

Choices in care

As dementia progresses people usually need more care and support. It is a good idea to consider all the options carefully before the situation reaches crisis point.

The local authority social services department should carry out a community care assessment for a person with dementia if one has not been carried out recently (for details see the Society's information sheet *Community care assessment*). Contact the local social services department to explain that more help is needed.

If a person with dementia is assessed as being in need of certain services, social services have a duty to provide these. Services vary from area to area but range from meals on wheels or day care, enabling the person to stay in their own home, to care in a care home. The views and preferences of the person receiving services should always be taken into account.

Even if it is concluded that the person's needs are not yet urgent enough to receive help from social services, an assessment will give everyone clearer information about the situation and the kinds of help available from other sources.

Carers may also ask for an assessment of their own needs.

Local voluntary organisations are a source of further information, advice and practical help. See the Society's information sheet *Voluntary organisations*.

Thinking it through

Once everyone is aware of the services available, a decision can be made about whether the person can remain in their own home, with additional support, or whether they would prefer to move into sheltered housing or a care home, for example.

You may also want to consider the financial implications of the options available. Social services should be able to give you an idea of the costs of the various services that are arranged through them. Services provided by the NHS, such as community nursing, are free. You will need to make your own enquiries if you are arranging services yourself, whether through a voluntary organisation or a private agency.

It is important not to rush into a decision. You might also want to talk to friends and relatives, other carers or your local Alzheimer's Society branch.

Help at home

If the person with dementia is staying in their own home, there are a number of points to consider:

Benefits

Check that all benefits are being claimed. Extra benefits for the person with dementia or their carer can make a great difference. More details on benefits and how to claim them are given in the Society's information sheet

Welfare benefits.

Equipment

Would equipment such as a raised toilet seat, a walking frame, a gas detector or a memory board make it easier for the person to stay in their own home? The Society's information sheet *Equipment to help with disability* gives details on what to look for and where to go for advice.

Adaptations or repairs

Adaptations such as a wheelchair ramp, a specially designed shower, improvements to the heating system or basic repairs might enable the person to remain at home. The Society's information sheet *Adaptations, improvements and repairs to the home* gives information about who to ask for advice and what kind of grants are available.

Practical help

Would meals on wheels, help with shopping, cooking or other domestic tasks, or assistance with bathing or dressing make a difference? Ask social services whether they can arrange these services or put you in touch with an appropriate organisation. Speak to your GP if nursing care is needed at home.

Company and breaks for carers

Would a befriending scheme, home care service, day care or respite care be helpful? Again, ask social services whether they arrange these services. You may find the Society's information sheet *Short term care* helpful if you are arranging respite care.

If social services are unable to arrange appropriate help, find out what services other organisations can provide. Ask at your local library or citizens advice bureau or at a local Alzheimer's Society or Age Concern group.

Counsel and Care and Age Concern publish helpful information sheets about help at home and what to look for when making your own arrangements.

Social services may have a list of local private home care agencies, and Counsel and Care and Alzheimer's Society branches can provide lists of private home care agencies, although these are not recommendations.

Sheltered accommodation

You may wish to consider sheltered accommodation. This enables people to continue to live independently but with the reassurance that help is at hand. It may be suitable for some, but not all, people with dementia. However, any move to new surroundings is likely to increase confusion and no sheltered scheme offers the constant monitoring and support available in a care home. Talk through the pros and cons with professionals involved in dementia care as well as with family and friends.

There are many different types of sheltered accommodation, both to rent and to buy, from bungalows and self-contained flats to bedsits with shared facilities. The support offered ranges from a community warden who lives on the premises and can be contacted by means of a community alarm to domestic help or provision of meals in extra care or very sheltered schemes. There are also some close care schemes offering accommodation on the same site as a care home and providing some care services.

The person can continue to receive services that they have been assessed as needing in sheltered accommodation in the same way as at home.

To find out more about sheltered accommodation schemes in your area, contact the Elderly Accommodation Counsel, which publishes lists of schemes. The Elderly Accommodation Counsel and Help the Aged also produce helpful information about the different types of schemes. Both organisations stress the importance of carefully checking the financial implications and of taking legal advice before committing to a scheme.

Care homes

It may be agreed that the best option is a move into a home providing residential or nursing care. Whether a person with dementia needs residential or nursing care depends on the degree of their dementia and on any other illnesses and disabilities.

Most care homes offering residential care are run privately or by voluntary organisations, although a few are still run by local authorities. Most care homes offering nursing care are also run privately or by voluntary organisations, although the NHS runs a few. Some homes are able to provide both residential and nursing care.

The Society produces information sheets on various issues relating to care in a care home. *Selecting a care home* gives information on finding a home and what to look for in a care home. *Paying care home fees* explains the different ways of funding care in a home. *Assessments for NHS-funded nursing care* explains the new arrangements for assessing and funding care home residents for the nursing element of their care.

Residential care

Most residential homes provide personal care for the residents who need it. This might include help with dressing, washing, going to the toilet and taking medicine. If you are considering a residential home, find out whether suitable care can still be offered if the person with dementia becomes more confused and dependent. A move to another home can be very upsetting.

Nursing care

Nursing homes always have a trained nurse on duty and can offer 24-hour nursing care in addition to personal care. Nursing care may need to be considered if the person with dementia is very confused and frail, has difficulties walking, has other illnesses or disabilities or is doubly incontinent, for example.

NHS continuing care

Very occasionally, someone with dementia who needs intensive care may be eligible for free continuing NHS care, usually in an NHS nursing home or in an NHS-funded bed elsewhere. To find out more, ask your GP or consultant.

Care plans

If, after assessing the person's care needs, social services agree that certain services should be provided, they will give you a written care plan outlining these services. This applies whether the person lives at home or in a care home. Care plans should be reviewed regularly and as needs change. Contact your social services department and ask for a review if one has not been carried out recently or you think it is necessary.

All care homes must also provide an individual care plan for each resident. This must be regularly reviewed to take account of changing needs.

Regulation and inspection

Since April 2002, all care homes in England have been regulated by the national care standards commission (NCSC) and in Wales by the care standards inspectorate. The role of these organisations is to protect vulnerable people. They have powers, under the Care Standards Act 2000 and associated regulations, to require care homes to care for residents appropriately and provide suitable accommodation for people's assessed needs.

Care homes should be inspected at least twice a year and you should be able to look at inspection reports. To find your area office in England, contact the national care standards commission and in Wales contact the care standards inspectorate.

Complaints

Always try to settle any difficulty at a personal level first, either with the person concerned or their manager. The problem may simply be due to a failure of communication or a misunderstanding. If an informal approach fails, there are a number of procedures you can follow, depending on the circumstances.

First, talk things through with someone who can advise you. Your local citizens advice bureau, Alzheimer's Society branch, Age Concern group, Counsel and Care group or the Relatives and Residents Association may be able to help. For details of how to contact these organisations, ask at your local library or see the Society's information sheet *Voluntary organisations*. Counsel and Care publishes a helpful information sheet about how to make a complaint.

Living at home

- If you have a complaint about any of the services provided by social services, contact your social services department. They will explain how to use their complaints procedure.
- If the complaint involves services provided by the NHS, you can use the NHS complaints procedure. Ask the particular service for a copy of their complaints procedure or contact your local health authority or NHS Direct on 0845 4647.
- If you have a complaint about another local authority department, a voluntary organisation or a private agency, ask them for a copy of their complaints procedure.
- If your complaint involves home care services, you can also complain to your area care standards office. This has powers to ensure that agencies providing home care meet certain standards.

Sheltered accommodation

First, discuss the problem with the landlord or managing agent. If you are unable to settle matters informally, ask whether they have a complaints procedure. If you want further help, you can contact AIMS, a department of Age Concern England that acts as an advice, information and mediation service for people in sheltered accommodation.

Care homes

All care homes are required to have a complaints procedure. Ask for a copy if you have not already been given one.

If arrangements for the care home were made through social services, you may wish to get some advice from the person in social services responsible for the care plan.

If your complaint involves nursing care provided by the NHS, ask your local health authority about the complaints procedure.

You can also complain about a care home through your local care standards office.

Contact addresses

Age Concern England

Freepost SWB 30375

Ashburton
Devon
TQ13 7ZZ

Freephone information line: 0800 00 99 66 (every day 7am-7pm) Website:
<http://www.ace.org.uk/>

Provides information, advice and fact sheets. Useful fact sheets include *Finding help at home* and *Finding residential and nursing home accommodation*.

AIMS (Advice, Information and Mediation Service)

Astral House
1268 London Road
London
SW16 4ER

Telephone: 0845 600 2001 (9.30am-4.30pm weekdays)
Email: aims@ace.org.uk
Website: www.ageconcern.org.uk/aims

Alzheimer's Society

Gordon House
10 Greencoat Place
London
SW1P 1PH

Helpline: 0845 300 0336 (8.30am-6.30pm weekdays)
Website: <http://www.alzheimers.org.uk/>

The Alzheimer's Society publishes many helpful information and advice sheets.

Care Standards

National Care Standards Commission
St Nicholas Building
St Nicholas Street
Newcastle-upon-Tyne
NE1 1NB

Telephone: 019 1233 3556
Email: query@ncsc.gsi.gov.uk
Website: <http://www.carestandards.org.uk/>

Care Standards Inspectorate for Wales
National Office
National Assembly for Wales
1 Alexandra Gate
Rover Way
Tremorfa
Cardiff
CF24 2SB

Telephone: 01443 848450

Carers UK

20/25 Glasshouse Yard
London
EC1A 4JT

Carers Line: 0808 808 7777 (weekdays 10am-12pm and 2pm-4pm)
Email: info@ukcarers.org
Website: <http://www.carersonline.org.uk/>

Publishes a useful booklet *Residential and nursing home care*.

Counsel and Care

16 Bonny Street
London
NW1 9PG

Advice line: 0845 300 7585 (weekdays 10am- 12.30pm and 2pm-4pm)
Email: advice@counselandcare.org.uk
Website: <http://www.counselandcare.org.uk/>

Useful fact sheets include *Help at home*, *What to look for in a home care agency* and *Community care and the NHS: guide to making complaints*.

Elderly Accommodation Counsel (EAC)

3rd Floor
89 Albert Embankment
London
SE1 7TP

Telephone: 020 7820 1343
Email: enquiries@e-a-c.demon.co.uk
Website: <http://www.housingcare.org/>

Publishes a useful booklet *For you and yours* and various fact sheets.

Help the Aged

207-221 Pentonville Road
London
N1 9UZ

Telephone: 020 7278 1114
Seniorline freephone: 0808 800 6565 (weekdays 9am-4pm)
Email: info@helptheaged.org.uk
Website: <http://www.helptheaged.org.uk/>

Publishes a useful booklet on residential care and an information sheet on sheltered housing.

Relatives and Residents Association

24 The Ivories
6-18 Northampton Street
London N1 2HY

Telephone: 020 7359 8148
Advice line: 020 7359 8136 (weekdays 9.30am - 4.30pm)
Website: <http://www.relres.org/>

For relatives and close friends of people in care homes. Can advise on a range of topics from how to get an assessment to what to do when problems occur in a home.

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