

Making decisions

A guide for family, friends and other unpaid carers

Helping people who are unable to make some decisions for themselves



There is a new law that can help - The Mental Capacity Act 2005

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This booklet provides information on the Mental Capacity Act 2005 and how it will affect you.
It is not a statutory Code of Practice issued under the Mental Capacity Act 2005
and is not a guide to how the law will apply to specific situations.

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In association with the Making Decisions Alliance, including:

The logo for the Making Decisions Alliance is a dark grey rectangle with the text 'Making Decisions Alliance' in white, sans-serif font.



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1. Introduction

About this booklet

The purpose of this booklet is to tell you about a new law called the **Mental Capacity Act** which will come into force during 2007. The booklet is for anyone who helps to care for someone over 16 who is unable to make some or all decisions. The inability to make a decision could be because of a brain injury or stroke, dementia, learning disability, mental health problems, alcohol or drug misuse, the side effects of medical treatment or any other illness or disability.

The person you care for may lack capacity to make decisions about money, health and other matters. You may need to help them to make those decisions or you may have to take action or make decisions on their behalf. The Mental Capacity Act sets out what should happen when someone lacks capacity to make decisions. This booklet explains:

- what the Act says about mental capacity
- how to decide if a person lacks capacity to make a decision
- how you can help a person plan in advance for what would happen if they lack capacity to make decisions in the future
- what will happen if a person can't make a particular decision
- how you can help a person make their own decisions
- on what basis you would take actions on behalf of a person who lacks capacity
- the role of family and friends when professionals are involved
- what to do if you think the Act is not being followed
- how the Code of Practice for the Mental Capacity Act will help you.

This booklet is not about detention or compulsory treatment under the Mental Health Act 1983. The 1983 Act is primarily about people who are diagnosed as having a mental health problem which requires that they be detained or treated in the interests of their own health or safety or with a view to protecting other people.

The new law only applies in England and Wales and unless specified, to people over the age of 16.

2. Why do I need to know about the Mental Capacity Act?

The Mental Capacity Act will be relevant to anyone who has a relative or friend who may lack capacity.

- It will clarify the process for caring for people who may lack capacity.
- It will clarify how decisions should be made for your relative or friend if they are unable to make those decisions for themselves.
- It sets out when you should be consulted about decisions made on behalf of your relative or friend.
- It sets out how your relative or friend is protected when others are making decisions on their behalf.

The Act applies whenever decisions are being made on behalf of a person who lacks capacity to make a particular decision for themselves. This includes any assessment of their need for treatment, services or support. The Act will provide a clear legal framework for dealing with mental capacity issues. It includes some new measures and safeguards and incorporates existing best practice.

However, there are certain decisions which the Mental Capacity Act does not allow anyone to make on behalf of a person who lacks capacity. This is because the decisions or actions are either so personal to the individual concerned or because they are governed by other legislation. This includes decisions in areas such as marriage or civil partnership, divorce, sexual relationships, adoption and voting.

The Act will be accompanied by a Code of Practice which provides guidance as to how it should work on a day-to-day basis. The Code explains in more detail what the key features of the new law are and some of the practical steps that people using and interpreting the new law will need to take into consideration. Certain people have a duty to have regard to the Code, including professionals, attorneys, deputies, paid carers and researchers. This means that they must

pay attention to the Code and be able to show that they are familiar with the guidance in it and if they don't follow it they must be able to give convincing reasons why not. You may also find the Code provides useful guidance in relation to the Act. If you are also an attorney (see part 8 of this booklet) or a deputy (see part 9) for the person you care for you will also have a duty to have regard to the Code.

If you want to know more detail about the Mental Capacity Act you can get the Code of Practice for free by downloading it from the DCA website at:

www.dca.gov.uk/legal-policy/mental-capacity/publications.htm

When does the Mental Capacity Act start to work?

There are two distinct phases: April and October 2007.

April 2007

- The new Independent Mental Capacity Advocate service (IMCAs) will become operational in England only (see part 7).
- The new criminal offence of ill-treatment or wilful neglect in England and Wales will come into force (see part 14).
- Sections 1-4 of the Act (the principles, assessing capacity and determining best interests - see parts 4-6) which are essential to how IMCAs operate will also come into force but only in situations where an IMCA could be involved, and for the purposes of the criminal offence. Sections 1-4 of the Act will **not** apply in any other situations until October 2007.
- The Code of Practice for the Act will be published and should be followed by those who must have regard to it in situations where an IMCA could be involved.

October 2007

- All other parts of the Act come into force including IMCAs in Wales.

3. What is Mental Capacity?

If you have mental capacity, it means that you are able to make your own decisions. The legal definition says that someone who lacks capacity cannot do one or more of the following four things:

- Understand information given to them.
- Retain that information long enough to be able to make a decision.
- Weigh up the information available to make a decision.
- Communicate their decision.

We all have problems making decisions from time to time, but the Mental Capacity Act is about more than that. It is specifically designed to cover situations where someone is unable to make a decision because the way their mind or brain works is affected, for instance, by illness or disability, or the effects of drugs or alcohol.

A lack of mental capacity could be due to:

- a stroke or brain injury
- a mental health problem
- dementia
- a learning disability
- confusion, drowsiness or unconsciousness because of an illness or the treatment for it
- substance misuse.

In all of these instances the person may lack capacity to make particular decisions at particular times. It does not necessarily mean that they lack all capacity to make any decisions at all. A person with a learning disability may lack the capacity to make major decisions but this does not necessarily mean that they cannot decide what to eat, wear and do each day. A person with mental health problems may be unable to make decisions when they are unwell, but able to make them when they are well.

4. What are the key principles of the new Act?

There is a lot of detail in the new law but there are some key principles that are important to understand.

- 1 All adults have the right to make decisions for themselves unless it can be shown that they are unable to make it. This means that people must not assume that someone cannot make decisions for themselves just because they have a particular medical condition or disability, or because they are of a particular age or appearance.
- 2 Everyone should be given all the help and support they need to make a decision before anyone concludes that they cannot make their own decision. This means that everyone helping to care for someone must make an effort to provide all the necessary information in a way the person can understand and then make it easy for them to try and explain what their preferences are. This may be through different ways of communicating; for example, it may be easier for a person with learning disabilities to understand something presented with pictures, photographs, videos or tapes. A deaf person may need the information explained using sign language.
- 3 People are allowed to make what we might think is an unwise or eccentric decision. We cannot say because we think the decision is unwise that the person does not have the capacity to make the decision. Many people make unwise decisions but this alone does not mean that they lack capacity to make decisions for themselves.
- 4 Any actions taken or decisions made on behalf of someone who lacks capacity must be done in their best interests, after considering what is known about their preferences (unless they have made a relevant and valid advance decision to refuse medical treatment - [see part 12](#)). It is still important to involve the person wherever possible in making the decision.

- 5 The final principle of the Act is to make sure that people who lack capacity are not restricted unnecessarily. So someone making the decision or acting for someone who lacks capacity must consider whether it is possible to do this in a way that would interfere less with the freedoms and rights of the person who lacks capacity.

5. Who decides if someone has capacity?

Anyone in a position where they might need to make a decision for someone who may lack capacity must decide whether that person is able to make the decision on their own. In many cases that decision will be your responsibility. There will be times when a professional will need to make a decision about the person's capacity. The Act says that before you, or anyone else, acts on behalf of someone else they must have a 'reasonable belief' that the person lacks capacity to make the decision for themselves.

Anyone - a health or care professional, other professional, relative or carer – might need to decide if a person has the capacity to make a particular decision.

How could I be involved in assessing capacity?

You may be involved in assessing capacity in two ways:

- 1 A professional may consult you about the person's capacity. For instance the person you are caring for might need to have an operation. The doctor might be unsure if the person has the capacity to consent to this. Often family members and those close to a person can provide valuable information to help assess a person's capacity and help explain things in a way the person can understand.
- 2 You may need to assess the capacity of the person because you need to do something in order to care for them. You are not expected to be an expert in assessing capacity, but you have to have a 'reasonable belief' that they lack mental capacity. You will need to think about:
 - Do they have a general understanding of what decision needs to be made?
 - Do they have a general understanding of the consequences of this decision?

- Can they weigh up this information and use it to make a decision?
- Is there any way you could help them to make the decision for themselves?
- Is there any way you can help them communicate their decision or their wishes and feelings?

You will need to think about this for ‘big’ decisions such as where to live, and for everyday decisions about what to eat or what to wear.

Just because the person makes a different decision from the one you would make or a decision you consider to be unwise does not mean that they lack capacity to make that decision.

How might I help a person to make a decision for themselves?

Sometimes people find it difficult to make a decision, but they do have capacity to make it with support. You may need to take a bit more time to explain the information. The person may need support with communication or information, such as an interpreter or information in Braille or pictures. In some cases an independent advocate, or other professional, may be able to help. For instance if the person you care for has communication difficulties it may be useful to consult a speech and language therapist; or if the person has been diagnosed with a particular condition it may be a good idea to get an opinion from a specialist like a psychologist or psychiatrist, or community learning disability nurse who is familiar with caring for people with that condition.

When might a person’s capacity change?

The Act recognises that someone’s mental condition and thus their ability to make decisions can change. For instance, the capacity of a person with dementia may deteriorate, so that they lack capacity to make decisions they used to be able to make for themselves. A person with a learning disability may learn new skills and gain new understanding so that they are now able to make decisions they

could not make before. A person with mental health problems may have capacity on one day but not the next. So an assessment of capacity will not be fixed. You will need to be aware of this if you provide care to someone over a period of time.

What is a reasonable belief?

The Act says that you must have a reasonable belief that a person lacks capacity to make the decision before you can act on their behalf. The word reasonable is important. Capacity can change, and a person can have capacity to make one decision and not another. You will need to decide what is a reasonable way to take account of this. For instance, if the person you are caring for has a condition that does not fluctuate, you might need to regularly make similar decisions on their behalf, such as what they should wear each day. If someone has a constant or degenerative condition, however, it might not be reasonable to expect you to make a new assessment every morning before helping the person to dress. However, over time you would need to remember that they may learn new skills and gain the capacity to decide what they should wear.

Example:

Mary cares for her son, Michael, who is 24, has a learning disability and is deafblind. Michael finds it very difficult to understand that he can make choices. As far as Mary can tell, he is not able to make decisions for himself. Michael attends a specialist day service five days per week and staff there are working to teach him about making choices. Mary knows that, given time, Michael will learn that he can make choices and that when he does, she will need to support him to make his own decisions. She regularly talks to the day service staff about this.

6. What happens if a person does lack capacity to make the decision for themselves?

If a person does not have capacity to make the decision for themselves, then others will have to act in their best interests ([principle 4](#)). Some people plan ahead and may have written an advance decision where they specified what sort of treatment they would not want to receive ([see part 12](#)). Or they may have stated what sort of care or treatment they are willing to receive ([see part 13](#)). Or they may have appointed an attorney ([see part 8](#)) to make certain decisions on their behalf. Sometimes the Court of Protection will appoint a person to make decisions on their behalf: a ‘receiver’ under the old law or a ‘deputy’ under the new Act ([see parts 9 and 10](#)).

If there is no relevant attorney or deputy with the necessary authority to make the decision in question someone else will have to decide what should happen. Depending on the particular decision, this could be you, or a professional. Whoever makes the decision must make it in the person’s best interests and in accordance with the principles of the Act ([see part 4](#)).

A decision might be needed on a wide range of caring actions such as diagnostic tests and examinations, medical procedures and nursing care and decisions about where someone lives or what services they need. It also includes care such as assistance with washing, dressing, eating or mobility carried out by you or by professionals.

When providing care, the carer or professional must have:

- assessed that the person lacks capacity
- assessed that the action they take is in the person’s best interests.

Professionals should normally record how they made this assessment in the person’s health record.

Example:

Hirut has a medical condition and her doctor feels that a blood test is needed to establish the most appropriate course of treatment. The doctor needs her consent to take a blood sample. Without her consent, the action could be illegal. But Hirut has a learning disability and after discussing it with her, the doctor concludes that she lacks the capacity to consent, because she does not understand what might happen if she does not have the test. Her doctor knows that he can lawfully take blood without her consent provided he reasonably believes that Hirut lacks capacity and that taking the blood is in her best interests.

How do I decide on best interests?

Anything done to or on behalf of someone who lacks capacity to make the decision for themselves must be in their best interests. The Act gives a non-exhaustive list of what you need to think about when working out what is in a person's best interests. This includes:

- Will the person regain capacity and be able to make the decision? If so, could the decision be delayed to allow this?
- As far as possible the person must be involved in any act or decision.
- If the decision is about life-sustaining treatment, the decision must not be motivated by a desire to bring about the person's death.
- The wishes and feelings of the person. This includes, any views they have expressed in the past, which would help to understand what their wishes, and feelings might be. This might be things they have written down, said to other people, or how they have behaved in similar circumstances in the past.

- Any beliefs or values they have that might influence the decision. This might include religious beliefs, cultural background or moral views.
- Any other factors they would be likely to consider if they were able to do so.

To do this, whoever is assessing what is in the person's best interests must consult with carers and anyone with an interest in their welfare and take into account their views, but this will depend on the situation and the decision that needs to be made. They will also have to consult anyone who the person concerned said should be consulted, and any attorney or deputy that has been appointed. Whoever is making the decision will then have to weigh up all the factors to decide what is in the person's best interests.

Providing care for a person who lacks capacity

You may need to assess what is in a person's best interests when you need to carry out care for them. The new Act offers reassurance that you will not be liable for your action provided you have a reasonable belief that the person lacks capacity and that the action you are taking is in the best interests (**principle 4**) of the person who lacks capacity.

The new law also says that you must also consider options which limit the person's rights and freedoms of action less (**principle 5**).

You should be clear about why you have made these decisions or taken these actions. If there could be disagreement about what is in the person's best interests, for example, if family members disagree about what should happen, you might want to keep a note of your decisions and why you made the decisions you did.

Example:

Peter is a young man who was studying at college until he was involved in a road accident and suffered a brain injury. He now lacks capacity to make any significant decisions about managing his money. The Court of Protection has appointed his father as his deputy so that he can invest the compensation that Peter has received. Peter's father knows that his son had very strong ethical objections to the actions of certain multi-national companies. He therefore picks an ethical investment fund. Even though he disagrees with his son's views, he takes account of them when determining what is in Peter's best interests.

The use of restraint

The Act allows you to legally carry out caring actions provided that you have assessed they are in the best interests of the person who lacks capacity. For example, going into someone's home without their permission to clean it for them or helping the person you care for to bath or dress.

However, where there are several different effective options available to you or a professional who is providing care or treatment, the Act says that you should use the one which is less restrictive. Sometimes it is necessary to physically restrain a person. The Act allows this but only if it is necessary to prevent the person coming to harm. For example, you may prevent the person you are caring for from stepping out into the middle of a busy road, if that person lacks capacity to understand the danger posed by traffic.

However, any restraint has to be reasonable and in proportion to the potential harm. You might prevent a person from going out alone because they cannot cross roads safely but it would be unreasonable for you to completely stop them from going outdoors to protect them from road traffic as this could amount to a deprivation of their liberty which is not permitted under the Mental Capacity Act.

7. When should I expect to be consulted?

The Act introduces a new requirement to consult anyone caring for the person or interested in their welfare (for example family, friends and unpaid carers) when deciding on best interests. Any person making a best interests assessment will have to consult anyone caring for the person or interested in their welfare. This will include family members even if they no longer provide much direct care but are still clearly interested in the welfare of their relative. It might also include close friends.

There may be times when it is not practical and appropriate for the decision-maker to consult close family and friends, for example, in an emergency situation it may not be possible to do so. So whether you are consulted will depend on what sort of decision needs to be made and the circumstances as the decision-maker assesses them. But when it is practical and appropriate you will have to be consulted. This will not mean that you are making the decision, and you should **not** be asked to give consent on behalf of another person.

You should be asked what you think would be in the person's best interests and whether you can give any information about the person's wishes, feelings, values or beliefs. You should not be asked what you would do in similar circumstances. The person deciding on best interests must take account of what you say but they will have to balance what you say with other information to make their final decision.

Example:

John has dementia. His doctor has suggested that he should have an operation to remove a cataract. John is no longer able to remember facts for more than a few seconds, often asking the same questions over and over again. It is clear that he is not able to make a decision about the operation. He therefore lacks capacity to consent or refuse the treatment offered, and so a decision has to be made on the basis of his 'best interests'.

John's wife is on holiday and his son comes with him to the appointment. Since the operation is not an emergency, the doctor decides that it is appropriate to wait until he can consult John's wife and a carer from the respite care home as well as his son. They are able to tell the doctor that in the past John has had no hesitation about consenting to anaesthetic or sedation. He also still enjoys watching sport on television, and his cataract is significantly affecting his ability to do this. However he does get very distressed if he wakes up in an unfamiliar environment, and John's wife is concerned that he will find the whole experience deeply distressing, especially if it involves a hospital stay.

The family, doctor and care worker all agree that a cataract operation will significantly improve John's quality of life and is in his best interests. It is agreed that John should have the operation as day surgery, with John's wife able to be with him the whole time to provide reassurance.

In most situations, people who lack capacity will have support from family members or friends, or from a deputy or attorney. However, the Act creates an **Independent Mental Capacity Advocate (IMCA) service** for cases where there is no one appropriate that can be consulted for decisions about serious medical treatment or changes in accommodation, for example moving to a hospital or care home. This service will be available in England from April 2007 and in Wales from October 2007.

In England Local Authorities and the NHS can also extend the IMCA service to care reviews about accommodation where they are satisfied that an IMCA would provide particular benefit. They can also extend the IMCA service to adult protection cases whether or not the person who lacks capacity has family or friends.

In Wales, the National Assembly for Wales will decide during 2007 if Local Health Boards and Local Authorities will be able to extend the IMCA service to care reviews and adult protection cases.

8. What is lasting power of Attorney (LPA)?

The new Act will allow people 18 and over to choose and appoint someone to make their health, welfare and/or financial decisions if in the future they lack capacity to make these decisions for themselves. This person is called an attorney and is appointed by a formal document called a **Lasting Power of Attorney (LPA)**.

There are two different types of LPA:

- 1 **A personal welfare LPA** is for decisions about both health and personal welfare, such as were to live, day-to-day care or having medical treatment.
- 2 **A property and affairs LPA** is for decisions about finances, such as selling the donor's house or managing their bank account.

The person making an LPA is called the **donor**.

The person/people who the donor chooses to act on their behalf is called the **attorney(s)**.

An attorney is appointed to make decisions as if they were the donor themselves. It is very different from being consulted by professionals, as in the end, where the LPA has given the power to the attorney, those decisions will rest with the attorney. Attorneys must act in the donor's best interests (**see part 6**) and follow the Code of Practice (**see part 2**).

The donor will be able to choose:

- the same person to be their personal welfare and property and affairs attorney
- different people for making different decisions relating to their personal welfare or finance
- only a personal welfare attorney
- only a property and affairs attorney.

The donor will also be able to specify whether their attorney can only make some decisions on their behalf. For instance a donor might want an attorney to make welfare decisions such as where he or she should live and about his care, but not medical decisions such as whether or not to have an operation.

How will attorneys be appointed?

When the Mental Capacity Act comes into force, if the person you are caring for has capacity to understand what it means to appoint an attorney, they can choose one or more people to make decisions on their behalf in the future, should they become unable to do this for themselves. As a relative, friend or other unpaid carer, you may be appointed as an attorney.

To appoint an attorney or attorneys the person will be able to get a special form from the Office of the Public Guardian (OPG) (see [part 11](#)), or stationers that provide legal packs. The form will have guidance on how to complete it and will also explain how the donor can place limits on what the attorney can do.

The most important thing is that the donor must be able to understand what it means to appoint an attorney and to be able to choose for themselves who they want to make decisions for them in the future. When completing the form they will also be able to choose who they want to be notified when the LPA is being registered. This does not have to be family members; it is up to the donor to choose. A certificate will also have to be signed to say that the donor understood what they were doing when signing the form and that there was no fraud or undue pressure on them when the LPA was being created.

If the person you care for no longer understands what it means to appoint an attorney then you might need to consider applying to the Court of Protection in order to be granted permission to make decisions on their behalf as a deputy (see [part 9](#)).

What are attorneys expected to do?

Before an LPA can be used, it must be registered with the Office of the Public Guardian. The donor could choose to register it as soon as the forms have all been completed, or the donor can leave the LPA unregistered until it is needed, at which point the attorney must register it. At registration of the LPA, people chosen by the donor and listed on the form must be notified. If the LPA is for health and welfare decisions, the donor might wish to consider early registration so it could be used in an emergency. There will be a fee for registration.

Agreeing to become an attorney means you will take on an important role as the attorney will be able to make decisions on behalf of the donor. Every attorney will have a duty of care and must follow the principles in the Act ([explained in part 4](#)). They will also have a legal duty to follow what is in the Code of Practice ([see part 2](#)) which has been written to help professionals, paid carers, deputies and attorneys know how the Act will work in practice. All decisions made by attorneys and any actions they take must be in the donor's best interests. If there is more than one attorney appointed jointly they will need to consult with each other to work out what is in the donor's best interests.

Personal welfare attorneys

A personal welfare attorney can only use the LPA once it has been registered and only when the donor is unable to make a particular health or welfare decision themselves. The decisions an attorney can make will depend on whether the donor has included any restrictions on the LPA form. If the donor wants the attorney to be able to make decisions about life-sustaining treatment they will need to specifically provide for this in the LPA form. The attorney cannot make financial decisions unless they have also been appointed as a financial attorney.

Example:

Jean is in the early stages of Alzheimer's disease. She appoints her daughter as welfare attorney to make any personal welfare decisions that she loses capacity to make herself. She talks to her daughter about things which are important to her such as wanting to stay near her friends, or to be able to go into a care home that allows pets. If her daughter has at some time to make decisions using the registered LPA, about where her mother should live, she is able to take account of the things her mother has stated when looking at her best interests.

Property and affairs attorneys

A property and affairs LPA could be used at any time after it is registered, unless the donor has said that it must not be used whilst they have the capacity to manage their own finances. Some people want their attorneys to take over the management of their finances even though they can still manage themselves. For instance, they may want their attorney to take on managing their bank accounts and dealing with their bills because they do not like dealing with money. Others may want their finance LPA used only when they lack capacity make decisions for themselves.

Unless the donor has placed any restrictions on the form then the attorney will be able to sign cheques, operate bank accounts, make investments and buy and sell property in the person's best interests. The attorney will have to keep the person's money separate from their own, and be able to produce detailed accounts should he/she be asked to do so by the Office of the Public Guardian (see part 11). Attorneys cannot make any decisions about health and welfare unless they are also a personal welfare attorney.

What happens if I am already the EPA attorney for the person I care for?

There is already a system for people to appoint attorneys for financial matters called an Enduring Power of Attorney (EPA). Existing EPAs will still be valid and can be registered after the Mental Capacity Act comes into force although new ones cannot be drawn up after this time.

If you are already an attorney and the EPA has been registered because the donor can no longer make their own financial decisions then you just carry on as before. You might find the Code of Practice (see part 2) and the principles of the Mental Capacity Act (see part 4) helpful. You are already expected to act in the donor's best interests.

If the EPA has not been registered because the donor is still able to make their own decisions, then after the Act comes into force a donor can:

- destroy the EPA and make a finance and property LPA
- keep the EPA for finance decisions
- in either case make a separate LPA for welfare decisions if they wish to.

If a donor decides to keep the EPA for their finance decisions the attorney can continue to use it unregistered unless it has been specified that it is only to be used if they no longer have capacity. If at some future date they are no longer able to make financial decisions for themselves then the attorney will need to register the EPA at that time. The same procedures that apply to EPAs will continue as now.

9. What is the role of a Deputy?

Deputies replace the current system of Court-appointed receivers to deal with property and affairs of someone who lacks capacity, but in future deputies could also be appointed to deal with personal welfare decisions.

If it is necessary to give someone continuing authority to deal with a series of on-going decisions, the Court of Protection ([see part 10](#)) can appoint a deputy to act and make decisions about property and affairs or to make personal welfare decisions on behalf of a person who lacks capacity. The court order from the Court of Protection will specify what powers a deputy should have. The court will make these powers as limited in scope and duration as possible. It can just make an order itself covering a one off decision that needs making. In most cases deputies will be appointed when a series of on-going decisions are necessary.

Being appointed a deputy means taking on an important role, as the deputy stands in the shoes of the person who cannot make the decision(s) him or herself. The deputy makes any decisions (about matters specified in the court order) on behalf of the person who is unable to make the decision themselves. Deputies will have a legal duty to follow the principles of the Act and always act in the best interest of the person. They also must follow the Code of Practice ([see part 2](#)).

Finance deputies will be much like the current receivers who look after the finances of the people who lack capacity and who need to make a range of financial decisions. Welfare deputies are new and will be appointed if a series of linked health or welfare decisions need to be made, so that a single order is not appropriate or where there are serious disputes about what is in the person's best interests.

How do I become a deputy?

If the person you care for has not appointed or is unable to appoint an attorney, and they need certain decisions made on their behalf which cannot be taken other than by bringing the matter to court, then you will need to apply to the Court of Protection (**see part 10**). An application form will be available from the Office of the Public Guardian. You have to be 18 or over to become a deputy. The Court will decide whether it thinks you are suitable to be a deputy. The Court will also decide if a deputy is needed, or whether it can just make an order to cover the particular decision that needs making.

Although you apply to the Court of Protection to become a deputy, in most cases the application can be decided on the information given in the forms, without any formal hearing.

The Office of the Public Guardian (**see part 11**) is responsible for supervising and supporting deputies. There will be fees for the costs of the application process and for ongoing supervision.

What do I need to do if I am already a receiver for someone?

If you are currently a receiver, when the new Act comes in, you will continue to act as before but will be known as a deputy for financial affairs. The August 2006 edition of Reaching Out for receivers explains the changes. See www.guardianship.gov.uk/formsdocuments/publications.htm for this edition of Reaching Out. More information will be sent to receivers nearer October 2007. If at any later stage the person you care for needs to have a welfare deputy appointed you will need to apply separately for that. For more information please go to www.guardianship.gov.uk

10. What will the new Court of Protection do?

The new **Court of Protection** will be able to make decisions about both property and affairs and personal welfare matters. The Senior Judge will be based in London and he will be assisted by specially trained judges at key locations in England and Wales. This will mean that any hearings can be nearer to the people concerned. The Court will make final decisions on capacity if there is uncertainty whether a person is able to make the decision in question. It will deal with decisions about the finances and property of a person who lacks capacity and certain serious medical treatment decisions, most commonly where there is a dispute about best interests. The Court will normally only hear personal welfare cases where parties have not been able to reach consensus about what is in the person's best interests by other means (see part 16).

In addition it will be able to:

- make one-off orders to deal with one off situations. For instance, where there is a serious dispute about where the person should live which has not been resolved by other means
- appoint deputies (see part 9)
- deal with applications to object to registrations of EPAs and LPAs. If necessary it will give directions to the attorney or deputy
- remove the powers of an attorney or deputy who has not been acting in the person's best interests and put alternative arrangements in place.

Although the Act does not generally cover children the Court will be able to make decisions about the property and affairs of a child under 16 if it is likely they will continue to need to have decisions made for them about finances after they are 18. In some situations, the Court could therefore make an order or appoint a deputy for a child.

Although many Court hearings will take place in key regional locations all applications should be made initially to the Court of Protection's Central Registry in Archway, North London. The Central Registry will deal with any urgent interim directions required and will then if necessary refer the matter to be heard at a regional court if this is in the best interests of the individual concerned.

Some people will need to get the Court's permission to make an application. The rules about this will be set out in the application forms and guidance.

There will be more information about how you can access the Court of Protection and who needs to seek permission for court action in 2007. It will be available in leaflet form and on the OPG website. The OPG Customer Contact Centre will always be a first point of contact and able to give advice ([see part 11](#)).

11. What will the Office of the Public Guardian do?

The Act creates a new public office - a **Public Guardian**. The Public Guardian will be supported by a new **Office of the Public Guardian (OPG)**. It will be responsible for the register of LPAs, EPAs and deputies. It will supervise deputies and arrange for Court of Protection visitors to visit you if you are a deputy and the person you care for, from time to time. It will follow up cases where there is any concern raised about the way attorneys and deputies are acting.

The OPG will be monitored by the Public Guardian Board and will be required to produce an annual report of its work throughout the year.

From October 2007, the OPG will provide a Customer Contact Centre which will be the first point of contact for anyone who needs advice or information about the Mental Capacity Act, becoming a deputy, when a single order may be appropriate, or making an LPA or registering either an LPA or an EPA.

12. What are advance decisions to refuse treatment?

An **advance decision to refuse treatment** allows people aged 18 or over to set out what particular types of treatment they would not want to have, should they lack capacity to decide this for themselves in the future. An advance decision can be about any treatment that a person does not want to receive at a time when they lack capacity, even if the refusal may result in their death. An advance decision does not need to be in writing, except for decisions relating to end of life treatment (see below) but it is helpful if it is.

Some people have views about what types of treatment that they don't want to have and would not consent to and an advance decision allows them to express these views clearly, before they lose capacity. If a person has made an advance decision refusing a particular medical treatment, and that advance decision is **valid** and **applicable**, then the decision should be followed and treatment should not be provided.

Advance decisions, currently also called advance directives or 'living wills', are possible under common law and the Mental Capacity Act puts them on a statutory footing and also explains what is required in law for an advance decision to be **valid** and **applicable**. In addition, the Mental Capacity Act introduces new safeguards to prevent the misuse of advance decisions.

This is a complex area and if you need more detail you should refer to the Mental Capacity Act Code of Practice or get expert advice.

What are the rules about advance decisions to refuse treatment?

The Mental Capacity Act introduces a number of requirements for making an advance decision. A doctor making a decision about treatment must be satisfied that the advance decision exists, is valid and applicable to the particular treatment in question.

A **valid** and **applicable** advance decision must be followed and takes precedence over any view that anyone else has about what is in the best interests of the person in question, even if the result is that the decision ends the person's life.

The following list gives a brief summary of some of the main requirements for advance decisions (For more detail you should consult the Code of Practice):

- It must be **valid**. The person must have had capacity to make the advance decision and the person must not have withdrawn it, or overridden it by making an LPA that relates to the treatment in the advance decision, or acted in a way that is clearly inconsistent with the advance decision.
- It must be **applicable**. It should make clear which treatment is being refused (detailed medical terms do not have to be used) and it should explain which circumstances the refusal refers to.

What are the rules about advance decisions to refuse life-sustaining treatment?

There are special requirements for making advance decisions to refuse life-sustaining treatment (any treatment that is needed to keep you alive and without which you might die). Such advance decisions must be in writing, signed and witnessed and the person making the advance decision must have stated that the decision is to apply even if life is at risk. If the statement is separate to the advance decision this also needs to be signed and witnessed. If someone makes an advance decision it should be reviewed from time to time to ensure that it continues to reflect their views.

Advance decisions do not allow people to refuse to be detained or treated without consent under the Mental Health Act. This is because even people who have capacity to consent cannot refuse such detention or treatment.

An advance decision cannot be used to ask for medical treatment - it can only say what types of treatment a person would refuse. Nor can a person use it to ask for their life to be ended.

For more information on advance decisions it is advisable to refer to the Code of Practice ([see part 2](#)).

What if the person I care for already has an advance decision (or 'living will')?

If the person you care for already has an advance decision, then it may still be valid when the Act comes into force. You should check that it meets the new rules particularly if it deals with life-sustaining treatment. More detailed guidance will be available at:

www.dh.gov.uk/consent

Where can I get more information about advance decisions?

You can read the relevant sections of the Code of Practice and a number of patient support groups and organisations provide information about making an advance decision. You will find details of how to contact them at the end of this booklet.

Example:

Helen is a retired nurse and is concerned that if she develops Alzheimer's disease she might be given treatment in the later stages of the disease which she would not consent to. For example, if she reaches the later stages of Alzheimer's she has decided that she does not want to receive artificial nutrition and hydration via tubes put into her stomach. She therefore writes an advance decision stating that in the later stages of Alzheimer's disease she does not want to receive artificial nutrition and hydration even if this puts her life at risk. Because of the requirements of the Act she also writes that the decision is to be applicable to life-sustaining treatment, signs next to the statement and asks someone to witness her signature.

13. Wishes and feelings and requests for treatment and care

Under the Mental Capacity Act, families, carers and health and social care professionals have a responsibility to give someone who lacks capacity care or treatment that reflects their preferences as far as possible. People can write down or tell others about their wishes and feelings and preferences about their future treatment or care. These statements must be taken into account when determining what is in the person's best interests, but they are not legally binding in the same way as advance decisions. Such statements can request certain types of treatment, which must be carefully considered, in particular if they have been written down. However, the request does not need to be followed if, overall it would not be in the best interests of the person who lacks capacity or if, in the doctor's professional judgement, the request is clinically unnecessary.

These statements can be about anything, including personal preferences such as having a shower rather than a bath or wanting to sleep with the light on. However, people cannot use such statements about their preferences to ask for their life to be ended.

Example:

Shahid has a degenerative condition. He wants to make sure that if he lacks mental capacity and needs people to help him with daily tasks, they recognise his cultural traditions. He therefore writes down a statement explaining his religious beliefs. Shahid asks for the statement to be filed with his medical notes so that in the future, if he can no longer make or communicate his own decisions, he receives the care that meets his needs. His family know that this statement will help to ensure that Shahid receives appropriate care.

14. Protecting people who lack capacity from ill-treatment or wilful neglect

From April 2007 the Act introduces a new criminal offence of ill-treatment or wilful neglect of a person who lacks capacity. This is intended to deter people from abusing, ill-treating or wilfully neglecting people who lack capacity. If convicted, people can be imprisoned or fined.

This could cover restraining someone unreasonably against their will, failure to provide adequate care, and also the more commonly understood types of abuse such as financial, sexual, physical and psychological abuse. Whilst the majority of people who are involved in the care of vulnerable people are entirely trustworthy, everyone should be alert to signs of abuse and take swift action to prevent or stop it. If you think someone is abusing, ill-treating or neglecting your friend or relative you can contact the police or social services.

15. Research

Research is an important way for us to understand illness and disability and to improve the care and support people receive. This could include testing how effective a certain type of care or treatment is in supporting those who may lack capacity, or finding out what caused a condition, for example, dementia. Sometimes this research will only be useful if it involves people who lack the mental capacity to agree to take part.

The Act allows such research to take place but sets out strict rules protect people who lack capacity to decide to take part in the research and to make sure their current or previous wishes are taken into account. These include:

- A recognised independent Research Ethics Committee must agree that the research is necessary, safe and cannot be done another way using people who are able to give their consent to the research.
- Researchers must talk to family members, partners and other carers or any other relevant person (such as an attorney or deputy) about whether to involve the individual who lacks capacity in the research. If they say that the person without capacity would not want to be involved in the research, then it cannot take place.
- The research must stop if the person without capacity shows any sign that they are not happy to be involved.
- The possible benefits of taking part in the research must be greater than any potential risk or harm to the person **or** it must help other people and must not hurt or upset the person.

16. Complaints, disputes and challenging decisions

There may be situations where you wish to challenge a decision or need to find a way to resolve a dispute. This might happen if you think you have not been consulted where it would be appropriate, or a decision is made which you do not think is in the best interests of your friend or relative. You may be involved in situations where there is disagreement, perhaps among family members or between family and a professional, about a decision such as what is in a person's best interests. There are a number of steps you can take in these situations.

- Involving an independent advocate (not an IMCA) who can help make sure your friend or relative's wishes and feelings are properly understood may help to resolve disputes.
- Making a formal complaint. The NHS, local authorities, voluntary and private care homes all have formal complaints processes. If your complaint is about the NHS then the local PALS (Patient Advice and Liaison Service) may be able to help. The equivalent agency in Wales is the local Community Health Council.
- The Office of the Public Guardian will be able to give advice and information about disputes under the Mental Capacity Act.
- The Court of Protection can make a ruling if other methods are not suitable. You might want to get help from a lawyer or Citizens Advice Bureau about this.

17. What if I want to know more about the MCA?

If you would like to know more about the Mental Capacity Act you can call 0845 330 2900 or email makingdecisions@dca.gsi.gov.uk

Other sources of useful information and guidance includes:

Title	Available from
Other information booklets like this one	You can view these electronically by going to: www.dca.gov.uk/legal-policy/mental-capacity/publications.htm To order hard copies you can email: reorder@inprintlitho.com
The Mental Capacity Act 2005	You can view this for free by going to: www.dca.gov.uk/legal-policy/mental-capacity/index.htm Or you can order a hard copy from TSO by calling 0870 600 5522 or emailing customerservices@tso.co.uk
The Code of Practice for the Mental Capacity Act	When the Code is published you will be able to download it for free by going to: www.dca.gov.uk/legal-policy/mental-capacity/index.htm You can order a hard copy from TSO by calling 0870 600 5522 or emailing customerservices@tso.co.uk .
Information on the IMCA service, IMCA Pilots and training materials for IMCAs	www.dh.gov.uk/imca

18. Some useful contacts

The following government departments are working together to implement the Mental Capacity Act in 2007

Department	What it is/does	Contact
Department for Constitutional Affairs (DCA)	Responsibilities include running the courts, and improving the justice system, human rights, information rights law, policy on running elections and modernising the constitution	5th Floor Steel House, 11 Tothill St, London, SW1H 9LH www.dca.gov.uk/ E makingdecisions@dca.gsi.gov.uk
Department of Health (DH)	Responsibilities include setting health and social care policy in England. The Department's work sets standards and drives modernisation across all areas of the NHS, social care and public health	Wellington House, 133-155 Waterloo Road, London, SE1 3UG www.dh.gov.uk T 020 7210 4850
Public Guardianship Office (PGO)	The administrative arm of the Court of Protection and part of the Department for Constitutional Affairs. It provides financial protection services for clients who are not able to manage their financial affairs because they lack capacity	Archway Tower, 2 Junction Road, London, N19 5SZ www.guardianship.gov.uk T 0845 330 2900 E custserv@guardianship.gsi.gov.uk
Welsh Assembly Government	Develops policy and approves legislation that reflects the needs of the people of Wales	Cathays Park, Cardiff, CF10 3NQ www.wales.gov.uk T 029 2082 5111

The following organisations were involved in writing and advising on this booklet

Organisation	What it is/does	Contact
Making Decisions Alliance	It includes: Action on Elder Abuse, Age Concern England, Alzheimer's Concern Ealing, Alzheimer's Society, Beth Johnson Foundation, Carers UK, Centre for Policy on Ageing, Cloverleaf Advocacy, Consumer Forum, Different Strokes, Down's Syndrome Association, Foundation for People with Learning Disabilities, Headway, Help the Aged, Horsham Gateway Club, Independent Advocacy Service, Kent Autistic Trust, Leonard Cheshire, Mencap, Mental Health Foundation, Mind, Motor Neurone Disease Association, National Autistic Society, North Staffordshire Users Group, The Oaklea Trust, Patient Concern, Powerhouse, Relatives and Residents Association, Respond, Rethink, Rett Syndrome Association, St Clements Patient Council, Scope, Sense, Skills for People, Stroke Association, Turning Point, United Response, WITNESS	www.makingdecisions.org.uk
Action for Advocacy	A resource and support agency for the advocacy sector, information, training and advice	PO Box 31856, Lorrimore Square, London, SE17 3XR www.actionforadvocacy.org
Age Concern England	The UK's largest organisation working to promote wellbeing of all older people. It provides vital services, information and support to thousands of older people - of all ages and backgrounds	Astral House, 1268 London Road, London, SW16 4ER www.ageconcern.org.uk www.accymru.org.uk Information line 0800 00 99 66
Alzheimer's Society	The UK's leading care and research charity for people with dementia, their families and carers	Gordon House, 10 Greencoat Place, London, SW1P 1PH www.alzheimers.org.uk Helpline 0845 300 0336
British Medical Association (BMA)	BMA represents doctors from all branches of medicine all over the UK	BMA House, Tavistock Square, London, WC1H 9JP www.bma.org.uk T 020 7387 4499 F 020 7383 6400

Organisation	What it is/does	Contact
Carers UK	Looks after family, partners or friends in need of help because they are ill, frail or have a disability	20/25 Glasshouse Yard, London, EC1A 4JT www.carersuk.org T 020 7566 7637 F 020 7490 8824
Down's Syndrome Association	Provides information and support for people with Down's Syndrome, their families and carers, as well as being a resource for interested professionals	Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex, TW11 9PS www.dsa-uk.com T 0845 230 0372 F 0845 230 0373
Foundation for People with Learning Disabilities	Works with people with learning disabilities, their families and those who support them to improve the quality of their lives and promotes the rights, quality of life and opportunities of people with learning disabilities and their families	Sea Containers House, 20 Upper Ground, London, SE1 9QB www.learningdisabilities.org.uk T 020 7803 1100
Headway – the brain injury association	Promotes understanding of all aspects of brain injury; and provides information, support and services to people with a brain injury, their family and carers	4 King Edward Court Service, King Edward Street, Nottingham, NG1 1EW www.headway.org.uk Helpline 0808 800 2244
MENCAP	Charity working with people with learning disabilities, their families and carers	123 Golden Lane, London, EC1Y 0RT www.mencap.org.uk T 020 7454 0454
Mental Health Foundation	A leading UK charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems, whatever their age and wherever they live	Sea Containers House, 20 Upper Ground, London, SE1 9QB www.mentalhealth.org.uk T 020 7803 1100
MIND	Leading mental health charity, working to create a better life for everyone with experience of mental distress. Provides information and support	15-19 Broadway, Stratford, London, E15 4BQ www.mind.org.uk Infoline 0845 766 0163

Organisation	What it is/does	Contact
National Autistic Society (NAS)	Champions the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs	393 City Road, London, EC1V 1NG www.autism.org.uk Helpline 0845 070 4004
National Care Association (NCA)	Represents the interests and provides services to support small and medium sized providers of social care in England and Wales	45-49 Leather Lane, London, EC1N 7JT www.nca.gb.com T 020 7831 7090
National Care Forum	Established to represent the interests of not-for-profit health and social care providers in the United Kingdom	3 The Quadrant, Coventry, CV1 2DY www.nationalcareforum.org.uk T 024 7624 3619
The National Family Carer Network	A network that provides a focal point for issues affecting families that include an adult with a learning disability	Merchants House, Wapping Road, Bristol, BS1 4RW www.familycarers.org.uk T 0117 930 2600
The National Family Carer Support Service	A network that provides support and information for family carers	Merchants House, Wapping Road, Bristol, BS1 4RW www.hftf.org.uk T 0117 930 2608
Patient Concern	An organisation committed to promoting choice and empowerment for all health service users. Provides information to service users	PO Box 23732, London, SW5 9FY www.patientconcern.org.uk E patientconcern@hotmail.com
The Relatives and Residents Association	An organisation for older people needing, or living in, residential care and the families and friends left behind. Offers support and information via a helpline	24 The Ivories, 6-18 Northampton Street, London, N1 2HY www.relres.org Helpline 020 7359 8136
RESCARE	The national society for children and adults with learning disabilities and their families	Steven Jackson House, 31 Buxton Road, Heaviley, Stockport, SK2 6LS www.rescare.org.uk T 0161 474 7323

Organisation	What it is/does	Contact
RESPOND	Provides a range of services for both victims and perpetrators of sexual abuse who have learning disabilities and those who have been affected by other trauma. Their services extend to support and training for families, carers and professionals	3rd Floor, 24-32 Stephenson Way, London, NW1 2HD T 020 7383 0700 F 020 7387 1222 www.respond.org.uk Helpline 0808 808 0700
Scope	Disability organisation in England and Wales, whose focus is people with cerebral palsy	6 Market Road, London, N7 9PW www.scope.org.uk T 020 7619 7100
Sense	Charity providing specialist information, advice and services to deaf blind people, their families, carers and the professionals who work with them. Funded to develop training materials which address the advocacy issues for deaf blind people	11-13 Clifton Terrace, Finsbury Park, London, N4 3SR www.sense.org.uk T 0845 127 0060 F 0845 127 0061 Text 0845 127 0062
Turning Point	The UK's leading social care organisation, providing services for people with complex needs, including those affected by drug and alcohol misuse, mental health problems and those with a learning disability	New Loom House, 101 Backchurch Lane, London, E1 1LU www.turning-point.co.uk T 020 7702 2300
United Response	A national organisation creating opportunities and services with people with learning difficulties and people with mental health problems	113-123 Upper Richmond Road, Putney, London, SW15 2TL www.unitedresponse.org.uk T 020 8246 5200 F 020 8780 9538 Minicom 020 8785 1706

Other booklets in this series include:

- 1 Making decisions about your health, welfare or finance. *Who decides when you can't?*
- 3 Making decisions. A guide for people who work in health and social care
- 4 Making decisions. A guide for advice workers
- 5 Making decisions. An Easy Read guide

These booklets are available in other formats on request.
To order:

- T 023 80 878038 or 023 80 878036
F 023 80 528324
E reorder@inprintlitho.com

The booklets are also available online at:
www.dca.gov.uk/legal-policy/mental-capacity/publications.htm

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