

Making decisions

...about your health, welfare or finance.
Who decides when you can't?



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

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...about your health, welfare or finance.
Who decides when you can't?

Helping people who are unable to make
some decisions for themselves

This booklet provides introductory information on the Mental Capacity Act 2005 and how it will affect the way you work. 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 black rectangular box with the text 'Making Decisions Alliance' in white, sans-serif font.

For better
mental health



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Contents

1	Introduction	6
	About this booklet	6
	Summary of the key points	7
2	What is the Mental Capacity Act and how could it affect me?	8
	What does 'mental capacity' mean?	8
	Why do we need a Mental Capacity Act?	9
	The Principles of the Act	10
3	When would someone assess my capacity to make a decision?	12
	Who decides whether or not I lack capacity?	13
	How would someone decide whether or not I lack capacity?	14
4	What happens if I am unable to make my own decisions?	15
	How does someone work out what would be in my best interests?	15
	Providing care or treatment for you if you lack capacity	17
	The use of restraint	17
	Protecting people from ill-treatment or neglect	17
5	What if I want to plan ahead in case I lack capacity in the future?	18
	Lasting Power of Attorney	18
	How do I make a Lasting Power of Attorney?	19
	What if I already have an Enduring Power of Attorney?	20
	Making an advance decision to refuse treatment	21
	Making advance decisions about life sustaining treatment	22
	What if I already have an advance decision (or 'living will')?	23
	Will this change the law on euthanasia or assisted suicide?	24
	Advance decisions and the Mental Health Act 1983	24
	Recording your wishes and feelings about treatment and care	25

6	What further support is available?	26
	Support from family and friends	26
	Support from an advocate	26
	Support if you do not have any family or friends	26
7	What will happen if I have not planned ahead?	29
8	Challenging decisions and raising concerns	30
9	What does the Act say about research?	32
10	How the new law is being supported	34
	Code of Practice	34
	Court of Protection	34
	Deputies	35
	What if I already have a receiver?	36
	Office of the Public Guardian	36
11	Further sources of information and guidance	36
12	Some useful contacts	39

1. Introduction

About this booklet

This booklet gives you information about a new law, the Mental Capacity Act 2005, which comes into force on 1 April 2007, and which will affect anyone who is unable to make some or all decisions. The inability to make a decision could be because of a learning disability, mental health problems, brain injury, dementia, alcohol or drug misuse, side effects of medical treatment or any other illness or disability.

The new law will help and support you if:

- you currently find it difficult to make decisions sometimes or all of the time
- you want to plan ahead in case you are unable to make decisions in the future.

This booklet explains:

- how the Mental Capacity Act could affect you
- how you can plan ahead now in case you cannot make your own decisions in the future
- how you will be protected if you are unable to make a decision either now or anytime in the future
- on what basis other people can take actions on your behalf if you cannot do so
- where to go for help and advice.

Another key source of information and more detailed guidance is the Code of Practice that accompanies the Act. It can be found online at www.dca.gov.uk/legal-policy/mental-capacity/index.htm

There will also be details of how you can order a hard copy of the Code of Practice on the website.

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 information in this booklet relates only to England and Wales and mainly to people over the age of 16.

Summary of the key points in this booklet:

- The new law protects your right to make your own decisions and to be involved in any decisions that affect you.
- There are a number of ways that you can plan ahead and set out in advance what you would like to happen should you be unable to make your own decision in the future (see part 5 of this booklet).
- If you are unable to make your own decision about something that affects you and if you have not planned ahead, other people will make decisions or take actions on your behalf in your best interests (see part 4 of this booklet).
- For most day-to-day actions or decisions, your family or carer will assess your capacity to make the particular decision. For more complex decisions, a more formal assessment may require the involvement of different people such as a doctor or other professionals (see part 3).
- When a decision is being made on your behalf, it must be in your best interests and the people who care for you or your friends and family must be consulted where practical and appropriate and their views must be taken into account (see part 4).
- If you do not have capacity to make a particular decision and you do not have any friends or family, for certain serious decisions such as serious medical treatment or moving into long-term care or a hospital, you will get extra support from an Independent Mental Capacity Advocate (IMCA) (see part 6).
- The Act provides a clearer legal framework for dealing with mental capacity issues and will help to ensure that fraud and abuse do not take place.

2. What is the Mental Capacity Act and how could it affect me?

What does 'mental capacity' mean?

If you have mental capacity, you are able to make decisions for yourself. 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. This could be by any possible means, such as talking, using sign language or even simple muscle movements such as blinking an eye or squeezing a hand.

The types of decision that are covered by the Act range from day-to-day decisions about things such as what to wear or eat, through to serious decisions such as where you live, deciding if you need to have an operation or what to do with your money and property.

The Mental Capacity Act applies to situations where you may be unable to make a particular decision at a particular time, to the extent that you cannot do one or more of the points above. For example, someone with dementia may be unable to retain information long enough in order to make decisions. Or someone with a mental health problem may feel too depressed to make a decision that he or she is able to make when feeling less depressed. In both these instances it may be the case that the person lacks capacity to make particular decisions at particular times.

This does not necessarily mean that a person lacks all capacity to make any decisions at all. A person with a learning disability may lack the capacity to make complex decisions but this does not necessarily mean that they cannot decide what to eat, wear and do each day.

Why do we need a Mental Capacity Act?

The Mental Capacity Act provides a clearer legal basis for making decisions and in doing so promotes best practice in supporting people who may lack mental capacity.

The Mental Capacity Act sets out in law what happens when people are unable to make decisions, i.e. when they lack capacity to make a particular decision. The Act provides protection and support should you find yourself in any of these situations.

The Act is there to:

- strengthen the right of people to make their own decisions and to be supported to do so
- protect those who may lack capacity to make a particular decision
- set out in which situations other people can make decisions and act on your behalf if you are unable to do so
- ensure you are to be involved in decisions that affect you
- help resolve disputes.

The Act is accompanied by a Code of Practice that provides more in-depth guidance. All professionals, such as GPs, doctors, social workers, and paid carers, **must** have regard to the guidance in the Code of Practice when they are supporting anyone who lacks capacity. This applies in all health and social care settings, including GP and hospital appointments, social care assessments and care review meetings.

The Principles of the Act

There are five key rules or principles that have to be followed by anyone who is supporting or working with a person who may lack capacity.

- 1 All adults are legally able to make a decision for themselves unless it is shown that they are unable to make it. This means that people must not assume that you cannot make a decision for yourself just because you have a particular medical condition or disability, or because of your age or appearance.
- 2 People should be supported as much as possible to make their own decisions before anyone concludes that they cannot make their own decisions. This may be through using different ways of communicating such as words, pictures or signs and providing information in different formats, such as tape or easy-to-read. In some cases an independent advocate may be able to help.

Example:

Isobel is an 18 year old woman with learning difficulties. Isobel does not use speech to communicate. Isobel's support worker communicates with Isobel through using symbols. A smiley face indicates what Isobel likes and a sad face what Isobel does not like. Isobel has used this system for several years at her residential school. Isobel is about to move from the residential school to a residential home. Her support worker wants to make sure that Isobel is involved in deciding what home she will move to. The support worker and Isobel visit different homes and the care worker takes photographs at all of the homes.

Isobel and the support worker then look at all the pictures. Isobel places photographs of two of the homes by the smiley face, showing she likes them, whilst others by a sad face. Isobel and the support worker do this several times and the care worker

moves the smiley face from one side of the table to the other. Each time, Isobel places the two same photographs by the smiley face and the others by the sad face. The support worker uses this information to work out that Isobel is able to decide which home to move to.

- 3 People are allowed to make a decision that may seem to other people to be an unwise or strange decision and a person should not be treated as unable to make a decision because of this.

Example:

Lucy, who has mental health problems, smokes cigarettes and continues to do so even though she has a severe chest condition. Doctors have explained to Lucy the risks if she continues to smoke and have advised her to give up. She continues to smoke, against the advice of health professionals.

However, it should not be assumed that Lucy cannot make a decision about her smoking just because she has decided to do something that some other people think is unwise or because they might think that she has made the wrong decision.

- 4 If a person lacks capacity any decisions or actions taken on their behalf must be taken in their best interests (unless they have made a relevant and valid advance decision to refuse medical treatment - [see part 5](#)). 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 when faced with a variety of options, the person making the decision or taking the action must think about whether it is possible to decide or act in a way that would interfere less with the freedoms and rights of the person who lacks capacity.

3. When would someone assess my capacity to make a decision?

The law expects you to be supported as far as possible to make your own decisions. This could be through providing information in a more simple way, such as using easier words or pictures, trying at different times of the day or when you are in better health or having a friend or an independent person to help you express your choice.

Someone must not make assumptions about your capacity because of your age or your appearance, such as skin colour or religious dress, or because of the way you behave or a condition you may have.

It is possible that your ability to make decisions can change. For instance, a person with dementia may find it harder to make decisions over time, so that they can no longer make some decisions that 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.

If you have a mental health problem, you may have capacity to make a particular decision on one day but not the next, and a decision may need to be delayed until you have regained your ability to make that decision.

Also, your capacity may depend on the type of decision to be made. For example, you may be able to make decisions about day to day things, such as what to eat for dinner and what to wear, but be unable to make a decision about financial things, like what to do with your savings.

Example:

Jermaine was in a rugby accident two years ago and sustained severe head injuries. Jermaine now has serious memory problems and has difficulty dealing with money. Jermaine has received a large financial pay-out from the accident to cover his care and other needs for the future.

Jermaine lives with his sister and she is concerned that he may not have the capacity to manage the large amount of money. Jermaine has said he would like to spend all the money on managing a rugby team and buying a very expensive car. This would result in Jermaine having no money left to pay for his care in the future.

It is agreed that Jermaine lacks the capacity to make serious financial decisions, but can manage his money on a day-to-day basis. The Court of Protection is asked to make a suitable order. The intention is that Jermaine will have an allowance that he will manage each week and his sister will manage the large investments for the future.

Who decides whether or not I lack capacity?

The starting point for everyone who may support you on a daily basis is that they should assume you do have capacity to make the decision for yourself. They must also follow the principles in the Act (see part 2).

Anyone - a health or care professional, other professional, relative or carer - might need to decide if you have the capacity to make a particular decision. In many everyday cases that decision will be the responsibility of your family or carers.

Where the decision you face is more complex, the more formal the assessment of your capacity may need to be and this may involve doctors or other professionals.

In medical decisions, where consent is needed for treatment or examination, the doctor or healthcare professional will decide whether or not you have capacity to consent. In legal decisions, such as making a will, the solicitor concerned will decide whether you have capacity to make that decision. Your family and friends and any other relevant people will also be consulted during an assessment.

How would someone decide whether or not I lack capacity?

The Act says that before anyone acts on behalf of someone who lacks capacity, they must have a reasonable belief that the person lacks capacity. If you lack capacity, actions can be taken or decisions can be made on your behalf if they are in your best interests. See [part 4](#) of this booklet for an explanation of best interests.

The word 'reasonable' is important. Capacity can change, and a person can have capacity to make one decision and not another. If a person has a constant or degenerative condition however, it might not be necessary for family or paid carers to make a new assessment, for example, every morning before helping you to dress. However you should be supported to make as many decisions as possible. In that way you may learn new skills and your capacity may improve over time.

Ultimately, any assessment of capacity will look at the legal definition of mental capacity which is outlined in [part 2](#).

If you are worried about your ability to make decisions or have been diagnosed as having a medical condition, such as Alzheimer's disease that may affect your ability to make decisions in the future, your GP should be able to give you more advice. A list of useful organisations and other sources of information can be found at the back of this booklet.

4. What happens if I am unable to make my own decisions?

The law says that it is important that every reasonable effort has been made to try to support you to make your own decision.

If you are unable to make a particular decision and you haven't made plans about this in advance (see part 5 of this booklet) then someone else, such as a carer or professional, will have to decide what should happen. In these circumstances you should still be involved in the decision-making process as much as possible and all actions and decisions must be taken in your best interests.

How does someone work out what would be in my best interests?

Although there is no single definition of what would be in a person's best interests, the new Act gives a non-exhaustive checklist of things that must be considered when another person is making a decision for you:

- Whether the decision can be delayed in case you regain the ability to make the decision in the future, for example, as a result of recovering from an episode or illness, learning new skills, or getting support with communicating your wishes.
- The law says that when someone is working out what is in your best interests, they cannot make a decision based merely on your appearance, age, medical condition, or behaviour.
- When deciding what would be in your best interests all the relevant information needs to be considered, and it is important to involve you as much as possible in decisions affecting you.
- Your wishes, feelings, values and beliefs. This includes any views you have expressed in the past that would help to understand what your wishes and feelings might be. This might be things you have said to other people, how you have behaved

in similar circumstances in the past and especially things you have written down. This places you at the centre of any decision being made on your behalf.

- The views of your family members, parents, carers and other relevant people who care for you or are interested in your welfare, if this is practical and appropriate. If you have named someone particular or given someone powers to decide for you then they should be consulted.
- If decisions are being made about treatment that is needed to keep you alive, people are not allowed to be motivated by a desire to bring about your death, and they must not make assumptions about the quality of your life.

Not all of these checklist factors above will be applicable, but it is still necessary to consider each of these, even if it is found that they are not relevant to the particular decision. Anything else that is relevant must be considered even if it is not included in the checklist.

Example:

Emma has been very unwell with stomach pains for two months. She has a learning disability and is scared of hospitals.

The doctor is very concerned about Emma's health and wants to do a test that will involve Emma having a tube put down her throat. The doctor has spoken to Emma's father, who confirmed that there is a family history of stomach cancer. The doctor's starting point is that Emma has capacity and he needs her consent to treat her.

After discussing the test with Emma, the doctor feels that Emma does not understand all the pros and cons of the test and therefore lacks the capacity to give or refuse consent. Taking into account further discussions with Emma's family and how ill Emma is, the doctor decides it is in her best interests that she has the test.

Providing care or treatment for you if you lack capacity

The Act allows people to legally carry out certain actions to do with your care or treatment provided that they have assessed that you lack capacity and that these actions are in your best interests. For example, going into someone's home without their permission to clean it for them, or giving someone medication for their condition.

However, where there are several different options available to the person who is treating you or caring for you, the Act says that they must use the one which is the least restrictive.

The use of restraint

Sometimes it is necessary to physically restrain a person. The Act allows physical restraint, but only if it is necessary to prevent the person coming to harm. For example, a carer may prevent you from stepping out into the middle of a busy road, if you lack capacity to understand the danger posed by traffic.

However, any restraint has to be reasonable and in proportion to the potential harm. A carer might prevent you from going out alone because you cannot cross roads safely, but it would be unreasonable for them to completely stop you from going outdoors to protect you from road traffic.

Protecting people from ill-treatment or neglect

The Act provides a new protection for people who may lack capacity, to keep them safe and prevent them from being harmed. This will apply to anyone who supports a person who lacks capacity to make their own decisions and to attorneys and deputies.

There will be a new criminal offence of ill-treating or wilfully neglecting a person who lacks capacity. This could cover restraining someone unreasonably against their will and also the more commonly understood types of abuse such as financial, sexual, physical and psychological abuse.

The new offence carries a sentence of up to five years imprisonment and/or a fine.

5. What if I want to plan ahead in case I lack capacity in the future?

There are several things you can do to prepare for the future, either by setting out some decisions in advance or by letting people know what you would like to happen if you lose the capacity to make decisions. It can also be helpful for your family, future carers, and for the people you have chosen to make decisions for you, to have your wishes clearly outlined.

The new Act allows you to appoint someone else to make decisions for you in the future, should you lack capacity to do this yourself. At the moment, the law allows you to appoint one or more attorneys in advance to make decisions about your finances only. From April 2007, as well as financial matters, you can also plan in advance and appoint an attorney to make decisions about health and personal welfare decisions for a time when you might lack capacity. This is considered below.

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) is a legal form which will allow you to choose someone else to manage your affairs on your behalf. The person that you can choose is known as an **attorney**, and can be a friend, relative or a professional. You can choose more than one person to act as an attorney on your behalf.

Your LPA will be specific to you – you decide who will have the power to control your affairs and the precise limits of that power. For example, you might want an attorney to make welfare decisions about your care but not make medical decisions on your behalf.

There are two types of LPAs:

- A property and affairs LPA will give powers to your chosen attorney(s) to make decisions about financial and property matters for you, such as selling your house or managing your bank account.

- A personal welfare LPA will give powers to your chosen attorney(s) make decisions about your health and personal welfare, such as where you should live, day-to-day care or having medical treatment.

The difference between these types of LPA is that a personal welfare LPA will only take effect when you lack capacity to make decisions. With a property and affairs LPA, you can specify that the attorney should only start managing your financial affairs after you lack capacity, sometime in the future. If you do not specify this, the attorney can start using the LPA after it is registered, but while you still have capacity.

All attorneys have to act in your best interests, as outlined in [part 4](#) of this booklet.

Example:

Jean is in the early stages of Alzheimer's disease. She appoints her daughter as a welfare attorney to make any personal welfare decisions she loses capacity to make. She talks through 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. When the LPA is needed, her daughter knows what her mother's wishes would be and this helps her act in her mother's best interests.

How do I make a Lasting Power of Attorney?

To make an LPA, you will need to complete a form, which you will be able to get from the Office of the Public Guardian (OPG). An outline of the role and powers of the OPG can be found in [part 10](#).

There are two forms, one for each type of LPA. If you want to create two LPAs, one for your property and affairs and another for your personal welfare, then you will need to complete two separate forms. Each form will contain guidance to help you fill it in.

You will be able to make an LPA if you are 18 or over and as long as you are able to understand what it means. To check this and to prevent fraud, you will need to provide a certificate, which is part of the LPA form. The certificate must be signed by an independent person stating that you fully understand what is involved in making the LPA, what it will mean to have one in place and that no fraud or undue pressure is being used to make you create the LPA.

After completing the form and the certificate, the LPA must be registered with the OPG before it can be used. There will be a fee for registration.

The OPG can be asked to look into what an attorney does, if someone thinks they might not be acting in a person's best interests. Any serious problems will be sent to a special court called the Court of Protection as outlined in [part 10](#). The Court has the power to remove the attorney if it is found that they have not been acting in the your best interests.

What if I have already made an Enduring Power of Attorney?

The new system of LPAs is going to replace the existing system of Enduring Powers of Attorney (EPAs) which currently allows people to appoint an attorney for property and financial matters. The new LPAs will give more protection and extra options.

If you have an existing EPA, either registered or unregistered, it can still continue to be used. If, at some time you are no longer able to make financial decisions for yourself then the EPA will need to be registered before it can continue to be used.

If you have already made an EPA and you still have capacity, you can either replace it with a new property and affairs LPA or you can keep your existing EPA. For more information on how to do this you should contact Customer Services at the Public Guardianship Office (PGO) on 0845 330 2900.

Finally, even if you already have an EPA (which only applies to finance and property matters), you will also be able to make an additional LPA for personal welfare decisions under the new law.

If you have an EPA or an LPA, under the new law the attorney will have to make sure they are making decisions in your best interests.

Making an advance decision to refuse treatment

An advance decision allows you to set out particular types of treatment you do not want should you lack the capacity to decide this for yourself in the future. Advance decisions are legally binding and must be followed by doctors and other health professionals, as long as they meet certain conditions.

People can already make advance decisions, currently also known as 'living wills' but the Act introduces a number of rules that you must follow when making an advance decision for them to be valid and applicable. If you already have an advance decision you should check that it meets these rules if you want it to take effect.

At the time that you make an advance decision, you must be 18 or over and have the mental capacity to make such a decision. It should make clear which treatments you are refusing, (although you do not have to use detailed medical terms) and you should explain which circumstances the refusal refers to. A doctor will need this information to decide whether an advance decision is valid and applicable to a particular treatment. If you are refusing treatment because of a particular religious or philosophical point of view then it is helpful to explain this in your advance decision.

You **cannot** make an advance decision to **ask** for a particular treatment – you can only say what types of treatments you would refuse.

An advance decision does not need to be in writing except for decisions relating to life-sustaining treatment (see below), but it is helpful if it is. You can get someone to write it down for you if you prefer. It is a good idea to talk to a doctor or nurse or patient support group before making an advance decision, but this is entirely up to you.

If you decide to make an advance decision, you should keep it up to date as your views and wishes may change over time. Health professionals may decide that an advance decision is not valid in circumstances where, since making it, you have done anything clearly inconsistent with the advance decision or you have made an LPA with authority to consent to, or refuse, the proposed treatment.

Making advance decisions about life-sustaining treatment

Some people choose to make an advance decision knowing that it may have the effect of shortening their life.

‘Life-sustaining treatment’ is any treatment that is needed to keep you alive and without which you might die. There are some specific rules to follow if you want to make an advance decision to refuse life-sustaining treatment.

This type of advance decision must:

- be in writing
- contain a specific statement which says that your advance decision applies even if your life is at risk.

The decision must be:

- signed by you (or by someone else that you appoint, in your presence, if you are unable to sign)
- signed in front of a witness
- signed by the witness in front of you.

If you do not follow these rules then your advance decision to refuse treatment may not apply to life-sustaining treatment.

Example:

Anthony has recently been told he has Motor Neurone Disease and wants to plan for the future. He has very strong beliefs on what treatment he would and would not want when he becomes seriously ill and when he is close to dying. He has decided he does not want to be fed or given fluids by a tube to keep him alive when he is about to die. Anthony is concerned that if he is unable to make a decision in the future, the doctors may make it for him.

Anthony writes an advance decision stating that in the future when he is close to dying he does not want to receive artificial nutrition or hydration (food and fluid by tube). The advance decision includes a written statement confirming that Anthony does not wish to receive artificial nutrition or hydration even if his life is at risk. Anthony signs the advance decision and a close friend of his witnesses his signature. The friend then signs the advance decision in front of Anthony.

This advance decision must be followed if and when it becomes relevant.

What if I already have an advance decision (or 'living will')?

If you have already made an advance decision, sometimes known as a 'living will', 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.

Will this change the law on euthanasia or assisted suicide?

No. You can use an advance decision to refuse life-sustaining treatment. However, you cannot use the advance decision to ask for your life to be ended. The new Act makes clear that it will not change the law regarding assisted suicide, neither does it change the law regarding murder or manslaughter.

Advance decisions and the Mental Health Act 1983

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

Example:

John is 29 years old and has experienced mental health problems most of his adult life. He sometimes hears voices telling him to hurt himself and on three occasions now, has been detained in hospital under section 3 of the Mental Health Act 1983. John has been treated with injections of antipsychotic medication whenever he has been detained ('sectioned'). John does not like having these injections as they make him feel physically ill and he has come to the conclusion that the side effects of the injections outweigh the benefits. He writes an advance decision stating that he does not wish to be treated with these injections in the future. He signs this in front of a close friend who then signs it in front of John. He then arranges for a copy of the advance decision to be placed in his health records held by the hospital and the local community mental health team. A few months later, John becomes extremely distressed by the voices in his head and is admitted to hospital under section 3 of the Mental Health Act. The psychiatrist treating John wants to administer an injection but John is so distressed that he lacks the capacity to give consent to the injection. The psychiatrist sees that John has made an

advance decision but, after careful consideration, decides that it is better for John to have the injection than not as the voices are telling John to hurt himself. The psychiatrist also gives John other medication to help him cope with the side effects of the injection. The advance decision has been made correctly but because John has been admitted to hospital under the Mental Health Act he can be treated for his mental health problem without his consent.

Recording your wishes and feelings about treatment and care

You can also write down or tell people about your wishes and preferences about your future treatment or care. These must be taken into account when determining what is in your best interests. Such statements can request certain types of treatment, which must be carefully considered, especially if they have been written down, but they will not always dictate the decision the person makes on your behalf as the key issue will be your best interests (see part 4 of this booklet).

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, you cannot use such a statement about preferences you may have to ask for your life to be ended.

Example:

Khalid is vegetarian and has a degenerative condition. He wants to make sure that if he loses mental capacity and needs people to help him with daily tasks that they recognise his personal beliefs. He therefore writes down a statement explaining that he only wishes to receive vegetarian food. Khalid asks for the statement to be filed with his health record so that in the future, if he can no longer make and communicate his own decisions, he receives food in line with his wishes.

6. What further support is available?

Support from family and friends

It may be useful to talk to different people before you actually make a Lasting Power of Attorney or advance decision. This could include talking to a GP or other health professional, solicitor, and family and friends. A number of organisations offer advice and support on the Act (see part 12).

Support from an advocate

Advocacy is also a useful source of support for you if you currently lack the capacity to make a decision or if you are worried that you may lack capacity in the future. An advocate is an independent person who helps to make sure your wishes are expressed and that your voice is heard.

Advocates are experienced in working with people who have not been fully and properly involved in decisions which affect their lives. Some organisations that provide advocacy can be found in part 12.

Support if you do not have any family or friends

In most situations, people who lack capacity will have a network of support from family members or friends who take an interest in their welfare, or from a deputy (see part 10) or an attorney appointed under a Lasting Power of Attorney (see part 5).

However, some people who lack capacity may have no one to support them with major decisions which will change the person's life. The Act creates a new advocacy service called an **Independent Mental Capacity Advocate (IMCA)**. An IMCA is a specific type of advocate that will only have to be involved if you do not have any family or friends who can be consulted. An IMCA will only be involved in specific situations:

- Where the decision is about serious medical treatment provided by the NHS.

- It is proposed that the person is moved into long-term care of more than 28 days in hospital or 8 weeks in a care home
- Where a long-term move (8 weeks or more) to different accommodation is proposed, such as a hospital, care home, or nursing home.
- In England, local authorities and the NHS can extend the IMCA service to care reviews and adult protection procedures where they are satisfied that an IMCA would provide particular benefit.
- In Wales, local health boards and local authorities will be able to extend the IMCA service to care reviews and adult protection procedures if the National Assembly for Wales approves this.

The IMCA Service is a new service to help support and protect the rights of particularly vulnerable people who lack capacity. The role of an IMCA is to support and represent you by:

- obtaining and evaluating relevant information - an IMCA can talk to you in private and examine and take copies of health and social care records such as clinical records, care plans or social care assessment documents
- discussing the proposed decision with professionals and others involved in your care and treatment
- finding out, as far as possible, your wishes and feelings - taking into account your beliefs and values
- considering alternative courses of action
- getting a further medical opinion where necessary, where the decision or action is about medical treatment
- providing a report with submissions for the person who instructed him or her.

If a situation arises where an IMCA is required, the person in the NHS or local authority who is making the decision (for instance a doctor or social worker) will request an IMCA for the person who lacks capacity.

Example:

Nikita has a learning difficulty and does not use verbal communication. She lives in a residential home that is closing and has no family or friends who visit her regularly.

Nikita's social worker contacts the Independent Mental Capacity Advocate (IMCA) service and requests an IMCA to represent Nikita and make sure her views are taken into account when the decision about a new home is made.

The IMCA spends time with Nikita at her home and the day service she attends. The IMCA also talks to the care staff about what Nikita appears to like doing. Nikita enjoys horse riding, but does not like being with more than two or three people at a time. Nikita likes to eat on her own and to watch movies with another woman at the home.

The IMCA uses this information to put forward Nikita's views about the type of home she would like to move to.

You can get further information on this in the Code of Practice which supports the Act and you can look at the Department of Health's IMCA web pages by going to www.dh.gov.uk/imca

7. What will happen if I have not planned ahead?

If you have not planned ahead, and a decision about your money, health or lifestyle needs to be made when you lack the capacity to make the decision then someone else will have to decide what to do.

Decisions will be made in your best interests which is explained in [part 4](#) of this booklet.

- The new law says that actions regarding your care and treatment can be carried out by someone else, as long as they are done in your best interests and follow the principles of the Act ([see part 4](#)). This could cover a wide range of actions carried out by carers or professionals such as assistance with washing, dressing, eating or mobility.
- If something needs to be done about your property and financial affairs such as redeeming an insurance policy or selling your house, then someone can apply to the new Court of Protection to deal with the situation, in your best interests. The Court will have authority to make orders about any healthcare or financial matters. There is a more detailed explanation of the role and remit of the new Court of Protection in [part 10](#).
- For complex or ongoing financial decisions or where a series of steps may be needed over a long period, the Court can appoint a [deputy](#) to make decisions for you. Again, the deputy must always act in your best interests, as explained in [part 10](#).

8. Challenging decisions and raising concerns

It may be the case that you disagree with the way you are being treated when you lack capacity. For example, if you have concerns about decisions made on your behalf, or actions being carried out connected to your care and treatment, or you may dispute the assessment made about whether or not you lack capacity to make a decision. There are a number of ways that you can get help to raise concerns, and it is recommended that you try to use informal methods first, before taking any legal or formal action. Informal methods could include using independent advocacy (see part 6) or mediation.

If you have a complaint about a healthcare related issue, the Patient Advice and Liaison Service (PALS) in England provides an informal way to resolve disputes quickly. PALS is an advisory body to support patients and families, and it does not investigate complaints. The equivalent agency in Wales is the local Community Health Council.

You can contact PALS by:

- phoning your local hospital, clinic, GP surgery or health centre and ask for details of the PALS
- phoning NHS Direct on 0845 46 47
- searching the Office Directory on the PALS Online website: www.pals.nhs.uk

If the complaint is still not resolved, or if it is a serious dispute, more formal methods can be used to raise concerns. For health related issues in England, the Independent Complaints Advocacy Service (ICAS) supports people to take forward NHS complaints in a more formal way. You can contact your local ICAS office direct, or through NHS managers at hospitals and GP practices, NHS Direct, or through PALS.

Complaints about social care can be referred in the first instance through your local authority's complaints procedures.

You will also be able to raise concerns and get general information about disputes under the Mental Capacity Act by contacting the Office of the Public Guardian (see part 10).

Finally, the Court of Protection (see part 10) will have the authority to make decisions about capacity and deal with disputes under the Act. There will be a procedure in place to appeal against a decision made by the Court of Protection.

9. What does the Act say about 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 such as Alzheimer's disease.

Sometimes this research will only be useful if it involves people who lack the mental capacity to agree to take part, such as investigating what causes conditions like dementia.

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

- the research must be agreed by a recognised independent Research Ethics Committee to say it is necessary, safe and cannot be done another way using people who have capacity
- researchers must talk to a family member, carer or other relevant person (such as an attorney or deputy) about whether to involve the individual who lacks capacity in the research. If they say the person who lacks capacity would not want to be involved in the research, it cannot take place
- research must not continue if the person shows signs of not wanting 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 will not hurt or upset the person.

Example:

George is asked to take part in a research project designed to study what effects an exercise programme has on the lives of people with Alzheimer's. The only way the researchers can test this is by involving people with Alzheimer's in the research. The panel of experts have already agreed that the participants may benefit from the study, and that the study will provide information that will be useful to others who work with people with Alzheimer's. They also agree that the study does not put those taking part at risk.

George is not able to understand the detail of the study so the researcher consults George's wife who agrees that he would have been interested in taking part in this sort of study. George is able to make decisions about which exercises he wants to take part in each day and the researcher respects these decisions.

10. How the new law is being supported

Code of Practice

The Act is supported by guidance in the Code of Practice, which provides guidance on how the Act will work in reality. The Code has legal status in that certain people must have regard to the guidance when they act in relation to a person who lacks capacity to make a decision. These people include attorneys, deputies, IMCAs, professionals (such as doctors, social workers and lawyers) and people being paid for their work (such as paid carers).

Unpaid carers and family members are not under the same duty to have regard to the Code but they are still expected to follow the general principles. The Code of Practice is designed to help these informal carers use the principles of the Act when making day-to-day decisions for a person who lacks capacity.

Court of Protection

The current Court of Protection only deals with decisions about finances and property. Health and welfare decisions are currently dealt with by the High Court.

The Act will create a new specialist Court of Protection from April 2007. The Senior Judge will be based in London and he will be assisted by specially trained judges who will be based at key locations in England and Wales. This will mean that any hearings can be nearer to the people concerned. The Court will have to make decisions in the best interests of the person who lacks capacity. 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 finance and property of a person who lacks capacity and also certain serious health/welfare 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 8).

The Court has powers to make tailor-made orders if this is thought to be in a person's best interests such as allowing someone to sign a tenancy agreement on behalf of a person with learning disabilities. It will also be able to appoint deputies (see below) with ongoing authority to make decisions for a person who lacks capacity.

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 more appropriate.

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 nearer to April 2007. It will be available in leaflet form and on the OPG website. The OPG Customer Service will always be a first point of contact and able to give advice (see part 11).

There will be a procedure in place to appeal against a decision made by the Court of Protection.

Deputies

If it is necessary to give someone continuing authority to deal with a series of long-term issues, the Court can appoint a deputy to make decisions on a person's behalf. This must be someone who is aged 18 years or over, and can be (among others) a relative, friend, or a professional, such as an accountant or doctor, or the Director of Social Services. If no one is able or wants to be a deputy, the Court can appoint a deputy from an approved panel.

The Court will tailor the powers of the deputy, based on the circumstances of the case. The deputy must always act in the

person's best interests (see part 4). The Office of the Public Guardian (see below) will make sure that deputies are doing their job properly, and a deputy will be accountable to the Court of Protection for any decisions they make on behalf of a person who lacks capacity.

You will be able to get more information about the duties of a deputy from the Office of the Public Guardian (see part 11).

What if I already have a receiver?

From April 2007 when the new Act comes into force, existing receivers will continue to act as before, but will be known as a deputy for property and affairs. More information will be sent to receivers nearer April 2007. If at any later stage a health and welfare deputy needs to be appointed, a separate application will need to be made. For more information please go to:

www.guardianship.gov.uk

Office of the Public Guardian

From April 2007, the Act creates a new public official - the **Public Guardian**. The Public Guardian will be supported by a new **Office of the Public Guardian**, (OPG). The OPGs role is to:

- register LPAs and EPAs
- supervise deputies appointed by the Court of Protection (see above)
- provide information to the Court of Protection
- give information and guidance on the Mental Capacity Act to the public.

The OPG will also help support attorneys and deputies to do their jobs. It will work closely with other organisations who support adults who have difficulty making their own decisions and will also work with the police and social services to respond to any concerns raised about the way in which an attorney or deputy is working.

The OPG will also look at problems or possible abuse and will send serious concerns to the Court of Protection.

The OPG will provide a Customer Services Unit which will be the first point of contact for anyone who needs advice of information about the Mental Capacity Act, becoming a deputy, or making an LPA or registering either an LPA or an EPA.

The functions of the Public Guardian will be monitored by the Public Guardian Board and will need to produce an Annual Report about what work it has been doing.

11. Further sources of information and guidance

Title	Available from
Free newsletter update on the implementation of the MCA. This will keep you up to date on events, communications products and training materials on the MCA	Email: makingdecisions@dca.gsi.gov.uk to subscribe Or telephone: 020 7210 0037/8
Other information booklets like this one	You can view these electronically by going to: www.dca.gov.uk/legal-policy/mental-capacity/publications.htm Or you can email makingdecisions@dca.gsi.gov.uk to order hard copies
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	You can download this for free by going to www.dca.gov.uk/legal-policy/mental-capacity/index.htm The website will also provide details of how you can order a hard copy.
Information on the IMCA service, IMCA Pilots and training materials for IMCAs	www.dh.gov.uk/imca

12. Some useful contacts

The following organisations were involved in writing and advising on the information booklets on the Mental Capacity Act.	
Organisation	What it is/does
<p>Department for Constitutional Affairs (DCA)</p>	<p>Responsibilities include running the courts, and improving the justice system, human rights, information rights law, policy on running elections and modernising the constitution</p>
	<p>5th Floor Steel House, 11 Tothill St, London SW1H 9LH www.dca.gov.uk/legal-policy/mental-capacity/index.htm T 020 7210 0038/39 E makingdecisions@dca.gsi.gov.uk</p>
<p>Department of Health (DH)</p>	<p>DH is responsible for 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</p>
	<p>Wellington House, 133-155 Waterloo Road London, SE1 3UG www.dh.gov.uk T 020 7210 4850</p>
<p>Public Guardianship Office (PGO)</p>	<p>PGO is 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 of mental incapacity</p>
	<p>Archway Tower, 2 Junction Road London, N19 5SZ www.guardianship.gov.uk T 0845 330 2900 E custserv@guardianship.gsi.gov.uk</p>
<p>Welsh Assembly Government</p>	<p>The Assembly develops policy and approves legislation that reflects the needs of the people of Wales</p>
	<p>Cathays Park, Cardiff, CF19 3NQ www.wales.gov.uk T 0845 010 3300</p>

Organisation	What it is/does	Contact
<p>Making Decisions Alliance</p>	<p>It includes: Action on Elder Abuse, Age Concern England, Alzheimers Concern Eating, 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</p> <p>www.makingdecisions.org.uk</p>	<p>PO Box 31856, Lorrimore Square London, SE17 3XR www.actionforadvocacy.org T 020 7820 7868</p>
<p>Action for Advocacy</p>	<p>A resource and support agency for the advocacy sector, information, training and advice</p>	<p>Astral House, 1268 London Road London, SW16 4ER www.ageconcern.org.uk www.accymru.org.uk T 020 8765 7200</p>
<p>Age Concern England</p>	<p>Age Concern is a source of advice and information for older people</p>	<p>Gordon House , 10 Greencoat Place London, SW1P 1PH www.alzheimers.org.uk Helpline: 0845 300 0336</p>
<p>Alzheimer's Society</p>	<p>Alzheimer's Society provides information and support for people with dementia and their carers</p>	<p>Gordon House , 10 Greencoat Place London, SW1P 1PH www.alzheimers.org.uk Helpline: 0845 300 0336</p>

<p>Association of Black Social Workers and Allied Professions</p>	<p>The Association aims to improve the quality of health and social care for Black users and staff</p>	<p>65 Woodrow, Woolwich , London, SW18 5DH T 020 8 854 7402</p>
<p>Association of Directors of Social Services (ADSS)</p>	<p>ADSS represents all the Directors of Adults Social Services (DASS) and Directors of Children's Services (DCS) in England, Wales and Northern Ireland</p>	<p>ADDSS Administrator, ADDSS Business Unit, Local Government House, Smith Square, London, SW1P 3HZ www.adss.org.uk T 020 7072 7433 F 020 7863 9133</p>
<p>British Association of Social Workers (BASW)</p>	<p>BASW is the largest association representing social work and social workers in the UK.</p>	<p>16 Kent Street, Birmingham, B5 6RD www.basw.co.uk T (0121) 622 3911 F (0121) 622 4860</p>
<p>British Medical Association (BMA)</p>	<p>BMA represents doctors from all branches of medicine all over the UK</p>	<p>MA House, Tavistock Square, London, WC1H 9JP www.bma.org.uk T 020 7387 4499 F 020 7383 6400</p>
<p>Carers UK</p>	<p>Looks after family, partners or friends in need of help because they are ill, frail or have a disability</p>	<p>20/25 Glasshouse Yard, London, EC1A 4JT www.carersuk.org T 020 7566 7637 F 0207490 8824</p>

Organisation	What it is/does	Contact
Down's Syndrome Association	Offers help for people with Down's Syndrome	Langdon Down Centre, 2a Langdon Park Teddington, Middlesex, TW11 9PS www.downs-syndrome.org.uk T 0845 230 0372 F 0845 230 0373
English Community Care Association	The largest representative body for community care in England	4th Floor, 145 Cannon Street, London www.ecca.org.uk T 020 7220 9595 F 020 7220 9596
Foundation for People with Learning Disabilities	Works with people with learning disabilities to improve the quality of their lives	Sea Containers House, 20 Upper Ground London, SE1 9QB www.learningdisabilities.org.uk T 020 7803 1100
General Medical Council (GMC)	GMC registers doctors to practise medicine in the UK	Regents Place, 350 Euston Road London, NW1 3JN T 0845 357 3456 F 0845 357 8001
Headway – the brain injury association	To promote understanding of all aspects of brain injury; and to provide 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 T 0115 9240800 Helpline 0800 800 2244

<p>Local Government Association (LGA)</p>	<p>LGA promotes the interests of English and Welsh local authorities – a total of just under 500 authorities</p>	<p>Local Government House, Smith Square London, SW1P 3HZ www.lga.gov.uk T 020 7664 3131 F 020 7664 3030</p>
<p>MENCAP</p>	<p>Charity working with people with learning disabilities, their families and carers</p>	<p>123 Golden Lane, London, EC1Y 0RT www.mencap.org.uk T 020 7454 0454</p>
<p>Mental Health Foundation</p>	<p>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</p>	<p>Sea Containers House (same address as Foundation for People with Learning Disabilities) www.mentalhealth.org.uk T 020 7803 1100</p>
<p>MIND</p>	<p>A mental health charity in England and Wales</p>	<p>15-19 Broadway, Stratford, London E15 4BQ www.mind.org.uk T 0208 519 2122</p>
<p>National Autistic Society (NAS)</p>	<p>NAS exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs</p>	<p>393 City Road, London, EC1V 1NG www.autism.org.uk T 0845 070 4004 (autism helpline)</p>
<p>National Care Association (NCA)</p>	<p>NCA represents the interests and provides services to support small and medium sized providers of social care in England and Wales</p>	<p>45-49 Leather Lane, London, EC1N 7JT www.nca.gb.com T 020 7831 7090</p>

Organisation	What it is/does	Contact
National Care Forum	The National Care Forum was established to represent the interests of not-for-profit health and social care providers in the United Kingdom	National Care Form, 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
Patient Concern	Patient Concern is an organisation committed to promoting choice and empowerment for all health service users	PO Box 23732, London SW5 9FY www.patientconcern.org.uk
The Relatives and Residents Association	The Relatives & Residents Association exists for older people needing, or living in, residential care and the families and friends left behind	24 The Ivories, 6-18 Northampton Street London, N1 2HY www.relres.org T 020 7359 8148
RESCARE	The national society for children and adults with learning disabilities and their families	Steven Jackson House, 31 Buxton Road Heaveley, Stockport SK2 6LS www.rescare.org.uk T 0161 474 7323

RESPOND	Challenging vulnerability and sexual abuse in the lives of people with learning disabilities	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
Royal College of Nursing (RCN)	The RCN represents nurses and nursing	20 Cavendish Square, London, W1G 0RN www.rcn.org.uk T 020 7409 3333
Royal College of Psychiatrists	The Royal College of Psychiatrists is the professional and educational body for psychiatrists in the United Kingdom and the Republic of Ireland	17 Belgrave Square, London SW1X 8PG www.rcpsych.ac.uk T 020 7235 2351
Social Care Association	A vibrant, inclusive and informed Association which visibly promotes positive practice within all social care services throughout the UK	Thornton House, Hook Road, Surbiton Surrey KT6 5AN www.socialcareassociation.co.uk T 020 8 397 1411
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

Organisation	What it is/does	Contact
Turning Point	Turning Point is 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

Please note that from April 2007 the Office of the Public Guardian will provide a Customer Services Unit which will be the first point of contact for anyone who needs advice or information about the Mental Capacity Act. Their contact details are:

Phone 0845 330 2900 or go online: www.publicguardian.gov.uk

From April 2007 you should contact the OPG if you need information on the Mental Capacity Act 2005.

This booklet will be updated once the Mental Capacity Act comes into force in 2007.

If there is anything you really liked or didn't like about the booklet please let us know so that we can improve the next booklet. Please write to us at:

Communications Team
Mental Capacity Implementation Programme
Department for Constitutional Affairs
5th Floor Steel House
11 Tothill Street
London
SW1H 9LH

Or email us:
makingdecisions@dca.gsi.gov.uk

Notes

