

Dementia Decisions



Are you making decisions
on behalf of someone
you're looking after?



This project was funded by the Department of Health

A carer's guide to the
Mental Capacity Act

Introduction

Foreword

I know the incredibly important role that carers play for their loved ones when they have received and are living with a diagnosis of dementia. People living with dementia can have a good quality of life for many years, living in a way that reflects their own wishes and personhood. I commend this guide to the Mental Capacity Act, which has been funded by the Department of Health. It is designed to help you if the person you are caring for needs help to make decisions, or if you need to make decisions on their behalf. It explains the things you might need to consider and the steps to take. Even if you feel that you don't need this guide at the moment, I would encourage you to look at pages 12-13 which will help you to plan ahead for a time when decision-making isn't as straightforward as it might be now.

Baroness Iora Finlay of Llandaff

Chair, National Mental Capacity Forum

Sitra, The Carers Trust and Care Charts UK designed this booklet to provide support and guidance about decision making for carers of people living with dementia.

We consulted widely with carers and professionals, who told us they needed clear and concise information which did not just direct them to other places. Carers also gave us examples of decisions they make with and for the person they care for. We have used their experience to bring alive how carers manage supported decision making to maintain a good quality of home life, whilst keeping the people they care for as independent and safe as possible.

We would like to thank the many carers and professionals who supported us in the design and content of the guide and in particular:

Together Tuesday: *Hadleigh Carers Suffolk*

Sutton Carers Centre: *Lone Carers Group*

Jill Jukes: *Carer*

Independent Dementia Support: *Andrea Scott*

Alzheimer's Society: *Sam Cox*

Suffolk Family Carers: *Michael Bright*

Thanks also go to the authors:

*Nigel Keir, Zoe Harris, Louise Marks,
and Wendy Green.*

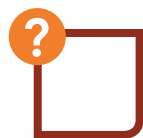
To help you further, there is a useful diary section for recording important decisions, a glossary to help explain the terms used in the booklet, and on the back page some helpful websites and telephone numbers.

Is this guide for you?

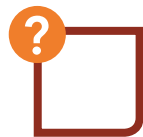
The Mental Capacity Act is a law designed to help people make decisions. It aims to promote decision making for as long as possible and help when a person can no longer make decisions independently.

It also supports and guides the people caring for them.

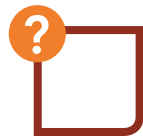
Are you making decisions on someone else's behalf?



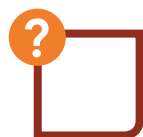
Are you finding that you have to make decisions for someone you care for who has memory problems or dementia?



Are you finding that someone you care for who has memory problems or dementia is no longer able to make certain decisions?



Does this worry you?



Are you comfortable making **some** decisions for the person you care for **but not** other 'bigger' or more significant decisions?



Would you like some help and guidance around any of these questions?



If your answer to any of these questions is "Yes" then this guide has the answers for you.

Did you know...

"I arranged for carers to come in each day to support my father. I use his money to pay for this care, although it was hard making the decision to spend his money, because he doesn't understand who pays. But he wouldn't eat or wash if the carers didn't come in, so we agreed this was in his best interests."

The **Mental Capacity Act (MCA)** provides help and protection for people who may not be able to make their own decisions. It makes it clear who can take decisions on another person's behalf. It describes in which situations they can make decisions. And it sets out how they should go about this.

It also protects the people making those decisions.

It also enables people to plan ahead in case they lose capacity at a later stage, by describing their wishes and preferences while they are still able to; this is called an Advance Decision. Planning ahead can also include putting a Lasting Power of Attorney in place which is covered later in the guide.

There is a **Code of Practice** that explains the Act. Although the code is aimed at professionals, it's helpful to be aware of what it says. So some of the advice and some of the examples in this guide are taken from the Code.

So what is the Mental Capacity Act for?

At the heart of the Mental Capacity Act are 5 key principles:

- 1** We should always start with the assumption that someone can make a decision unless it is proved otherwise.
- 2** We should give all appropriate help before concluding someone cannot make their own decisions.
- 3** We should accept the right of individuals to make what might be seen as eccentric or unwise decisions, or decisions that we may not agree with.
- 4** We should always act in the best interest of the person for whom the decision is being made.
- 5** When making a decision on behalf of someone, consideration should be given to the option that is the least restrictive of their basic rights and freedoms.

Points to consider...

We should not assess someone's 'general capacity' to make all decisions.

A person's capacity refers to their ability to make a particular decision at the time it needs to be made. We cannot, and should not, assess someone's 'general capacity' to make all decisions. We also should not assume that they will be unable to make that same decision on another occasion.

Be clear what decision the person needs to make and then assess whether they can make that particular decision for themselves.

Can they make that particular decision at that time?

There are many ways that can help to make decision-making easier

A person should always be helped to make all the decisions for themselves that they are able to make. There are many ways of making decision-making easier such as talking through the idea of setting up direct debits to make bill paying easier.

A person's capacity to make a particular decision may vary over time. Their ability to make that decision should be assessed at the time the decision needs to be made. If the decision can wait then it should wait until a time when the person may regain the capacity to make it themselves.

If it can wait, then it should wait.

If possible, agree ahead how decisions are going to be made.

It might be a good idea for you and the person you care for to agree in advance (or on days when they are able to have this conversation) how decisions are going to be made. This can include listing the important decisions that need to be made, when is a good time to make the decision, how the person you are caring for wants to be involved in the decision and who else should be involved. Finally, agree who can make the final decision if they are unable to.

How do you assess capacity?

Who can assess capacity?

Responsibility for assessing capacity usually rests with the person who is responsible for providing the support around the issue or decision that is being made. In the majority of day-to-day decisions such as what to wear, what to eat or drink or whether someone can safely leave the house, the assessor and decision maker is often the vulnerable person's carer. If you are a carer of someone who has had dementia for a while, you are probably making a lot of these decisions already. Remember this does not need to be a doctor or a social worker, although you may find their input helpful.

"I had to arrange a few days respite care for my husband, because I was exhausted. I felt guilty making this decision as I thought he would be very distressed. But it was in his best interest as well as mine, as it is important I am fit and well."

However, for more complicated decisions and decisions that may have longer-term consequences, you may require a formal assessment by a professionally qualified person if you are uncertain. Examples of these decisions are the person you care for needing an operation, selling their home/moving home or giving up their tenancy. If you feel a formal assessment is needed you should speak to your Social Worker or a medical professional as they will know how to help. Organisations like Age UK, Carers Trust and Alzheimer's Society may also be able to advise you.

We should always assess capacity at the time a decision is being made and not assume the person cannot make that decision.

Assessing if someone has capacity to make this decision

If you start to have doubts about someone's ability to make particular decisions...

You are not expected to be medically qualified to assess capacity; it is sufficient to use what you know, see and experience to demonstrate your assessment and then be able to explain that. If, however, the decision in question is a big and important one, it may be advisable to seek support with an assessment or a formal diagnosis. If you need help with a diagnosis, talk to your GP and ask for a referral to a Memory Clinic or specialist dementia advisor.

"Mum has started wandering without knowing where she is going. Once she was brought home by a neighbour late at night all cold and wet. I worry about locking her front door at night – is that safe? But we know she is not keen to move out of her home. We are talking to the social worker about what choices she has and what is the least restrictive option."

The Mental Capacity Act has set out how you begin to make this assessment.

So, you first need to consider: does the person have an impairment of the functioning of their mind?

This may be due to a memory problem, dementia or as a result of other illness such as a stroke, heart condition, urinary tract infection or a long term condition such as a learning disability or a brain injury.

If the answer is yes then it will be helpful to ask yourself the following questions:

Can they...

Understand the information about the decision being made?

For example: "I asked my husband how he could get his money out of the bank,' he replied 'Our daughter does that for me,' I asked what bank accounts he had and he appeared confused and told me 'I like to sit in the garden.'"

Retain that information long enough to make the decision?

This is not a memory test, and it is perfectly acceptable to use other methods, such as a notebook or picture chart, to support memory. What is important is that the person can recognise how the information relates to the decision. For example: "I asked Sharon what she liked about the home we had just visited, Sharon did not recognise the picture of it and asked 'Are you taking me to get a cat?' She had not understood the reason for visiting the home so we had to explain why we visited in a way she could understand."

Use or 'weigh-up' that information to help them make the decision?

Including being aware of likely risks in making or not making decisions.

For example: "I discussed with my husband the risk of further falls at home, he told me that he knew he could fall again but said 'All I want to do is stay at home and I would rather take that risk than go into residential care.' I conclude that he was weighing the information and considering risks."

Communicate their decision?

Can they let you know their decision by other means such as nodding, pointing or writing it down? Difficulty in communicating should not be a reason for deciding that someone lacks capacity to make a decision.

If you believe that the person you care for 'fails' any one of these questions, then you can reasonably conclude that they do not have the capacity to make that decision. You do not have to record this, but it might be useful to record such instances – or keep some kind of decision-making diary. You can then see what kinds of decisions are needing your help or are actually needed to be made by you. This will also help explain what has happened if someone else wanted to know or challenged the decision being made.

See diary section at the end of this guide.

Making decisions

If you have decided that someone lacks capacity to make a particular decision...

There are two things to consider:

- that any decision you now make for them is in their best interests and
- that the decision you make is the least restrictive of their rights and freedoms.

To do this it helps to consider the following things:

- do whatever is possible to encourage the person to take part, or to improve their ability to take part, in making the decision.
- consider whether the person is likely to regain capacity (e.g. after receiving medical treatment for an infection). If so, can the decision wait until then?
- try to think of all the things that the person who lacks capacity would take into account if they were making the decision for themselves.
- don't make assumptions about someone's best interests simply on the basis of their age, appearance, condition or behaviour.
- try to find out their views, including their past and present wishes and feelings. Take into account the way they did things in the past when they were able to make decisions. Their preferences may be obvious through behaviour or habits or they may have talked about these in the past, or written them down. Written down wishes are known as an Advance Statement or a Living Will.
- take into account any beliefs and values that you know they hold that would be likely to influence the decision in question, for example religious or cultural, but also moral or political views they hold.

“It was very difficult but I decided to move my mum into residential care, she was lonely and unsafe at home, she had always enjoyed company so I thought it was the best choice for her.”

- consider any other factors the person themselves would be likely to consider if they were making the decision or acting for themselves.
- if the decision concerns life-sustaining treatment this should not be motivated in any way by a desire to bring about the person’s death, whatever your view of their quality of life, unless they have made a specific decision to refuse life-sustaining treatment. These decisions should always be discussed with medical professionals.
- if it is practical and appropriate to do so, consult other people for their views about the person’s best interests. In particular, try to consult:
 - anyone previously named by the person as someone to be consulted on either the decision in question or on similar issues.
 - anyone else who helps with caring for the person: close relatives, friends or others who take an interest in the person’s welfare.
 - any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney made by the person. This is explained later.
 - any deputy appointed by the Court of Protection to make decisions for the person. This is also explained later.
- avoid restricting the person’s rights – see if there are other options that may be less restrictive of their rights.

“I always put my husband in elasticated trousers now, so it is easier for him to go to the bathroom. I know he never liked them, but it is less distressing for him than dealing with accidents.”

Other things that the Mental Capacity Act covers

The Mental Capacity Act allows a person to give someone the legal permission to make decisions on their behalf; it allows a court to appoint someone on that person's behalf if they can no longer do that and it also allows people to make decisions ahead. We have described these below.

Lasting Powers of Attorney

The Mental Capacity Act covers Lasting Powers of Attorney. A Lasting Power of Attorney (LPA) is a legal document that lets you choose people that you trust as your Attorneys to make decisions on your behalf about your:

- a) **Finances and Property and**
- b) **Health and Welfare**

You can choose to have both types of LPA or just one. You can appoint one or more people to act as Attorneys for each of these areas.

You must have mental capacity to make an LPA, so you should consider planning for the future and arranging an LPA as soon as you are concerned about someone's memory or when they have been diagnosed with dementia. Remember this means 'someone has the ability to make a specific decision at the time it needs to be made'.

The Mental Capacity Act Code of Practice explains more and gives examples including how attorneys must act.

How do we put a Power of Attorney into place? This is done through the Office of the Public Guardian. You can apply online to the Office of the Public Guardian or speak to them for guidance. Many people find that they can do this themselves or you can ask a friend to help you complete a LPA application. If you struggle or would prefer help then you may wish to use a solicitor or a legal professional, however this isn't always necessary. Do ask them if this is an area they are experienced in.

There is a fee to register an LPA, but there is financial help available towards the cost if you are on a low income, so do ask about fee exemption. Age UK, Alzheimer's Society or your local Carers Trust service can also provide advice.

Contact information for the Office of the Public Guardian can be found on the back page.

Enduring Power of Attorney

You may have heard of an Enduring Power of Attorney. These were in place before the Mental Capacity Act and applies to financial and property decisions only and not to health and welfare decisions. If an Enduring Power of Attorney is in place, it is still legally valid. However, if you wish to also cover decisions on health and welfare you will need to take out an LPA for this (see above).

Court Appointed Deputies

If there is no LPA in place the court can appoint someone to make decisions for the person. They are called 'Deputies' and can be appointed to make decisions on financial/or health and welfare matters, but most usually they support people with financial matters; Deputies for welfare and healthcare are rare.

Advance Decisions and Advance Statements

An Advance Decision allows you to set out your wishes to have or refuse a particular treatment or about end of life care. Advance Decisions must be written down and should be made known to the person making the decision on their behalf. This would normally be a medical practitioner and they are legally bound to follow that decision.

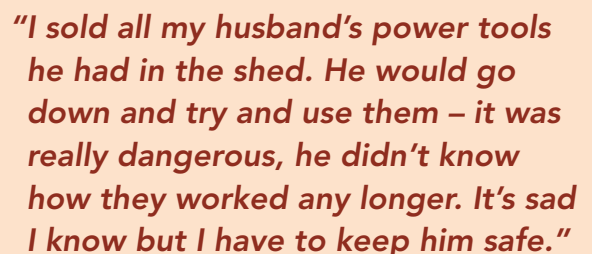
All Advance Statements or other decisions must be taken account of at the time that decision needs to be made. However, if the decision-maker has good reason to believe it would not be in the person's best interest in the circumstances at that time, these statements do not have any legal force, and whilst they must be taken account of, there is not a legal requirement to follow them.

If you are in this position, again it is useful to record this in the diary.

Organisations such as Alzheimer's Society have model forms you can use to write down your Advance Decisions or Statements.

Independent Mental Capacity Advocates (IMCA)

Sometimes the person you care for may not have anyone to speak up for them when they lose their capacity to make a longer-term decision other than you, their carer. It may be that for some reason you do not want to represent them; or they don't want you to. In this case, an IMCA can be instructed to represent them. An IMCA is arranged by the local authority but are independent. You can apply for an IMCA by contacting the service who provides IMCAs in your area directly or through contacting your local authority or asking a social worker if you have one. Age UK and Carers Trust might also be able to advise you, but only the local authority can arrange it.



"I sold all my husband's power tools he had in the shed. He would go down and try and use them – it was really dangerous, he didn't know how they worked any longer. It's sad I know but I have to keep him safe."

Deprivation of Liberty Safeguards (DoLS)

If the person you care for has to go into hospital or a registered care home it is possible that they might not be able to walk around freely, do certain things or leave the building. This would happen if they were unwell or unsafe and at risk of harm when doing this action. This is called 'deprivation of liberty' and means that they do not have the freedom to do that particular action without supervision. It is sometimes necessary, but should only be done as a last resort and only when it is considered to be in the person's interests and to protect them from harm. It should not, for example, be done for the convenience of staff. If this decision is taken it has to be checked to ensure it is appropriate. This check is carried out by the local authority. As the person's carer you should be consulted about any decisions that are made in this respect and such decisions are governed by the Mental Capacity Act.

There are two public bodies that help administer the Mental Capacity Act

Office of the Public Guardian. This is the office that registers LPA. It also supervises Deputies appointed by the Court and provides information to help the Court of Protection make decisions. They also follow up any concerns raised with them about Attorneys or Deputies and can work together with other agencies, such as a Doctor, the Police or Social Services to do this.

The Court of Protection. The Court of Protection appoints and has power to remove Deputies. This Court has the final judgment on capacity or DoLS matters where there have been disagreements or where an issue is particularly complicated or sensitive.

"I know it is not ideal, but I have to recline my husband in his chair when I go to the bathroom; he sometimes tries to stand, then falls and hurts himself and I can't get him up. As there is no-one else in the house, I feel this solution is in his best interests as the alternative is for him to move into residential care, which none of us wants. I make sure this is for the shortest possible time – just a few minutes."

We have described here some real life examples. There are examples of assessing capacity, illustrating good use of the principles of the Act, making best interest decisions and use of a Lasting Power of Attorney.

My husband still wishes to drive into town, but his driving is very erratic and I feel he is unsafe. He doesn't think his driving is affected but sometimes he even drives on the wrong side of the road. For his own and other people's safety I have had to hide the car keys. I know this restricts his independence but I also know that he is not safe on the road. I reassure him that we can still get out and about by other means so we are not stuck indoors.

We put an LPA into place for my wife's financial affairs and later we also set one up for her health and welfare. But although I knew her wishes with regard to her money and property and her Will, we never discussed her care needs. As her condition deteriorated, she found it distressing when I helped her with her personal care. We resolved this by getting in female carers, but I wish we had had this conversation when she was well enough to tell me how she felt. Even though these conversations are difficult I urge everyone to have them; it really helps to know your loved one's views before it arises.

As a best interest decision, I arranged for a physiotherapist to visit Mum's home to facilitate mobility. Even though I had suggested it lots of times, she wouldn't arrange it herself as she wasn't able to recognise or understand she was struggling and what the physio could help with.

I had to lock the door, so my father couldn't get out, when my daughter suddenly had an epileptic fit. It was just for the time I needed to take care of her needs – I was worried he would get lost or hurt.

Summary

We consulted with many carers during the writing of this guide and they gave us a number of examples of the common decisions that are made with or for someone with dementia.

They include:

Day-to-day decisions such as:

- choosing appropriate clothing
- what someone should eat and drink
- helping or reminding someone to take their medication
- deciding if it is safe for someone to go out alone
- deciding if someone can be left at home on their own

These are decisions that are often made by the person who is caring for them on a day-to-day basis.

Big and important decisions such as:

- managing money
- driving
- setting up care services
- medical and treatment decisions
- long term care arrangements

These decisions are best made by people who know the person well and with professional advice when appropriate; this may be their carer or a professional such as their Social Worker or GP. These may also be some of the decisions that are made by a person authorised under a Power of Attorney.

Each decision is however subject to the same considerations:

Does the person have the capacity to make this decision?

- **IF YES**, let them make it.
- **IF NO**, then you can make a decision that is in their best interest and has regard to the least restrictive, practical and appropriate option.

Glossary

Advance Decision. Someone can state in advance in writing that they do not wish to receive certain treatments if they should lose capacity in the future. An Advance Decision that is made correctly is legally binding.

Advance Statement. This is a general statement of someone's wishes, and what is important to them. It is usually written down and can contain any information they feel is important for others to know, such as religious, cultural, food and care preferences. It should be taken account of at the time that decision is being made, but it is not legally binding. Also sometimes referred to as a Living Will.

Best interest decision. Any decision made on behalf of someone who lacks capacity, should be done in their best interest. This means trying to consider what the person would have done or wanted had they the ability to make it themselves.

Capacity. Capacity means the ability of someone to make a particular decision at the time it needs to be made. The law is clear that you should assume that someone has capacity unless established to the contrary; lacking capacity should be always be assessed and not be assumed.

Carer. For the purposes of this booklet, a carer is someone who cares for someone with dementia but are not doing so on behalf of an organisation or service. This is usually a husband or wife, partner, other relative or close friend.

Court of Protection. This court rules on disputes and disagreements and complex cases around mental capacity and Deprivation of Liberty.

Dementia. A term used to describe a variety of symptoms or diseases (of which Alzheimer's is the most common) that affects the way the brain functions. Brain functions get worse over time and dementia is also likely to affect behaviour and personality.

Deprivation of Liberty Safeguards, sometimes abbreviated to DoLs. If the person being cared for has to go into hospital or a care home it is possible that they will need to be deprived of their freedom to move around or to do certain things. This will only happen when it has been properly applied for and authorised.

Glossary

Enduring Power of Attorney. Similar to an LPA but only covers financial and property matters and would have been established before the Mental Capacity Act of 2005.

Lasting Power of Attorney. A legal way of appointing someone to make decisions on a person's behalf once they have lost capacity to make the decision. The appointing of an LPA should be made whilst the person still has capacity. There are now two kinds of Lasting Powers of Attorney, one covering financial and property matters and the other health and welfare matters.

Mental Capacity Act 2005. A law designed to provide a legal framework for assessing capacity and decision-making. It is governed by a **Code of Practice** to which paid carers have to adhere.

Office of the Public Guardian. This public body administers Lasting Powers of Attorney applications and appoints Deputies to make decisions on someone's behalf where there is no Power of Attorney in place.

Dementia Decisions



If you would like more information or explanation about any of the issues raised here and how they relate to your situation then the following organisations can help. They are national organisations with local services. You can also talk to your social worker or GP. If they don't know they will help find someone to support you. Show them this leaflet.

Alzheimer's Society

0300 222 1122

www.alzheimers.org.uk

Carers Trust

To find your nearest Network Partner call 0300 772 9600 or visit:

www.carers.org

Carers UK

0808 808 7777

www.carersuk.org

Age UK

0800 169 2081

www.ageuk.org.uk

NHS Choices

www.nhs.uk/Conditions/dementia-guide

Admiral Nurses

0800 888 6678

www.dementiauk.org

You can also get information about Power of Attorney from www.gov.uk and search for Office of the Public Guardian or Power of Attorney.

This project was funded by the Department of Health