

Dementia Care

This guide explores common questions around dementia care and suggests ways to get the support you need.



By 2025 there will be over one million people with dementia in the UK

What support is available? If you have been diagnosed with some form of dementia, ask your GP what extra support you may need and what is available.

This will help you, your family and friends to plan for the future with your care team. You may also wish to consider joining a group or organisation which can provide you with further information and support. There is a list of organisations at the end of this factsheet.

It is important to ask for an NHS continuing health care assessment. This will help you find out what you'll be expected to contribute towards the cost of your care and how your income and savings will be affected. If you have very high-level needs, then the NHS may have a responsibility to pay. This care is called NHS Continuing Health Care or fully funded health care. If you are turned down, you have the right to appeal. Advice and information is available from the Alzheimer's Society: www.alzheimers.org.uk/continuingcare

When choosing a home, it is important to find out exactly what you would be charged, and what proportion of the cost you would eventually be responsible for.

How do I know if it is time to go into a home?

Many people see admission to some sort of residential care as a last resort, although a few people welcome it and make it a positive choice. If you have been diagnosed with some form of dementia, you need to consider what extra support you will need and how you will cope if the necessary level of support isn't available in your own home.

People choose the timing of admission for many different reasons. On balance, it is the point at which your quality of life would be better in a care home than it would be in your own home.

For example, it might be the case that your circumstances change and your main carer isn't able to care for you any longer. It might be the case that you are no longer 'safe' and might need a higher level of care. Sometimes people with dementia go out and cannot get home again. Sometimes people might not remember to take the medication that is essential to their health, or might inadvertently take it too many times.

Ideally, you will have given this some thought before something happens that forces the choice, for example an admission to hospital for an acute illness or following an accident. It might be the case that, in hospital, your ability to stay at home is questioned, either because your mental state has deteriorated or you might have limitations due to, for example, a broken limb. If you are in hospital and agree to transfer to a care home, the head of that care home will usually come to the hospital to meet with you and do an assessment, to ensure that the home can best meet your needs.

What should I look for in a home?

Care homes in England are regulated by The Care Quality Commission and are classified by the types of services they are registered to provide. Links to the Care Quality Commission together with regulators for Scotland, Wales and Northern Ireland appear at the end of this factsheet.

Details of care homes including the services for which they are registered are available from The Quality Care Commission and from your local authority.

Excellent advice on care homes is also available through this BBC web link: <http://news.bbc.co.uk/1/hi/programmes/panorama>

You can ask your G.P. to arrange for an assessment of needs to help you and your care team decide what kind of care will be required. If you have been given a diagnosis of dementia, this assessment will recommend the type of care for you. Homes are classified by type of care: one type is nursing and the other is residential. People with dementia might qualify for either type of care.



Location

When choosing a home, it might help to consider the location and how accessible the home is to those who want to visit. Moving into a different environment is disorientating for anyone; for people with dementia, the impact is much more severe so contact with people who are familiar becomes essential.

Quality of care

The quality of care is another key factor. You might find it useful to consider what that might mean beyond basic physical care.

Would you want to participate in communal activities? Would you object to someone of the opposite sex or someone much younger performing intimate personal care? Are there any factors that relate to your beliefs and customs that need to be observed? It will be important to spend time at any care home you are considering. What is the quality of interaction between staff and residents? Are residents engaged in meaningful activity?

These questions will help you to frame your choices. Regular assessments from your care team will help to ensure that your ongoing needs will be met.

A guide to choosing a care home is available from the Alzheimer's Society: www.alzheimers.org.uk

What if I can no longer handle my own affairs?

It is a really good idea to arrange for a Lasting Power of Attorney (LPA) to be given to someone you can trust with your financial affairs and also who you would trust to make decisions on your behalf if your capacity for decision-making becomes compromised by dementia.



This web link provides a form you need to complete and helpful information about what LPA means.

www.publicguardian.gov.uk

What if I can't cope with the person I am caring for?

The most important thing is to ask for help when you feel you cannot cope any longer and to talk to someone about it. It might be possible to access more home care that would lighten your load and make it possible to care more easily. You could choose to have some respite care for the person with dementia and then you could return to caring for him or her. You can ask your GP or Social Worker to do a further needs assessment to see if the person with dementia is entitled to extra support. Carers are also entitled to an assessment of needs to help them in their role as a carer depending upon their circumstances.

You can apply for this assessment by clicking on this web link or by contacting the social services

department of your local council.
www.direct.gov.uk/en/CaringForSomeone/CaringAndSupportServices

If you are considering a care home, you need to discuss this with the person with dementia and agree what criteria you will use to choose the home. If this type of discussion is no longer an option, you can make a list based on what you know about that person's preferences.

How do I complain if I think that my relative or friend is not receiving adequate care?

There will be a complaints process that you need to follow for any formal complaint. The first step is to raise the concern with a member of the care home staff. Be as precise as you can, and try to suggest how the issue might be resolved. Ideally, by being clear, direct and constructive, the problem can be resolved quickly.

If the solution is not obvious, you need to ensure that you have clear information about what has happened and when, so that you can make a statement of complaint.

The following link details the process you need to follow: www.direct.gov.uk/en/HealthAndWellBeing/HealthServices/CareHomes

This is a government direct link and explains how to make your complaint. It includes advice on whose help you can enlist if the complaint is not resolved to your satisfaction. You can also write directly to your care home regulator, listed at the end of this factsheet. A voluntary organisation such as your local Citizen's Advice Bureau can help you to make your complaint.

Further information and advice

The Alzheimer's Society

Tel: 0845 300 0336
or visit: www.alzheimers.org.uk
The helpline is usually open from 8.30am to 6.30pm Monday to Friday.
The Alzheimer's Society provides care services and undertakes research focused on improving the quality of life for people affected by dementia.

For Dementia

Tel: 020 7874 7210
or visit www.fordementia.org.uk
'For dementia' works to improve the quality of life for people with dementia and their carers.

The National Dementia Strategy

www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy
The National Dementia Strategy is a government initiative.

My Home Life

Tel: 020 7278 1114
or visit: www.myhomelife.org.uk
My Home Life works to improve the quality of life for people in care homes.

Relatives and Residents Association

Tel: 0207 359 8136
or visit: www.relres.org
Relatives and Residents Association offers support and advice for older people needing, or living in, residential care and the families and friends left behind.

Counsel and care

Tel: 0845 300 7585
or visit: www.counselandcare.org.uk
Counsel and care provides advice and information.

These four independent regulators of health and social care provide information and directories about health and social care services and care homes in the UK:

Care Quality Commission (England)

Tel: 03000 616161
or visit: www.cqc.org.uk

Scottish Commission for the Regulation of Care

Tel: 0845 603 0890
or visit: www.carecommission.com

Care and Social Services Inspectorate for Wales

Tel: 01443 848450
or visit: www.csiw.wales.gov.uk

Regulation and Quality Improvement Authority (Northern Ireland)

Tel: 028 9051 7500
or visit: www.rqia.org.uk

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