OPG601

Office of the Public Guardian

Making decisions

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

The Mental Capacity Act

Making decisions

...about your health, welfare or finances. 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 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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1. Introduction

About this booklet

This booklet gives you information about the Mental Capacity Act 2005 (the 'MCA'), which affects anyone who is unable to make some or all decisions for themselves.

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 MCA helps and supports you if:

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

This booklet explains:

- how the MCA could affect you;
- how you can plan ahead now in case you cannot make your own decisions in the future;
- how you are 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; and
- where to go for help and advice.

Another key source of information and more detailed guidance is the Code of Practice that accompanies the MCA. It can be found online at www.publicguardian.gov.uk

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 that 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 Mental Capacity Act 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 particular decisions. 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 MCA provides a clear legal framework for dealing with mental capacity issues and helps to ensure that fraud and abuse do not take place.

2. What is the Mental Capacity Act and how does 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 MCA 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.

However, some types of decisions (such as marriage or civil partnership, divorce, sexual relationships, adoption and voting) can never be made by another person on your behalf if you lack capacity and the MCA does not change this. This is because these decisions or actions are either so personal to the individual or because other laws govern them.

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

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

The MCA 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; and
- help resolve disputes.

The MCA 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 MCA

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

1. All adults have the right to make decisions for themselves unless it is shown that they are unable to make them. 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 decision before anyone concludes that they cannot make their own decision. This may be through using different ways of communicating such as words, pictures or signs and providing information in different formats, such as audio or Easyread. 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 MCA is to make sure that people who lack capacity are not restricted unnecessarily. So the person making the decision or taking the action must consider 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 Mental Capacity Act (see part 2).

Anyone - a health or care professional, other professional, relative or carer - might need to decide whether 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 to be made is more complex, the more formal the assessment of your capacity may need to be and this may involve doctors or other professionals.

For medical decisions where consent is needed for treatment or examination, a doctor or healthcare professional will decide whether or not you have capacity to consent.

For legal decisions such as making a will, the solicitor concerned will decide whether or not you have capacity to make the decision.

Your family, friends and any other relevant people should also be consulted during an assessment but this will depend on the situation and the decision that needs to be made.

How does someone decide whether or not I lack capacity?

The MCA 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 decisions.

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 MCA 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 MCA 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 (principle 4). 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 MCA says that they should use the one which is less restrictive.

The use of restraint

Sometimes it is necessary to physically restrain a person. The MCA 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. If a person uses excessive restraint they could be liable to a range of civil and criminal penalties.

What are the Mental Capacity Act 2005 Deprivation of Liberty Safeguards?

The Mental Capacity Act 2005 Deprivation of Liberty Safeguards (MCA DOLS), which come into force in England on 1 April 2009, provide a legal framework to prevent unlawful deprivation of liberty occurring. They protect vulnerable people in hospitals or care homes who lack the capacity to consent to the arrangements made for their care and/or treatment but who need to be deprived of their liberty in their own best interests to protect them from harm. Primary care trusts (PCTs), local authorities, hospitals and care homes have a statutory responsibility for administering and delivering the MCA DOLS at a local level.

If you want to find out more about what MCA DOLS means for you or your organisation, the MCA DOLS Code of Practice, which explains in detail how MCA DOLS' processes and procedures work, can be downloaded at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085476

Or you can visit the website at: www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm

The Welsh Assembly Government has published three guidance booklets to assist managing authorities and supervisory bodies identify the key processes in the safe and effective use of the safeguards:

1. Guidance for Managing Authorities working within the Mental Capacity Act Deprivation of Liberty Safeguards.
2. Guidance for Supervisory Bodies working within the Mental Capacity Act Deprivation of Liberty Safeguards.
3. Standard Forms and Letters for the Mental Capacity Act Deprivation of Liberty Safeguards.

The Welsh Assembly Government has also published a range of information leaflets which managing authorities and supervisory bodies may use to assist in providing information to the relevant person. These can be found at www.mentalcapacityact.wales.nhs.uk

Protecting people from ill-treatment or wilful neglect

The MCA provides a new protection for people who may lack capacity, to keep them safe and prevent them from being harmed. This applies to anyone who works with or supports a person who lacks capacity to make their own decisions, as well as to Attorneys (see part 5) and Deputies (see part 10).

There is a new criminal offence of ill-treating or wilfully neglecting a person who lacks capacity. This covers 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 Mental Capacity Act allows you to appoint someone else to make decisions for you in the future, should you lack capacity to do this yourself. Previously the law allowed you to appoint one or more Attorneys in advance to make decisions about your finances only. Since 1 October 2007, as well as for 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 that allows 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 is 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 gives 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 gives 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 the two types of LPA is that a Personal Welfare LPA only takes 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 must have regard to the Code of Practice (see part 2) and act in your best interests (see part 4).

Example:

Jean is in the early stages of Alzheimer's disease. She appoints her daughter as a Personal Welfare Attorney to make any personal welfare decisions she loses capacity to make. She talks through things that are important to her such as wanting to stay near her friends and being able to go into a care home that allows pets. When the LPA is needed, her daughter knows what her mother's wishes are 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 need to complete a form which you can get from the Office of the Public Guardian (OPG). An outline of the role and powers of the OPG can be found at 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 contains guidance to help you fill it in.

You can 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 means 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 is a fee for registration. You can also choose who you want to be notified when the LPA is being registered. This does not have to be family, it is up to you.

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 your best interests.

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

The new system of LPAs replaces Enduring Powers of Attorney (EPAs) which only allow people to appoint an Attorney to manage their property and financial matters. The new LPAs give more protection and extra options including the ability to appoint an Attorney to manage your personal welfare matters as well as your property and affairs.

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 you should contact the OPG or visit www.publicguardian.gov.uk

Finally, even if you already have an EPA (which only applies to finance and property matters), you can also make an additional LPA for personal welfare decisions under the Mental Capacity Act.

If you have an EPA or an LPA, under the Act the Attorney has 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, also known as 'living wills' but the MCA introduces a number of rules that you must follow when making an advance decision for it 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, 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; and
- 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; and
- 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 made an advance decision (sometimes known as a 'living will') before the MCA came into force then it may still be valid. However, you should check that it meets the new rules, particularly if it deals with life-sustaining treatment. More detailed guidance on this is available at www.dh.gov.uk/consent

Does 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 MCA 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).

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, family and friends. A number of organisations offer advice and support on the Mental Capacity 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 are listed 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 Attorney appointed under a Lasting Power of Attorney (see part 5).

However, some people who lack capacity may have no one (other than paid staff) to support them with major decisions which will change the person's life. The Mental Capacity Act creates a new advocacy service called the Independent Mental Capacity Advocate (IMCA). An IMCA is a specific type of advocate that only has to be involved if you do not have anyone appropriate 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;
- where 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, and in Wales Local Authorities and Local Health Boards, can extend the IMCA service to specific situations if they are satisfied that an IMCA would provide particular benefit. These are:

- care reviews about accommodation or changes to accommodation; and
- adult protection cases (even if the person who lacks capacity has family and/or friends).

The IMCA service helps 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 and suggesting these to the decision-maker;

- getting a further medical opinion where necessary, where the decision or action is about medical treatment; and
- providing a report with submissions for the person making the decision.

If the IMCA disagrees with the decision made, they can also challenge the decision-maker.

If a situation arises where an IMCA is required, the person in the NHS, Local Authority or Health Board 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 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 about IMCAs in the Code of Practice which supports the MCA and you can look at the Department of Health's IMCA web pages at 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 Mental Capacity Act 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 MCA (see part 4). This covers 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 Court of Protection (the 'Court') to deal with the situation in your best interests. The Court has authority to make orders about any healthcare or financial matters. There is a more detailed explanation of the role and remit of the Court 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

You may disagree with the way you are being treated when you lack capacity. For example you may have concerns about decisions made on your behalf, 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 you can get help to raise concerns, and it is recommended that you try to use informal methods 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. 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; or
- 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) has authority to make decisions about capacity and deal with disputes under the MCA. There is a procedure in place to appeal against a decision made by the Court of Protection.

9. What does the Mental Capacity Act say about research?

Research is an important way for us to understand illness and disability and to improve the care and support that 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 Mental Capacity 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. They include the following:

- 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.
- The 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 Mental Capacity Act is supported

Code of Practice

The Act is supported by the Code of Practice (the 'Code'), which provides guidance on how the Act will work in reality. The Code has legal status and certain people must have regard to it when they act in relation to a person who lacks capacity to make a decision. This means that they must pay attention to the Code and be able to show that they are familiar with the guidance in it. If they don't follow the Code they should be able to give convincing reasons why not. 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 don't have the same duty but they are still expected to follow the general principles and will find the guidance useful. The Code is designed to help them use the principles of the Act when making day-to-day decisions for a person who lacks capacity.

Court of Protection

The Mental Capacity Act created a new specialist Court of Protection. The Senior Judge is based in London and is assisted by specially-trained Judges who are based at key locations in England and Wales. This means that any hearings can be nearer to the people concerned. The Court has to make decisions in the best interests of people who lack capacity.

The Court makes final decisions on capacity if there is uncertainty about whether a person is able to make the decision in question. It deals with decisions about the finance and property of a person who lacks capacity and also certain serious health and welfare decisions - most commonly where there is a dispute about best interests. The Court normally only hears 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. This may include allowing someone to sign a tenancy agreement on behalf of a person with learning disabilities. It also appoints Deputies (see below) with ongoing authority to make decisions for a person who lacks capacity.

Although many Court hearings 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 deals with any urgent interim directions required and then if necessary will refer the matter to be heard at a regional court if this is more appropriate.

Some people need to get the Court's permission to make an application. The rules about this are set out in the application forms and guidance available by calling 0845 330 2900 or at www.publicguardian.gov.uk.

For more information about how you can access the Court of Protection and about who needs to seek permission for Court action, see contact details at part 11.

There is 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 of Protection 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, 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 tailors the powers of the Deputy according to 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 (page 37) makes sure that Deputies are doing their job properly, and Deputies are accountable to the Court of Protection for any decisions they make on behalf of a person who lacks capacity.

You can 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?

Form 1 October 2007 Receivers are known as Deputies for property and affairs. If a personal welfare Deputy needs to be appointed, a separate application needs to be made. For more information please go to:
www.publicguardian.gov.uk

Office of the Public Guardian

The Public Guardian is a public official supported by the Office of the Public Guardian (OPG). The OPG's role is to:

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

The OPG also helps support Attorneys and Deputies to do their jobs. It works closely with other organisations who support adults who have difficulty making their own decisions and also works 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 also looks at problems or possible abuse and sends serious concerns to the Court of Protection.

The OPG has a phone number (see Part 12) which is the first point of contact for anyone who needs advice or information about the Mental Capacity Act, becoming a Deputy, making an LPA or registering either an LPA or an EPA.

The Public Guardian is monitored by the Public Guardian Board and produces an Annual Report about the work it has been doing.

11. What if I want to know more about the Mental Capacity Act?

If you would like to know more about the Mental Capacity Act you can call 0845 330 2900
or email customerservices@publicguardian.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.publicguardian.gov.uk
The Mental Capacity Act 2005	You can view this for free by going to: www.publicguardian.gov.uk 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 it for free by going to: www.publicguardian.gov.uk 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

12. Some useful contacts

The following government departments work together to implement the Mental Capacity Act

Department	What it is/does	Contact
Office of the Public Guardian (OPG)	The Office of the Public Guardian supports and promotes decision-making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005	www.publicguardian.gov.uk T 0845 330 2900 E customerservices@publicguardian.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
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 ORT 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.hft.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	Standon House, 21 Mansell Street, London, E1 8AA www.turning-point.co.uk T 020 7481 7600
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:

OPG602 Making decisions:
A guide for family, friends and other unpaid carers

OPG603 Making decisions:
A guide for people who work in health and social care

OPG604 Making decisions: A guide for advice workers

OPG605 Making decisions: An Easyread guide

OPG606 Making decisions:
The Independent Mental Capacity Advocate (IMCA) service

Making decisions booklets are available to download at: www.publicguardian.gov.uk and are available in English, Welsh and Braille formats. There is also an Easyread booklet and Easyread Audio version. Contact the Office of the Public Guardian for more information.

OPG607 Deprivation of Liberty Safeguards:
A guide for primary care trusts and local authorities

OPG608 Deprivation of Liberty Safeguards:
A guide for hospitals and care homes

OPG609 Deprivation of Liberty Safeguards:
A guide for relevant person's representatives

Deprivation of Liberty Safeguards booklets are available at: www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm

The Mental Capacity Implementation Programme published this booklet. It was written by Turning Point, Scope and Mind who are members of the Making Decisions Alliance.

OPG601 Making decisions...about your health, welfare or finances.
Who decides when you can't? (04.09)

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