

What every carer needs to know: a guide to mental capacity



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The views expressed in this document are those of Carers UK.

Glossary

A brief glossary of some terms used in this guide (there is more detailed information in the rest of the guide)

Mental capacity – this is used to describe the level of understanding a person has to make decisions. People are described as lacking capacity when they are unable to make a particular decision.

Mental impairment – this refers to a mental illness or disturbance of the brain. It includes dementia, learning disabilities, mental health needs, some effects of strokes or the effects of brain injury.

Social worker – we have used the term ‘social worker’ throughout the guide to describe a professional working in social care. Sometimes this role will, in practice, be filled instead by a ‘care manager’.

Best interests – this phrase is used a lot in mental capacity law, because decisions that are made on behalf of people without the mental capacity to make the decision themselves must be based on what will be in their best interests.

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Introduction

This booklet is for carers who look after people aged over 16 in England and Wales who may not be able to make some decisions for themselves. They may be unable to make the decision because of dementia, learning disabilities, brain injury or reasons connected with mental illness.

It gives an outline of some of the law contained in the Mental Capacity Act 2005.

The key points are:

- People should be supported to make their own decisions wherever possible.
- If the person cannot make a decision, that decision must be made in the person's best interests.

- As a carer you have the right to be consulted about any best interest decision made by professionals, such as social workers and health staff.
- In some situations, carers can be granted legal powers to make decisions on behalf of the person they care for.

There are some examples to try and show how things should be for carers and the people they care for. This is what you should expect and what you are entitled to by law.

1 Some useful background information about mental capacity and the law

Mental capacity means the level of understanding a person has to make decisions. Some people may have had very limited mental capacity from birth. Other people may develop an illness or suffer an injury later in life that affects their understanding.

1.1 When can people make their own decisions?

Some people can make all decisions in life; possibly with help and advice. Some people can make some decisions, about what to eat, or what to wear, but not bigger decisions such as whether to have an operation or where to live. Other people can make almost no decisions in their lives.

The law takes a positive approach. It starts by presuming someone has enough understanding (mental capacity) to make decisions. If there is a real doubt about this, the law sets out a method to judge whether someone has capacity to make a particular decision (see 1.2) eg whether to pay their rent or to spend the money on other things, or whether to move into a care home.

It is easy to think that a person cannot make a decision when they want to do something that we think is wrong or harmful. If someone wants to live on their own, but they will be at risk because they are forgetful, then we naturally want to protect them and keep them safe. But the law says that, provided

the person understands the risks they are taking and chooses to take those risks, they are capable of making the decision and have the right to make decisions even if we think they are unwise.

In the real world, it can be very hard to decide whether someone is making a decision we think is unwise, or whether they are lack capacity to make the decision at all. There are many borderline cases. That is why the law has set out a way to decide when people can make their own decisions.

Before deciding that a person lacks the capacity to make a decision, the law says that as much support as possible must be given to help the person decide for themselves. For instance, this might include making sure the person is comfortable, explaining things very carefully and clearly, using sign language, or having someone else there who is good at communicating with and understanding the person. In many cases you, the carer, are better at communicating with the person than a professional, because you have had a lot of practice and know the person well.

CASE STUDY

Chris is 28 and lives with his parents. He has a significant learning disability. He says that he wants his own flat and that he can live there by himself, “no problem”. He says he doesn’t want any help. His mother and father think that he cannot live on his own without help. They feel that he will need help, and that without it he could come to harm, because he wouldn’t be able to manage any of the basics of looking after himself. But he does not recognise this. They support his desire to have his own flat, but only if he accepts some help. They are prepared to help him manage money, to ensure that his rent gets paid on time, but they cannot continue to manage his day to day care if he leaves home.

The law says that we must presume that Chris has the mental capacity to make these decisions, unless there is good reason not to. Chris’s parents, who have been caring for him for all his life, think that he does not have the capacity to choose where to live, because he does not recognise he will need help once he has his flat. See the next box.

1.2 How is mental capacity assessed, and who decides whether a person can make a decision?

The law asks:

- (1) *Does the person have any mental impairment? If so,*
- (2) *Does that prevent the person making a decision?*

There are four more questions to ask to find out whether the person can make the decision:

- Can they understand the information needed to make that decision?
- Can they remember the information for long enough to make the decision?
- Can they weigh up the consequences of deciding one way or another?
- Can they communicate their decision? (This may be by a nod or a blink, as well as by speech or by signing).

For day to day living, these decisions are often made by you as carers – for instance, deciding whether a person can choose what to wear that day, what to eat or what activities to do.

Some decisions about mental capacity are the responsibility of other people. For example, a social worker carrying out a community care assessment is responsible for judging whether someone can make a decision about their care support or where they want to live. Medical staff are responsible for judging whether someone can make a decision to have health treatment. Professionals, like

carers, must make every effort to help the person to understand the information and to make a decision, before judging that the person can or cannot make their own decisions. Your knowledge of the person will help make sure that this is done properly.

CASE STUDY

A social worker carries out an assessment of Chris’s mental capacity to make a decision about moving into a flat and receiving help to live independently. Chris’s mum first explains to the social worker everything she does for Chris at the moment. The social worker then tells Chris everything he would need to do for himself if he lived on his own without anyone to help him. She chooses her words carefully and Chris’s mother helps to explain things to Chris when she sees that he doesn’t understand the social worker. Both Chris’s mum and the social worker think that he understands the information they have given him, but he cannot remember it a few moments later. He cannot explain what could happen to him if he didn’t have any help/care and support. The social worker agrees with Chris’s parents that this is a decision Chris is unable to make.

1.3 If the person I care for can’t make a decision, who makes it?

Best interests decision-making

If the person can’t make a decision, then someone else has to take that responsibility. Very often, you, as a carer, do that about all sorts of important day to day things. If it is a decision about community care services or health treatment, then usually the social worker or doctor has to make the decision, but with your help and advice.

The law says that where a person can’t make their own decisions they must be made in the ‘best interests’ of the person. That means taking all the relevant factors into account, including:

- consulting you as the carer and any other family members and close friends
- involving the person as much as possible and listening to what they say
- as far as possible, their past opinions, values and beliefs must be taken into account
- restricting the person’s freedom as little as possible.

As the carer you probably know more about the person you care for than anyone else, and you want the best for them. Consulting you means involving you in the decision about best interests; listening to your opinions and respecting your knowledge of the person. If the person has lost mental capacity because of an illness or an injury, then you will be able to explain what they were like and what was important to them when they were able to make all their own decisions.

CASE STUDY

The social worker discusses the situation with Chris and with his mum and dad. Her opinion is that it is in Chris's best interests to have some help each day. Chris's parents agree with this and they also think that Chris will accept this. The conclusion is that he will have a support plan with a care worker coming in every morning to make sure he is ready and can get the bus to the college where he is doing a gardening course, and to meet him off the bus every evening and help him prepare his evening meal. This will be reviewed at a meeting with everybody there in three months' time.

This guide does not cover human rights and equality law, but it is important to remember that when professionals are considering what is in the best interests of someone who lacks capacity to make important decisions, they must ensure that the decision upholds basic human rights and does not unfairly discriminate.

CASE STUDY

Tina has dementia and is cared for by her husband, Paul. She is admitted to hospital after she falls and breaks her pelvis. The hospital staff think that she would be safer in a care home once she is discharged from hospital. Both Tina and Paul are devastated at the idea of being separated.

Tina has been assessed as lacking capacity to decide where to live. The hospital staff and the social worker consult Paul about Tina's best interests and recognise that they must balance the couple's strong wish to continue to live together at home against the risk to Tina's safety. Everyone agrees that it is in Tina's best interests to live at home with a support package. This decision recognises the right of Tina and Paul to enjoy their private, family and home life.



2 Lasting powers of attorney and court appointed deputies

2.1 What is a lasting power of attorney and how will it help?

A lasting power of attorney allows someone else, such as a carer, to make decisions on behalf of a person who has lost the capacity to make specific decisions themselves.

It can be very useful for a carer to be an attorney, because carers who are also attorneys have more rights to make decisions for the person they care for.

But the person must be able to make the decision to grant the power of attorney. If the person you care for does not have the capacity to do this, it is not an option (see 3 for alternatives). Some people grant a lasting power of attorney to their partner, son or daughter when they are getting older or when they have had a diagnosis of dementia.

There are two types of LPA:

1. A property and affairs LPA - this lets the

attorney manage the person's money. It can relate to some of the person's money or all of it. That will be up to the person who is granting the power. The person granting the power can also decide if they want the option of their attorney managing their money even if they still have capacity to make these decisions themselves, or if they want their attorney to manage their money only if they no longer have the mental capacity to do it themselves. Sometimes it is useful to have an LPA in place even when the person still has capacity to manage their own money, for instance if the person is in hospital for a long time and cannot get to the bank.

If you are a financial attorney, you can only make the decisions about the person's money and property that it says in the LPA, not any others.

CASE STUDY

Rehana's father, Tariq, is a widower. He owns his own house. Tariq is diagnosed with Alzheimer's disease. He decides to make a LPA so that Rehana can manage his money and property for him when he is no longer able to do it himself. The LPA has been registered (see 2.2) and Rehana has started to manage his financial affairs.

Rehana lives nearby and cares for him as much as she can, but, after caring for Tariq for four years, Rehana feels that she cannot manage without more help.

She asks for a community care assessment of Tariq, and her own carer's assessment. She tells the social worker that Tariq has often forgotten to eat or to wash when she comes round, that it is no longer safe for him heat up the food she leaves for him, and that he needs more help than she is able to give. Rehana explains that she has a job and a family of her own, and that she feels she is neglecting them.

The social worker talks to Tariq with Rehana's help and they both agree that he cannot make a decision about his own care or where he should live. Rehana explains that he has always said he would never go into a care home, but that he has been with her to visit a cousin who lives in sheltered housing and he liked that. They agree that it is in his best interests to move into an extra care housing scheme with on-site care support and a community alarm system. This will involve Rehana, as his financial attorney, selling his house, and buying a flat in an extra care housing scheme and investing the remaining money for his benefit.

- ii. A health and welfare LPA – this lets the attorney make the decisions about health treatment and care which the cared for would make if they still had capacity. It can cover all aspects of health and care or just some; the person granting the power decides that. An attorney can only make decisions that the person lacks capacity to make themselves.

CASE STUDY

Molly is the health and welfare attorney for her Auntie Betty who she lives with. She has the power to make all health treatment decisions on Betty's behalf. She has cared for Betty since she became too ill to look after herself. Betty has a degenerative illness and can no longer make major decisions for herself. The consultant believes that surgery may help relieve pain for Betty.

Even if Molly did not have a health and welfare LPA, the consultant would need to consult her about whether the surgery was in Betty's best interests. However, because Molly is Betty's health and welfare attorney she can consent or refuse consent for the operation on Betty's behalf. Of course Molly has to make decisions she believes are in Betty's best interests.

2.2 How do you set up a lasting power of attorney?

The person granting the power has to complete a form. There are separate forms for a property and affairs LPA and for a health and welfare LPA. Someone called a 'certificate provider' has to certify that the person understands what they are doing and has not been put under any pressure to complete the form. The certificate provider must be either a professional (such as a solicitor, a doctor or a social worker) or someone who has known the person for at least two years (as long as that person is not a member of the family of the person or the attorney and there is no conflict of interest).

The forms and instructions about how to fill them in are on the website of the Office of the Public Guardian and they will send you a free set. (see Section 7 for contact details)

They are quite long and detailed, but you do not necessarily need a solicitor to complete them.

Before the LPA can be used, the completed forms have to be sent to the Office of the Public Guardian to be registered. An attorney cannot make decisions using the power until the registration is completed. There is a fee of £120 for each LPA, but if the person making the LPA is on some specified means-tested benefits, the fee may be waived. Details of this and all other aspects of making an LPA are on the Office of the Public Guardian's website.

3 If there is no lasting power of attorney in place, what other ways are there of managing a person's money?

3.1 Appointees

If the person is on benefits and does not have the capacity to manage their money, then you can apply to become an appointee so the benefits are paid to you for you to manage in the person's best interests.

There is a scale of fees payable to the OPG.

In many cases carers can be deputies. You only need a solicitor if the person's estate is large or complicated.

You have to be over 18 and must apply in writing to the Department for Work and Pensions office dealing with the benefits. The DWP will normally visit. Being an appointee relates to benefits, but you can usually also be an appointee for tax credits (contact Revenue and Customs) or for housing benefits (contact the local authority).

The Court of Protection has a general enquiry line 0300 456 4600. Further information about applying to be a deputy is on the Direct Gov website at

www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/UsingtheCourtofProtection/DG_176235

3.2 Court appointed deputy

The Court of Protection can appoint a deputy to manage the finances of a person who cannot manage themselves. This can include making decisions about buying or selling property, or agreeing to financial contracts such as signing a tenancy agreement or paying for services. You do not generally have to go to Court for this, but there are several forms to fill in and there is a fee of £400. That fee may be reduced or waived depending on the person's finances. Deputies are supervised by the Office of the Public Guardian to make sure they are using the person's money in their best interests.

N.B. The Court of Protection can also appoint a health and welfare deputy, but this usually only happens where there is a disagreement between family members and professionals and the case has to go to the Court of Protection for a best interests decision to be made (see 6).



4 Carers and community care assessments

If you look after someone else you are entitled to a carer's assessment. This is a chance to tell Social Services how you are getting on as a carer and what help you need. You should have a chance to speak privately if you want to; to talk about whether you can realistically carry on caring at the same level, and whether you want to. You can also discuss how your caring is affecting your work, education or leisure time. For instance, if you aren't working, but would like to try and get back to work, or if you feel that you need more time to see friends or to be with other family members, you should tell the social worker about that in your assessment.

It is well worth asking for a carer's assessment, because it will help Social Services to see the full picture.

When the social worker is consulting you about the support needs and best interests

of the person you care for, they must also consider your needs as a carer and not push you to do more than you can or want to do. Remember it is not going to help the person you care for if you are under so much pressure that you make yourself ill.

The person you care for is also entitled to a community care assessment. On the basis of that assessment, and information from the carer's assessment, Social Services will then decide whether the person you care for is eligible for any help from them. During this process, decisions should be made with your help about the person's mental capacity, as well as their other needs, what will be in their best interests and what sort of support and help they need. This must not place an unacceptable burden on you as a carer.

5 Direct payments

If you as a carer and/or the person you care for qualify for help or support from Social Services, you will probably be offered a personal budget (sometimes called an individual budget).

This funding must be used to meet the community care needs of the person you care for (or yours if you are entitled to any carer's services). The money can be spent on care services arranged by the local authority, or it can be provided to you or the person you care for as a direct payment, so that you and/or the person you care for can decide how best to spend the money to meet care and support needs.

5.1 Can someone who has limited mental capacity still receive a direct payment?

The person you care for may be able to understand the idea of a direct payment and make decisions about their care and support, but may not be able to manage all aspects of a direct payment. For instance they may not be able to manage the money themselves or keep records of how it is spent. In that case they can ask you to help them with managing the direct payment.

If the person you care for does not have the capacity to decide whether to choose to have a direct payment, you may be able to receive the direct payment yourself and make all the decisions and manage the money. If the local authority thinks that you are best placed to receive the direct payment, that you will be able to manage it, and that you will act in the best interests of the person, then you can be appointed as a 'suitable person' to arrange the care and support through a direct payment.

Many people find direct payments very useful as they have more choice and control over the services coming into their home, but others find them a struggle to manage and do not want them. The local authority can offer a direct payment to you or the person you care for, but you or the person you care for can choose whether or not you want to go down this route. If not, the alternative is to receive a package of care arranged by the local authority.

CASE STUDY

Errol suffered a brain injury in a car accident. As a result he is both physically disabled and unable to make some decisions about his health treatment and his care. In hospital he says he wants to go back home to live with Joe. When he is ready to leave hospital, the consultant, the hospital social worker and the occupational therapist consult his civil partner, Joe, about Errol's future care. Joe also wants Errol to continue to live at home and so Joe has a carer's assessment.

Because Errol is assessed as lacking capacity to choose to have a direct payment, there is the option of Joe acting as the suitable person and managing Errol's direct payment. The social worker and Joe discuss the pros and cons of having a direct payment as opposed to having services arranged. Joe opts for a direct payment because he thinks it is important for Errol's well-being that they choose their care workers and there may be more flexibility about when they support Errol.

Joe thinks he can manage the evening and night-time care himself, but not the morning and days, as he has to leave early for work. Joe also says that he will need one night a week free to be able to meet his friends away from home so that he can relax and recharge his batteries.

Together with the social worker, Joe develops a support plan which enables Errol to be helped to get up, washed and dressed and to provide him with care support and stimulation during the day, until Joe gets back from work, and one evening's respite each week.

The hospital social worker explains to Joe that the responsibility for Errol will pass to the local area team where they live and a social worker from there will contact him in the next month to arrange to meet both of them and to review the arrangements to make sure that it is manageable for both of them. In the meantime, Joe is put in touch with the local Independent Living Centre who will help him manage the direct payment and recruit staff.



6 What happens if I disagree with a decision that social services or health want to make about the person I care for?

This might happen if you cannot agree about whether the person you care for does or does not lack mental capacity, or if you disagree with the professionals' opinion about what is in the best interests of the person. For example, you might think that the person you care for cannot make a decision to accept a direct payment, but social services thinks they can make that decision and therefore should have direct payments. Another example is where a doctor thinks it is in the best interests of the person you care for not to have an operation, but you disagree.

The first step is to try and sort out the disagreement informally, by negotiating with the professionals and explaining your point of view. If you still cannot reach agreement, there are two things you can do: You can make a complaint, using the local authority or health complaints procedure. This is quite a straightforward process and can help to sort out problems. There should be a leaflet produced locally telling you how to do this. If you don't feel confident about doing this, you can ask for advice and/or help from one of the organisations listed (see 7).

Complaints can take time so if you are worried that the person you care for is being put in danger you should consider contacting the local safeguarding team. You will be able to get in touch with the team through the local authority social services/adult social care in your area.

If there is a serious dispute the local authority should apply to the Court of Protection. They should not wait to see if you as a carer will do it.

However you can apply to the Court of Protection yourself. The Court of Protection is set up especially for cases involving people who may or who do lack the capacity to make particular decisions. The judges are specialists in mental capacity issues.

As well as dealing with financial deputies (see 3.2), the Court of Protection has wide powers to do things like:

- decide whether a person has capacity to make a particular decision for themselves;
- make best interests decisions on either financial or welfare matters affecting people who lack capacity to make them;
- appoint deputies to make health and welfare decisions for people lacking capacity to make those decisions, for instance where there is a serious disagreement between the family and the professionals;

- decide whether a power of attorney is valid, and remove deputies or attorneys who are not carrying out their duties or not acting in the best interests of the person.

If you are thinking of applying to the Court of Protection, you do not have to have a solicitor, but it will be helpful to get legal advice from someone who understands how the Court of Protection works. Find out the procedure from one of the organisations listed (see 7) or from the Court of Protection itself (see section 3.2). For some applications to the Court of Protection legal aid is not means-tested, but it is for most.

If a case goes to the Court of Protection, then the person you care for will need a "litigation friend". The role of the litigation friend is to make sure that the best interests of the cared for person are represented in court. Sometimes you as a carer can act as litigation friend, but if there is a dispute with professionals usually arrangements are made for the Official Solicitor to play that role.

7 How can I get more advice and information and where can I turn if I need support or advocacy?

There are further factsheets available online at www.carersuk.org These provide more detailed advice on healthcare issues, hospital discharge, going into a care home and care at home, including when the local authority wants someone to move away from home.

Age UK:

England and Wales - 0800 169 6565
www.ageuk.org.uk
(Info & support for over 60s)

Alzheimer's Society:

England and Wales - 0845 300 0336
(National and local information, advice and support for people with Alzheimer's and their carers)

Citizens Advice:

England and Wales -
www.adviceguide.org.uk
(Local offices for advice/representation)

Counsel and Care:

England and Wales - 0845 300 7585
www.counselandcare.org.uk
(info and support for older people and their carers)

Hafal:

Wales - 01792 816 600
www.mentalhealthwales.org
(the principal organisation in Wales working with individuals recovering from severe mental illness and their families)

Hft:

England and Wales - 0117 906 1751
www.hft.org.uk
(information and support for family carers of people with a learning disability)

Mencap:

England and Wales - 0808 808 1111
(minicom 0808 808 8181)
www.mencap.org.uk
Wales - 0800 8000 300
(Info and advice for people with a learning disability, their families and carers)

Office of the Public Guardian

Helpline 0300 456 0300
www.publicguardian.gov.uk
(Supports the public guardian's role in dealing with all aspects of attorneys or court appointed deputies)

Princess Royal Trust for Carers:

England and Wales - 0844 800 4361
www.carers.org
(info, advice and support services across a UK network of carers' centres)

Rethink:

0845 456 0455
www.rethink.org
(info, advice and community services for people affected by severe mental illness and their carers).



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