

DEMENTIA



UK
Foundation



This factsheet was produced jointly with British Telecom. It was created from a study which followed the introduction of the Mental Capacity Act (2005). For the first time, researchers from UCL Mental Health asked family carers from different walks of life and with all types of circumstances about difficult decisions they had made on behalf of a friend or relative with dementia. Although this information is designed to support family members making decisions for people with dementia, keep in mind that there is rarely a single correct answer. Each decision that you make will be influenced by your own individual circumstances.

Getting Help: Involving Health and Social Services

People with dementia are often unaware of the problem. In order to get them to initially see a doctor, carers are recommended to use an appointment with the GP about a separate issue, either for yourself or your relative, to bring up the memory problems. It may also be helpful to ask the GP to invite your relative to come for a check-up.

Sometimes the doctor might not be able to see that there is a problem. It often takes time for a diagnosis of dementia to be made, which can be very difficult. You can highlight the problems with your relative's memory and functioning to your GP.

Carers can sometimes find doctors are reluctant to refer people to specialist care services such as memory clinics. It can often help to directly ask your GP for a referral to a specialist clinic or social services. Don't wait for a crisis. Medical confidentiality can make it difficult for you to get information from doctors. You can go with your relative to see the doctor. Once the GP knows that

your relative gives permission, they will continue to give you information.

The information given about dementia when your family member is first diagnosed can seem over-whelming. You can ask for a follow-up for information if you need more time or a copy of letters. Specialist doctors and nurses will provide (if permission is given) copies of their letters to your GP. You can also ask for a written summary from them to refer to.

After your relative's diagnosis, you can contact their care team if you are unsure of anything. The Internet can be a valuable source of information. If you prefer to receive printed information, contact the local Alzheimer's Society or Age UK. Many Alzheimer's Societies also run courses.

Often people with dementia are reluctant to accept services. It can help to involve a doctor or other professional to persuade your family member. It can help to introduce changes slowly and one at a time, to allow your relative to get used to them or ask a doctor to explain the need for them.

You can also emphasise that, rather than hindering their independence, care services can increase your relative's quality of life and allow them to live at home comfortably.

You can ask for help from family and friends as well as voluntary organisations and professional services.

You can talk to family members about how using services can help retain their independence. You can ask for a review with any social or health professionals if you feel your relative's needs require reassessment or you feel you need more help. If a service given to your relative is inappropriate, it can be changed.

What Help is Available for Carers?

Organisations, such as Alzheimer's Society and Age UK, offer services including meeting with others in similar situations. You can find out about these organisations online, or ask a professional. Acceptance of the problem and help from family, friends and the local community is valuable. There are lots of services available for carers, including respite care in a care home if you are in need of a break.

Planning the Future: Legal & Financial Matters

Sorting out Power of Attorney or Wills or Advanced Decisions is daunting. Planning ahead is important as your relative may not be able to make these decisions later.

"Set up a Power of Attorney as early as you can, when the person can sign themselves." Wife

A Lasting Power of Attorney says who your relative would like to make decisions on their behalf if there comes a time when they cannot decide themselves. They must understand the document when they sign.

Power of Attorney can allow carers to pay their family member's bills, provide money for their care needs and regulate their finances.

There are many options with Power of Attorney; it can be only for money or also for care matters. It can be set up to be activated in the future and either be given to one person or shared. Some find it more acceptable to obtain Power of Attorney for both members of a couple.

"If we did Lasting Power of Attorney for both my parents, it wouldn't feel like it was just for my mum because she's dementing." Son

You can complete the forms yourselves, on paper and online but some people prefer to use a solicitor, the Citizens Advice Bureau or Age UK.

One option to help your relative retain some financial control would be to leave manageable amounts of money for your relative. Even if you take over control of their finances, you can

organise for your relative to have small amounts of money, so they do not feel like they have lost financial independence. Some people sort out finances through joint accounts.

"He could no longer sign cheques so we changed all our financial things to joint." Wife

If you have not set up Power of Attorney early enough, the Court of Protection can set up an appointee to manage your relative's money if they are unable to consent.

Your relative should make a Will as soon as possible while they are able to understand. A solicitor can help make a Will. You can also do this by yourself or with the help of the Citizens Advice Bureau, Age UK or online services.

What about the decision to drive?

People with a diagnosis of dementia should not drive unless they have informed the DVLA who have agreed that they can continue and their insurance company also knows the diagnosis. Giving up driving can be difficult for people to accept but families are often able to use persuasion. It can help if you emphasise it is the doctor's decision.

Planning the Future: If You Can No Longer Care

Some carers make a plan in case something happens to them and they can no longer provide care for their relative. The Carers Emergency Card Scheme operates in most areas allowing carers to draw up and register a plan. The carer has a card and if anything happens, the carer (or someone with them) calls the 24-hour helpline and they make the agreed arrangements.

If you are worried that something may happen to you, you can discuss plans for your relative with your family and make a decision for this eventuality.

If you suddenly could not care (perhaps because you were taken ill) and there was no plan, social services would arrange emergency care for your relative.

Planning Other Medical Care

As a carer, you may be asked to give your opinion or to decide about medical care for your relative. Some people with dementia continue to decide about their own health, and can provide input on what medical care they receive. Sometimes, when people with memory problems are near the end of their lives, carers may be asked about artificial nutrition and resuscitation.

Many families also discuss options for research. Most want to take part in research to help their relatives or others.

If you are asked about taking part in research it may be supportive to you and may help improve dementia care.

If the person for whom you care needs an operation, you may need to consider how a general anaesthetic will impact on your relative's health and how the health problem affects them. You may also need to consider the impact of your relative's memory problems on their recovery.

"She has arthritis on her knees, but she won't understand how to do physiotherapy. To me, it's not worth it." Daughter

Most people find the responsibility of making decisions about resuscitation and artificial nutrition extremely difficult. It can be helpful to discuss these issues with your relative in the early stages of their illness. You can always discuss these issues with friends, family members and healthcare professionals. It is important to think about what the person you care for would have wanted when they were able to decide. The quality of life your relative will have is an important factor to consider.

Planning the Future: Care Home?

Some families decide never to use a care home. Most people want to care at home for as long as possible and services can help. People often feel guilty about admission of a family member to a care home. Whatever plans you have, bear in mind that circumstances change. Many carers found that despite their previous view that they would never

consider a care home, they were left with no choice.

It is often helpful for you to discuss the decision with other family members, a health professional or social worker. Sometimes it is easier for others to see if a care home is needed. Talk to the social or memory service about your options. Getting more help may prevent needing a care home.

Staying at home can be impossible if your relative does not accept care. Sometimes it can be unsafe to keep them at home. It can become impossible for families to continue to manage at home, especially when there are other demands such as work and young children or the carer has their own health problems.

Making a decision about moving your relative into a care home is very difficult and an emotional process. Use available information, help and support. Friends and family can also help make the decision.

Family members sometimes decide to live in a care home and take an active part in the choice.

Often people are no longer able to choose at the point they need a care home. Your choice depends on you and your relatives' needs and priorities. Remember you can ask the manager for the home inspection reports (also available on the regulatory bodies' websites).

If you belong to a religious or secular community organisation, they may have connections to care homes. You are still family and involved even after your relative goes into a care home.

"As your relative becomes less communicative, you almost become their eyes and ears. You know your family member very well." Daughter

What financial help is available?

Care homes are means tested. Organisations such as Alzheimer's Society can provide information.

Age UK

(Age Concern and Help the Aged have now combined)

www.ageuk.org.uk

0800 169 65 65

Alzheimer's Society

www.alzheimers.org.uk/factsheets

0845 3000 336

Admiral Nurses Helpline

<http://www.dementiauk.org>

0845 257 9406

Advance Directives

www.direct.gov.uk/

[engovernmentcitizensandrights/death/preparation/dg_10029683](http://www.direct.gov.uk/en/GovernmentCitizensandRights/DeathPreparation/dg_10029683)

Carers Direct

www.nhs.uk/carersdirect

0808 802 0202

Citizens Advice Bureau

www.citizensadvice.org.uk

0845 050 5250

Carers Emergency Scheme

www.carersuk.org/Information/Findinghelp/EmergencySchemesList

Carers UK

www.carersuk.org

020 7490 8818

Dignity in Dying

www.dignityindying.org.uk

0870 777 7868

DVLA

www.dft.gov.uk/dvla

0300 790 6806

Elderly Accommodation Counsel

www.housingcare.org

020 7820 1343

Hartford Foundation

www.thehartford.com/alzheimers/index.html

00 11 860 547 5000

Pick's Disease Support Group

www.pdsg.org.uk

0845 458 3208

Power of Attorney (Office of the Public Guardian)

www.publicguardian.gov.uk

0300 456 0300

Social Services

www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/MentalHealth/index.htm

Specialised Early Care for Alzheimer's

www.specal.co.uk

01993 822 129

The Leveson Centre for the Study of Ageing, Spirituality and Social Policy

www.leveson.org.uk/levesoncentre/index.htm

01564 778 022

The Probate Service

www.hmcourts-service.gov.uk/infoabout/civil/probate/index.htm

0845 30 20 900

Linda Roy

National Equality Officer

Email: lroy@cwu.org

Tel: 0208 971 7238