

# Dementia Choices

Making key decisions



## Making key decisions

This Dementia Choices factsheet comes from a study which followed the introduction of the Mental Capacity Act (2005).

For the first time, researchers 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.

This factsheet was created from their advice, and includes what carers said in their own words.

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.

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# Section 1 – Getting Help: Involving Health and Social Services

## How can I persuade my relative to see a doctor to find out what's wrong?

People with dementia are often unaware of the problem.

*“He refused to discuss his diagnosis. He refused all help; no form of carer.” Wife*

*“The hardest thing was to convince my wife there was something wrong. She didn't want to know. She wouldn't talk about it.” Husband*

Carers recommended using an appointment with the GP about a separate issue, either for yourself or for your relative, to bring up the memory problems.

*“I used to be a bit conniving ... say I'm coming to see the doctor. That's the only way I could get her there.” Husband*

*“He hates going to the doctors. They sent a letter saying that they needed to see him, and I just said ‘It's common courtesy’.” Wife*

It often helped to go with them to the GP.

*“He convinced the doctor there was nothing wrong, and in the end I accompanied him to the surgery.” Wife*

## What can I do if the doctor can't see there's 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.

*“It took me about 18 months to get the doctor to give her a test. Later my daughter found the gas turned on, so when I left for work I had to turn it off. Then I really pushed the doctor.” Husband*

## What can I do to get referred to a specialist clinic?

Carers can sometimes find doctors are reluctant to refer people to specialist care services such as memory clinics.

*“We just had to persuade the GP to be referred to specialist care and that took months.” Wife*

It can often help to directly ask your GP for a referral to a specialist clinic or social services.

*“Ask for a referral to a specialist, ASAP, and contact social services at the same time.” Husband*

## What can I do if the doctor won't talk to me because they say information about my relative's health is confidential?

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.

*“I noticed my mum was forgetting things. I'd rung the GP and he wouldn't speak to me.” Daughter*

*“It's not bad getting information with the doctors because the doctors know me. I had to get my mother's permission to represent her.” Daughter*

## What information can I get about my relative's illness?

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.

*“It was an awful lot to take in. You’re given all this information.” Wife*

After your relative’s diagnosis, you can contact their care team if you are unsure of anything. Many local Alzheimer’s Societies run courses and send information. The Internet is also valuable (see Section 6).

*“Get as much information as possible ... it is there.” Wife*

### What happens if my family member refuses help?

Often people with dementia are reluctant to accept services. It can help to involve a doctor or other professional to persuade your family member.

*“He’ll do it for the doctor but not for me.” Wife*

*“So long as you say there’s a doctor, she will listen to that authority.” Daughter*

It can help to introduce changes one at a time, to allow your relative to get used to them.

*“She kept saying “No, I don’t want carers”. The professional said “Try and help slowly”. I said “Once a week”. They started a care package and it is every day now.” Son*

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

*“We were lucky that mum had friends. That was really helpful.” Son*

*“There was a good social network and the Church itself was very helpful.” Son*

You can talk to family members about how using services can help retain their independence.

*“He couldn’t stay at home all day so the day centre is better than him being in a nursing home, so it’s kind of a compromise.” Wife*

### What can I do if things aren’t working?

You can ask for a review with any social or health professionals if you feel your relative’s needs require reassessment.

*“If you feel you need more help, contact them. It is always worth it to tell them you want a review.” Daughter*

If a service given to your relative is inappropriate it can be changed.

*“In his first day centre, as he didn’t speak English, he used to fall asleep. The consultant wrote to the social worker and he was transferred to a Chinese Association.” Wife*

### What help is available for carers?

Organisations, such as Alzheimer’s Society and Age UK, offer services including meeting with others in similar situations.

*“Talk to other people about it. See what strategies they have got, but don’t try and do it all on your own, you end up then resenting.... If you get help you can still love them.” Husband*

*“I was a member of the local Alzheimer’s carers’ group and I’ve really found them enormously helpful.” Friend*

You can find out about these organisations online, or ask a professional.

*“I asked the nurse, she downloaded lots of information.” Wife*

Acceptance of the problem and help from family, friends and the local community is valuable.

*“Never be ashamed or embarrassed about asking for help and look within your local community.” Husband*

*“My advice to other carers would be stop trying to think about it in a logical way because their illness isn’t logical.” Husband*

### Things to THINK about:

- If your relative is reluctant to go to the GP it may help if you go together or use an appointment for something else to discuss memory or ask the GP to invite them to come for a check-up.
- Highlight the memory issues and problems to the GP.
- If you go to the GP with your relative ask for permission to be given about their confidential information.
- Ask if you want the GP to refer to a memory or social services. Don’t wait for a crisis.
- If the information after diagnosis seems overwhelming, you can discuss things further with a member of your relative’s care team.
- 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.
- 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.
- Some people with memory problems are reluctant to receive care or admit that anything is wrong. It may help to introduce services slowly, 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.
- If you are unhappy with the care or treatment your relative is receiving ask for a review.
- There are lots of services available for carers, including respite care in a care home if you are in need of a break.

## Section 2 – Planning the Future: Legal & Financial Matters

### Where do I start?

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.

*“My advice is to get it done sooner rather than later.” Husband*

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

*“It’s important to know when to register with the Office of the Public Guardian because I think we really left it too late.” Wife*

### What is Power of Attorney? Why do I need it? How can I set it up?

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.

*“We made Lasting Power of Attorney for the three of us; myself, my husband and my brother in law.” Wife*

*“I only did property and financial affairs. It fitted in with all our discussions about what we were doing with our money.” Wife*

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.

*“The whole Power of Attorney process is quite complex.” Daughter*

*“The best thing I ever did was to get a good solicitor and leave it to him.” Husband*

*“I would advise people to seek help which is given freely, Citizens Advice Bureau for instance.” Daughter*

### How can I help my relative retain some financial control?

One option is to leave manageable amounts of money for your relative.

*“I left his account open and every Friday morning thirty pounds went into that.” Niece*

*“Whilst she was still able she wanted her own money, of course you do for independence.” Husband*

Some people sort out finances through joint accounts.

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

### What can I do if I 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.

*"The Court of Protection is the only option I've got now, because my wife can't sign." Husband*

### 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.

*"My husband was a little unhappy about the driving, but he accepted it. I think he was both unhappy and relieved." Wife*

It can help if you emphasise it is the doctor's decision.

*"I was already getting worried about his driving, then we saw one of the doctors and when I asked he said, "I don't think he should" and he agreed actually. That's one of the few decisions I pushed him into." Wife*

### What should I do about Wills?

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.

*"Before she was diagnosed, we made wills. I know that we've done that." Husband*

*"I made wills. My advice is to get it done sooner rather than later." Husband*

### Things to THINK about

- At the early stages of your relative's diagnosis, it is helpful to plan for the future by considering whether your relative is able to and would like to make a Power of Attorney, and/or a Will or an Advanced Decision.
- Power of Attorney can be shared with other family members.
- Although these processes can seem daunting, organisations such as the Citizens Advice Bureau, Age UK and solicitors can help.
- 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.

## Section 3 – Planning the Future: If You Can No Longer Care

### What about if something happens to me?

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.

*“My greatest fear is if something happened to me.” Wife*

*“Other arrangements would have to be made for his care and what my children would have to do and I’ve set everything out. Everything is there, financially, all the affairs ready.” Wife*

*“You have to decide everything for the future. You just have to. That’s the practicalities of life.” Wife*

Often, it helps if families can discuss this together and make plans.

*“If say my father died, I don’t know if my mother would still be able to manage. That’s the sort of thing you have to think about.” Daughter*

Others feel that things should be sorted out as they happened.

*“If I became ill, the social services would have to make decisions or the district nurse.” Wife*

*“I decided I will just take each day as it comes. You can’t look too far in the future.” Wife*

### Things to THINK about

- 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.
- The Carers Emergency Card Scheme operates in most areas, for carers to register a plan. The carer has a card and if necessary the carer (or someone else) calls the 24 hour helpline and they make the agreed arrangements (see Section 6).

### Section 4 – Planning Other Medical Care

#### What decisions will I have to make about general 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.

*“My husband decided he wanted an operation and physically, he’s much better than he was.”* Wife

Sometimes, when people with memory problems are near the end of their lives, carers may be asked about artificial nutrition and resuscitation.

*“When it got very close to the end of his life, they did ask me whether I wanted him to be fed through his stomach. The doctor gave me the facts and didn’t try to influence me, but it seemed that to prolong his life would be cruelty.”* Wife

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

*“If they ever came out with a drug I don’t mind making that decision for my sister to be given a chance.”* Sister

*“Doing research is to her benefit and to other people’s benefit.”* Daughter

*“Not too much is known about Alzheimer’s yet, and it would help in the future.”* Wife

*“I really wanted to be part of the research, because my own experience was horrible.”*

*Anything that can be done to stop other people having that same experience has to be worthwhile.”* Daughter

#### What factors will I have to take into account?

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.

*“The doctor said “She has to have the anaesthetic for dentistry” so I had to sign for her. She couldn’t have all that pain.”* Sister

*“The operation made his mental abilities much worse, and we knew it was a risk and it happened.”* Wife

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.

*“My mum was talking about when she was going to die before she even got unwell. I wasn’t to have her resuscitated.”* Daughter

You can always discuss these issues with friends, family members and healthcare professionals.

*“Resuscitation was the biggest decision. I consulted with my children and my wife’s sisters.” Husband*

It is important to think about what the person you care for would have wanted when they were able to decide.

*“I think he wouldn’t have wanted to be kept alive by artificial means.” Wife*

*“I know he would volunteer, partly because he did participate in research.” Wife*

The quality of life your relative will have is an important factor to consider.

*“I would not like my sister to be resuscitated. She has got no quality of life so why put her in the same predicament and for us to be in sorrow longer?” Sister*

### Things to THINK about

- It is helpful to keep in mind what the person for whom you care would want, if they were able to make the decision about medical care for themselves.
- It may be helpful to discuss with your relative what they want if their health deteriorates.
- If you are asked about taking part in research it may be supportive to you and may help improve dementia care.
- Family, friends and professionals can support you to make these decisions.

### Section 5 – Planning the Future: Care Home?

#### How can I make a decision as to whether my relative needs a 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.

*“And my husband said “Promise me one thing, you’d never put me into a home”, and I said, “I promise”.” Wife*

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.

*“And because I had my brother close to me saying ‘a care home’, he could see it from a different angle to me and then I decided.” Daughter*

*“At the end of respite, the man in charge in the home said “How can you take him home? It always needs two people to see to him.” So, I decided to leave him there.” Wife*

*“The GP thought that it was quite irresponsible, the idea that we should wait until my husband had an accident or something very serious happened.” Wife*

Staying at home can be impossible if your relative does not accept care.

*“He refused to have anyone looking after him at home.” Wife*

Sometimes it can be unsafe to keep them at home.

*“He was very aggressive. Every time I wanted to do something, he pushed me.” Wife*

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.

*“Once my wife went into care, it took the pressure off me. It wouldn’t have been so bad if I’d been retired and I could look after her 24/7.” Husband*

*“I’ve got quite bad arthritis so there’s no way I could physically look after her.” Son*

#### How can I decide on a care home?

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.

*“It’s not very easy to make a decision..... on somebody else’s behalf, it’s even worse.” Wife*

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

*“My mum had chosen to go there. She just went in there. She had a lovely room.” Daughter*

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).

*“It’s within walking distance so that it would be easy to bring her home.” Son*

*“The television wasn’t on all the time. Residents are sitting in small groups. They encourage people to talk to each other. It really had a very pleasant feel.” Wife*

*“I was looking for a home which was both residential and nursing, in case my husband needs nursing later, he doesn’t have to be moved.” Wife*

Staff are very important.

*“The staff were very outgoing and friendly, it was the way they interacted with the residents.” Wife*

If you belong to a religious or secular community organisation, they may have connections to care homes.

*“We went to a Jewish care home, which was very important to me.” Wife*

### What happens after my relative goes into a care home?

You’re still family and involved after they go 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.

*“The cost was an issue. I looked at all the information available on the Internet, contacted Alzheimer’s Society and so forth.” Wife*

## Things to THINK about

- Circumstances change. Many carers found that despite their previous view that they would never consider a care home, they were left with no choice.
- Caring for a relative is difficult. Talk to the social or memory service about your options. Getting more help may prevent needing a care home.
- A care home can become the right decision when your own health or the health of your relative deteriorates or there are other competing demands. It may become unsafe for them to continue living at home.
- Family or professionals may be able to help you make the decisions.
- When choosing a care home, look for features such as location, staff interaction with residents and activities for residents.
- Care homes can sometimes be found through links with secular and religious community organisations.
- Residential care is means tested. Financial advice is available through organisations such as Alzheimer’s Society and Age UK.

### Section 6 – Resources for Carers

- 1 Age UK ( “Age Concern” and “Help the Aged” have now combined)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)  
0800 169 65 65
- 2 Alzheimer’s Society  
[www.alzheimers.org.uk/factsheets](http://www.alzheimers.org.uk/factsheets)  
0845 3000 336
- 3 Admiral Nurses Helpline  
<http://www.dementiauk.org>  
0845 257 9406
- 4 Advance Directives  
[www.direct.gov.uk/en/governmentcitizensandrights/death/preparation/dg\\_10029683](http://www.direct.gov.uk/en/governmentcitizensandrights/death/preparation/dg_10029683)
- 5 Carers Direct  
[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)  
0808 802 0202
- 6 Citizens Advice Bureau  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
0845 050 5250
- 7 Carers Emergency Scheme  
[www.carersuk.org/Information/Findinghelp/EmergencySchemesList](http://www.carersuk.org/Information/Findinghelp/EmergencySchemesList)
- 8 Carers UK  
[www.carersuk.org](http://www.carersuk.org)  
020 7490 8818
- 9 Dignity in Dying  
[www.dignityindying.org.uk](http://www.dignityindying.org.uk)  
0870 777 7868
- 10 DVLA  
[www.dft.gov.uk/dvla](http://www.dft.gov.uk/dvla)  
0300 790 6806
- 11 Elderly Accommodation Counsel  
[www.housingcare.org](http://www.housingcare.org)  
020 7820 1343

- 12     Hartford Foundation  
[www.thehartford.com/alzheimers/index.html](http://www.thehartford.com/alzheimers/index.html)  
00 11 860 547 5000
- 13     Pick's Disease Support Group  
[www.pdsg.org.uk](http://www.pdsg.org.uk)  
0845 458 3208
- 14     Power of Attorney (Office of the Public Guardian)  
[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)  
0300 456 0300
- 15     Social Services  
[www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/MentalHealth/index.htm](http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/MentalHealth/index.htm)
- 16     Specialised Early Care for Alzheimer's  
[www.specal.co.uk](http://www.specal.co.uk)  
01993 822 129
- 17     The Leveson Centre for the Study of Ageing, Spirituality and Social Policy  
[www.leveson.org.uk/levesoncentre/index.htm](http://www.leveson.org.uk/levesoncentre/index.htm)  
01564 778 022
- 18     The Probate Service  
[www.hmcourts-service.gov.uk/infoabout/civil/probate/index.htm](http://www.hmcourts-service.gov.uk/infoabout/civil/probate/index.htm)  
0845 30 20 900

This factsheet was created by Gill Livingston, Dina Rickman, Shilpa Bavishi, Claudia Cooper, Monica Manela and other team members from the UCL mental health sciences and dementia research centre teams. The research was funded by BUPA foundation.

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