge, Edinburgh EH1 1YS Tel: 0131 622 8283

Alzheimer Scotland has a helpful booklet, A positive choice:

Choosing long-stay care for a person with dementia. This booklet looks at how to cope with the emotional effects of deciding on long-stay care, and covers the practicalities in detail.

Call the Dementia Helpline on 0808 808 3000 for a free copy.