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Artwork by Alex Milton, a man with autism.

Introduction

The booklet has been written primarily for adults with autism¹. It includes a section for family members and carers and may be useful for professionals who work with people with autism and their families. We recognise that the topic is a complex one and that some individuals with autism may need assistance in understanding the information contained in this booklet.

If you are reading this and need further help to understand the *Mental Capacity Act*, it may help you to ask a family member, advocate, social worker or GP.

In 2007 new legislation called the *Mental Capacity Act 2005* (also referred to as 'the Act' in this guide) came into effect in England and Wales. This will help and support people who find it difficult to make decisions some or all of the time, and will help people to plan ahead in case they can't make decisions in the future. Most of the Act came into force in October 2007, but some parts of it came in to force in April 2007.

The Act applies to people aged 16 and over. It will apply to some people who have a learning disability, mental health problems, brain injury or illnesses such as dementia and will also include some people with autism. The Act will apply where an individual's ability to make a decision is affected. It may not relate to all decisions at all times; for example, you may be capable of making a decision about what to wear or eat but not about how to spend your money.

The law makes it clear how other decision makers such as parents, carers and health or care professionals can decide if you have capacity to make a specific decision. If you are unable to make a decision, it helps to make sure that the right decision is made for you. It tells you who may make decisions in your best interests, how you can nominate others to make decisions for you in the future and how you can plan how you would like to be treated in the future.

If you don't have any appropriate family or friends to make certain decisions in your best interests and you lack capacity to make that decision yourself, the law also says that you can get support from an Independent Mental Capacity Advocate (IMCA).

¹ For the purposes of this document 'autism' refers to all conditions on the autistic spectrum, including Asperger syndrome.

Summary of the key points in this booklet

- Mental capacity is when a person has the ability to make a decision about something.
- The *Mental Capacity Act 2005* sets out the legal rights for supporting and protecting people who are assessed as lacking mental capacity. This may include, for example, some people with learning disabilities, mental health problems, brain injury or dementia, when their ability to make a decision is affected. The Act will also apply to some people with autism or Asperger syndrome.
- The Act will affect people in England and Wales who are 16 years and over.
- The Act covers a wide range of decisions on personal welfare, health care and financial matters.
- There are five key rules or principles of the Act:
 - › Every adult has the capacity to make their own decisions until it is shown that they can't.
 - › A person must be given support to help them make decisions.
 - › Nobody should be stopped from making a decision just because others may think it is unwise.
 - › If a decision is made for a person who lacks capacity, it should be in their best interests.
 - › When anything is done or decided for a person without capacity, it must be the least restrictive of his/her rights and freedoms.
- The Act sets out a clear test for assessing whether a person lacks capacity to take a particular decision at a particular time.
- In everyday situations, a family member or carer can decide if a person is able to make a decision. In other complex situations, health or care professionals may need to decide.

- If someone does not have capacity to make certain decisions and also do not have anyone appropriate to be consulted about the best decision for them, (ie friends or family), an Independent Mental Capacity Advocate (IMCA) will be appointed.

This is only a short summary. If you need more help to understand the Mental Capacity Act, it may help you to ask a family member, advocate, social worker or GP.

What is mental capacity?

Mental capacity is when you have the ability to make decisions for yourself. The law says that to do this you need to be able to do all of the following things:

- understand the information given to you in relation to a decision
- remember that information long enough to make a decision
- use or weigh up the information available
- communicate your decision in any way which can be recognised (if you need help to communicate, you should be assisted to in any way which is practical and appropriate, considering all the circumstances and your needs).

Capacity should be decided for each specific decision; lacking capacity to make one decision, doesn't automatically mean you lack capacity to make another.

What powers does the Mental Capacity Act 2005 have?

The *Mental Capacity Act* is a new piece of legislation. It would be unlawful for a decision maker to ignore this legislation. The Act is supported by a Code of Practice which provides further guidance and gives practical examples of how the provisions in the Act should be implemented. Although the Code of Practice is only guidance rather than law, the courts expect it to be followed unless there is good reason not to. The code must be followed by professionals (detailed in s42(4) of the Act) such as doctors and social workers.

There are five principles of the Act. These principles underpin the legal requirements in the Act and so apply to any action done or decision made under the Act. These principles must be adhered to by anyone using the Act such as those assessing capacity and making decisions on behalf of those who lack capacity. The principles are:

- 1 It is assumed that you have capacity to make decisions, unless it is proven otherwise.
 - › An adult has the right to make their own decision regardless of a particular disability or condition; you must be seen as capable of making a decision unless it is shown that you are not.
- 2 Every effort should be made to provide you with the necessary help and support to enable you to make and communicate a decision before anyone decides that you lack capacity.
 - › Information should be presented in a way you can understand, and you should be given the help and support you need to enable you to make the decision yourself.

- 3 It should not be assumed that you lack capacity if you make a decision that other people view as being unwise.
 - › The *Mental Capacity Act* concerns your capacity to make a decision, not how sensible the decision is. If someone disagrees with a decision you have made, this is not a reason to assume you lack capacity.
- 4 If you lack capacity to make a decision, any decision made for you must be in your best interests.
 - › See page 10 for more information about how decisions are made in your best interests.
- 5 Before any decision is made on your behalf, consideration should be given to whether it is possible to make a decision that is the 'least restrictive' which means that your rights and freedom of action are limited as little as is necessary.
 - › If you lack capacity and anyone does anything to or for you, the option the decision maker chooses must be both in your best interests and they must consider whether a less restrictive option would be as effective.

What type of decisions does the Act cover?

The law looks at your capacity to make decisions about your personal welfare. This means financial, health and social care decisions such as:

- washing, dressing, help with eating
- nursing care - in hospital/care home/community
- occupational therapy, physiotherapy, podiatry
- homecare services
- social care
- moving to a care home or other accommodation
- the contact you have with others
- medical and dental treatment, diagnostic tests.

Your capacity in relation to other decisions such as marriage, civil partnership, and how you vote in elections are not covered by the Act.



Woman in the sensory room of a National Autistic Society day service.

Who decides if I lack capacity?

The law says that you must be assumed to have capacity unless it is proved to be otherwise through this legislation. This means that a diagnosis of a particular condition, type of behaviour, your age or appearance cannot automatically mean you lack capacity.

"This does not mean that Isaac lacks the capacity to make a decision."

Isaac has an autism spectrum disorder. His behaviour is often aggressive and he can hit out at his carers. This does not mean that Isaac lacks the capacity to make a decision; only by applying the test of capacity (see page 3) can it be proven that he does lack capacity.

Before deciding that you do not have capacity to make a decision, the law says that all practicable steps must have been taken to help you make the decision. For example, this may mean that you need extra time, to be in a different setting or to have information about the decision in a different format such as written information.

"He did not lack the capacity to make the decision."

John has Asperger syndrome. He sometimes gets very anxious in unknown situations; this can make it difficult for him to make a decision. His social worker

needs to know which day service he would prefer to attend; she asks him this at the end of a visit to both services. John's anxiety levels are high because he is in a strange environment and finds it difficult to absorb the information the social worker is giving him. To help him make the decision, the social worker needs to take steps to help him make the decision. She takes John back home (an environment he feels less anxious in) and provides him with written information about both day services to help him remember the options. John's anxiety levels decrease and he is able to make the decision about which service he preferred. He did not lack the capacity to make the decision.

If a carer or service doesn't agree with your decision, this doesn't mean that you don't have the capacity to make the decision. As long as you are able to understand the information, retain that information, take account of the information and communicate your decision, you have the capacity to decide whatever you think is best.

"Colin has Asperger syndrome. He wants to book a holiday for himself on the coast."

Colin has Asperger syndrome. He wants to book a holiday for himself on the coast. His carer doesn't think this is a good



idea because Colin has difficulties with social interaction and daily routines. She is concerned that he will not be able to cope on his own. She applies the test of capacity (see page 3) and the outcome is that Colin has the capacity to decide, despite her concerns over his decision.

In everyday situations, it may be family members or carers who will decide if you are capable of making a decision. In other situations, health or care professionals, other professionals, relatives or carers may need to decide if you have the capacity to make a decision. If the decision that needs to be made is quite simple or a day-to-day decision, the way your capacity is assessed will also be quite simple.

"Clare goes to leave the building without her coat."

Clare has autism. She needs help with most daily activities, including dressing herself and can find it very difficult to understand the consequences of an action. She and her carer are planning to go for a walk, it is January and cold outside, and Clare does not like being cold. Clare goes to leave the building without her coat. This is quite a simple decision and so the carer's assessment of Clare's capacity is also simple; after talking to her briefly about the decision, from her answers, he realises that although she does not like

being cold, she does not understand that she will be cold if she goes out without a coat.

When the decision is more complex, the assessment of capacity may need to be more formal and could involve professionals such as doctors or solicitors. Friends, family and other relevant people should also be consulted, although sometimes this will depend on the situation and the decision that is to be made.

"He has been seen by his GP because he has had a very bad cough."

Peter also has autism. He has been seen by his GP because he has had a very bad cough. The GP thinks he may need an x-ray to see what is causing the cough. Because this is a more complex decision and the GP is the one taking the decision about the need for an x-ray, the GP will be the person who decides if Peter has the capacity to make the decision. In doing this he may also consult other professionals as well as Peter's brother who visits regularly.

How is a decision made as to whether or not I have capacity?

The *Mental Capacity Act* is very careful to make sure that everything is done to help you make the decision. It is important for decision makers to remember that capacity can change - you may have the capacity to make a decision at a particular time but not another, or you may have the capacity to make some types of decisions but not others. Before anyone makes a decision in your best interests, they must have a 'reasonable' belief that you lack capacity. This is important as capacity can change over time, so decision makers need to check regularly that you still lack capacity.

The law sets out a 'test for capacity'; these are certain things that you must be able to do to be seen as capable of making that decision. For this test to be applied there has to be evidence of "an impairment of, or disturbance in the functioning of, the mind or brain". The key point is that there is evidence.

If there is such evidence, then the rest of the second stage of the 'test for capacity' can be applied.

"Ali has autism and needs some medical treatment."

Ali has autism and needs some medical treatment. There are a few options and the doctor needs to know if Ali has the capacity to decide on the best form of treatment.

To be seen as capable of making a decision, you must be able to:

- 1 Understand the information relevant to the decision
 - You must be able to understand:
 - › the nature of the decision
 - › the purpose of the decision
 - › the consequences of making or not making the decision.
 - What can help you understand?
 - › You need the right amount of information; the more complex and serious the decision, the more information you will need
 - › The information should be provided in a way that is appropriate for you – you may need more time to understand, to have pictures or written information, or a change of physical environment in which to process the information.
 - › It may help if the information is presented to you by people you are familiar with, such as family or carers, or they may be consulted about the methods of communication that are best for you.

"The doctor gives Ali and his father some easy-to-read leaflets."

Ali's father has come to see the doctor with him and tells the doctor that Ali usually understands information better when it is presented in a visual format. The doctor gives Ali and his father some easy-to-read leaflets about the different treatments and about the condition that he is seeing the doctor for.

2 Retain the information

- This means that:
 - › You must be able to retain the information long enough to make a decision.
 - › If you have a poor short-term memory it does not automatically mean you aren't capable of making the decision.
 - › Support can be used to help you retain the information, such as notebooks, photos, videos or voice recorders.

"Ali carries a notebook with him."

Ali carries a notebook with him which helps him to remember things. He uses this to help him retain the information the doctor has given him.

3 Use or weigh the information

- You must be able to:
 - › consider the benefits and risks of any available options
 - › take the information into account
 - › use or weigh up the pros and cons as part of the decision-making process – have you considered all the information rather than making an impulsive decision?

"Ali spends some time with his father and the doctor."

Ali spends some time with his father and the doctor looking at the information and

weighing up the consequences of the decision. His father explains to him what the outcome of each option would be in a balanced way. Ali is then able to understand the benefits and also the side effects of the different treatments available.

4 Communicate the decision

- You do not have to communicate this decision verbally; you can use the method that is best for you – written information, signing, using pictures – as long as your method of communication can be recognised by the assessor.
- The assessor must take all practical and appropriate steps to help you communicate, including asking other people to assist such as, a speech and language therapist.

"Ali often uses PECS."

Ali often uses PECS (the Picture Exchange Communication System) to support his communication. After he has made a decision he uses his PECS to help him tell the doctor which option he would like to try.

In the example above, we have assumed that Ali does have the capacity to make the decision, with a little support from the use of visual information and his father. In the next section we will look at what happens when the test of capacity shows that someone does not have the capacity to make a decision.

What happens if I do not have capacity to make a decision?

The *Mental Capacity Act* says that where the test for capacity has been applied and you do not have capacity to make the decision yourself, the decision made for you must be in your best interests. Best interests cannot be based simply on someone's age, appearance, condition or behaviour. The Act sets out a checklist that must be followed to ensure that decisions are made in your best interests. All points of this checklist must be considered:

- all relevant circumstances
- will you regain capacity so you can make your own decision sometime in the future and if so, can the decision wait?
- your past and present wishes and statements
- your beliefs and values (eg religious, cultural or political beliefs)
- other factors you would consider if you were able to do so (eg if you have dependents or pets)
- consult others if practicable and appropriate on their views about what is in your best interests (eg someone you have requested to be consulted, carers, relatives, attorneys, deputies or an existing advocate)*
- you must be encouraged and permitted to participate in any act or decision made
- the least restrictive option must be considered – can the same result be achieved in a way that interferes less with your rights and freedoms, is there a need to act at all?

*Additionally, Section 4(5) of the Act applies, which states:

"Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death."

The person who decides what is in your best interests is referred to as the 'decision maker'; this is the person who needs to make the specific decision for you. For instance:

- **medical treatment** - the doctor proposing the treatment would be the decision maker
- **nursing care** - the nurse providing the care would be the decision maker
- **daily decisions about general care** - carers, friends or family would make the decision.

Certain decisions can only be made by the Court of Protection (see page 17 for more on the Court of Protection); this is often when there are serious disputes about what is in your best interests.

Some decisions cannot be made for you or in your best interests as part of the Act:

- It couldn't be decided that it would be in your best interests to enter into any family relationships, such as marriage/civil partnership, divorce (consenting to a decree of divorce on the basis of two years separation). There are separate capacity tests for some of these decisions.
- Someone cannot vote on your behalf.
- Someone cannot use the Act to give you mental



health treatment if you are detained and being treated under part IV of the Mental Health Act 1983.

The *Mental Capacity Act* also provides some protection to you if you are lacking capacity and are inappropriately restrained or deprived of your liberty. The Act describes restraint as:

- the use of force – or the threat of using force – to make you do something you are resisting, or
- the restriction of your freedom of movement whether you are resisting or not.

The Act says that a person taking action that is intended to restrain you if you lack capacity will only be protected from liability if they believe that the restraint is necessary to prevent harm to you. They must also make sure that it is in your best interests and that the amount and type of restraint used and the amount of time it lasts is a proportionate response to the likelihood and seriousness of harm. Restraint must not be used just so that a carer or professional can do something more easily; if restraint is necessary to prevent harm to you if you lack capacity, it must be the minimum amount of force for the shortest amount of time possible.

The *Mental Capacity Act* Code of Practice gives the following example about appropriate restraint. It focuses on a man called Derek who lacks capacity.

Derek, a man with learning disabilities, has begun to behave in a challenging way. Staff at his care home think he may have a medical condition that causes him distress. They take him to the doctor, who thinks Derek might have a hormone imbalance.

But the doctor needs to take a blood test to confirm this, and when he tries to take the test Derek attempts to fight him off.

The results might be negative – so the test might not be necessary. But the doctor decides the test is in Derek's best interests, because failing to treat a problem like a hormone imbalance might make it worse. It is therefore in Derek's best interests to restrain him to take the blood test. The temporary restraint is in proportion to the likely harm caused by failing to treat a possible medical condition.

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How can I be sure decisions are made in my best interests?

If you have been assessed as lacking capacity and you have no friends, relatives, carers (not paid/professional carers) or others appropriate to consult in deciding what your best interests are, the NHS and local authority (local health board in Wales) have a duty to appoint a special type of advocate also known as an IMCA.

The NHS has a duty to appoint an IMCA if they are proposing:

- serious medical treatment
- a stay of more than 28 days in hospital or eight weeks in a care home
- a change of accommodation to another hospital for more than 28 days or another care home for more than eight weeks.

The duty is on the local authority to instruct an Independent Mental Capacity Advocate (IMCA) where they are proposing to change or provide residential accommodation for eight weeks or more.

Sometimes the NHS organisations and local authorities will make decisions together about moving a person into long-term care. In these cases, the organisation that must instruct the IMCA is the one that is ultimately responsible for the decision to move the person.

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An IMCA is a special type of advocate who is independent of the person making the decision. The role of the IMCA is to:

- support you if you are assessed as lacking capacity
- obtain and evaluate relevant information
- find out what alternative courses of action are available
- find out what your feelings and wishes would be.

An IMCA may also be appointed in other circumstances, such as those surrounding care reviews or adult protection cases.

The IMCA has certain powers/functions. They can:

- interview you in private
- examine or copy records which the record holders consider relevant
- make suggestions that must be taken into account
- get a further medical opinion if necessary
- challenge a decision via the Court of Protection.

"Rita has autism and lives in a residential home."

Rita has autism and lives in a residential home. A permanent change to her accommodation has been proposed but the test of capacity has shown that Rita is not capable of making a decision herself. In the absence of any friends or family to consult, the local authority appoints an Independent Mental Capacity Advocate to represent and support Rita.



For certain decisions, the Court of Protection may appoint a deputy (for more information about deputies, see page 18). They can deal with decisions relating to finance, property, and some personal welfare and healthcare decisions. The Court of Protection will specify the type of powers the deputy will have and how long their powers will last for. The person appointed may be somebody who knows you in a professional or personal capacity, such as a carer or family member, or they may be in a certain position, such as the director of adult services for a local authority.



Artwork by a man with autism.

How can I make decisions about how I want to be treated in the future?

The *Mental Capacity Act* also sets out ways for you to decide now how you would like to be treated in the future. There are two ways this can be done; we will look at each in turn.

Advance decisions

An advance decision is a way for you to plan ahead and make clear your wishes about refusing treatment, including life-sustaining treatment.

Refusing treatment

You can make an advance decision to say what types of treatment you would refuse which under the Act's requirements are legally binding. Advance decisions about refusing treatment do not have to be in writing (except when they relate to life-sustaining treatment), although it is helpful if they are. When you make the advance decision, you must be over 18 and have the mental capacity to make the decision. You will need to be clear about which treatments you would refuse and in which circumstances this refers to; you do not have to use medical terminology to do this. A doctor will use this information to decide if the decision is valid and if it applies to the particular treatment. If you have decided to refuse treatment because of certain religious or philosophical beliefs, it can be helpful to explain this in the advance decision.

If your views or wishes change over time, you can change the advance decision as long as you have the mental capacity to do so. By keeping the advance decision up-to-date, it can help health professionals to see that it is valid. If you have not kept it up-to-date and after making it you do something which is clearly inconsistent with the advance decision, the health professional may decide that it is not valid.

Life-sustaining treatment

You can also make an advance decision to say that you do not wish to receive treatment that is needed to keep you alive. For instance, if your wish was not to be put on a 'life-support' machine or machine that breathed for you, you can write an advance decision which will apply should this situation arise and tell professionals that you don't want this to happen. You can change the decision whenever you like, as long as you have the capacity to do so.

To be valid the advance decision for life-sustaining treatment must be:

- in writing
- signed by you or someone else in your presence and as directed by you. The signature must be witnessed and the witness must sign the paper
- a statement in the advance decision which states that it will apply even if the life of the person making it is at risk.

"Her religious views mean that she wouldn't want to receive a blood transfusion."

Jenna has an autism spectrum disorder. She is a Jehovah's Witness and her religious views mean that she wouldn't want to receive a blood transfusion. She writes an advance decision explaining this and the reasons underlying it.

"He asks his GP to help him by witnessing an advance decision to ensure his wishes are known."

Arjun has Asperger syndrome and has decided that if he was to need life-saving treatment, such as being put on a life support machine, he would like to refuse this treatment. He asks his GP to help him by witnessing an advance decision to ensure his wishes are known if he loses the capacity to decide in the future. Arjun and the GP sign the paper. There is also a written statement in the advance decision which says that it will apply even if Arjun's life is at risk. Sometimes Arjun discusses the advance decision with his GP, making sure his decision is kept up-to-date.

Advance decisions for both refusing treatment and life-sustaining treatment, if clearly valid and applicable to the treatment have authority over all other views and must be followed; this means they cannot be overturned by the court. However, the advance decision would not override decisions about mental health treatment given under the treatment powers of the *Mental Health Act 1983*.

You may make a general statement requesting particular treatment. Your request does not have to be followed but will be taken into account when somebody needs to make a best interests decision on your behalf.

Lasting power of attorney

A lasting power of attorney (LPA) refers to the

process by which you can appoint someone of your choice to make certain decisions should you ever lack the capacity to make these decisions yourself. You can only make this legal document if you understand what it means. The two types of LPA are:

- a **property and affairs LPA** allows your chosen attorney to make decisions about property and financial matters
- a **personal welfare LPA** allows your chosen attorney to make decisions about health and personal welfare such as medical treatment, where you live or day-to-day care.

The personal welfare LPA will only take effect once you lack capacity, however, the property and affairs LPA can take effect as soon as it is registered (even if you still have capacity) unless you specify that it starts after you lack capacity.

To make an LPA you will need to complete a form, which will be available from the Office of the Public Guardian. You will need to complete a different form for a personal welfare LPA than for a property and affairs LPA, although you can appoint the same or different person for each LPA.

You must be over 18 to make an LPA; you must also understand what it means. Part of the LPA form is a certificate which needs to be signed by an independent person. The certificate states that you fully understand what is involved in the LPA, what it means to have one in place and that you are not being put under pressure to create the LPA. When you have filled in the form and had the certificate signed, it needs to be registered with the Office of the Public Guardian before it is valid for use.

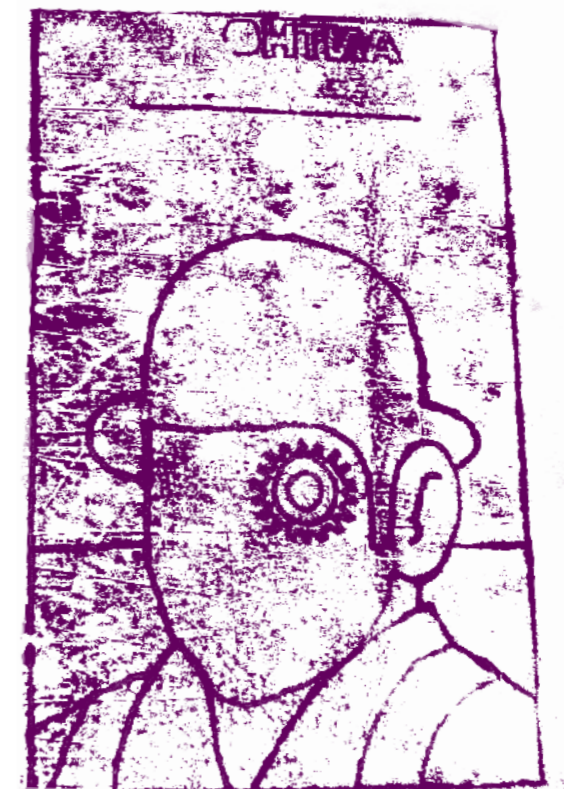
Challenging decisions

If you are unhappy with a decision that has been made about your capacity, decisions that have been made on your behalf or the way you are being treated, you can challenge the decision. It is expected that the dispute should be resolved informally wherever possible; however, there are formal routes of complaint if this is unsuccessful. A dispute could be resolved informally by, for example, using an advocate to help the person communicate their point of view or involving a mediation service. Resolving the dispute informally is usually more effective because it can be less stressful for all involved and lead to a quicker result.

Formal routes to resolving disputes will entail following complaints procedures of the organisation involved, for instance those of the local authority that is responsible for the service, or complaining to an ombudsman who can investigate your complaint without going to court. As a final step, the Court of Protection may be involved in the decision.

If you don't agree with the results of a test of your capacity, you need to raise your concerns with the person who made the assessment. The person who made the assessment will need to show that they have followed the principles of the Act and correctly applied the test of capacity. If the person who made the assessment was a professional, then they will also need to show that they have had regard to the Code of Practice.

The Office of the Public Guardian can provide general information about disputes and the Act; they may also address concerns over the actions of an attorney or deputy acting on behalf of someone who lacks capacity.



Artwork by a man with autism.

Court of Protection

The *Mental Capacity Act* changed the role of the Court of Protection. The new Court of Protection is responsible for decisions relating to property, finance, welfare and healthcare. Before you can bring something to the Court of Protection, you should have tried all other avenues of decision-making and assessing capacity. These are the things we have looked at earlier in this booklet.

The type of decisions the court may make include:

- one-off situations, where there is a dispute as to whether you have capacity to make a decision. For example, if there is no agreement over your ability to make a decision regarding a particular treatment, the court can decide if you have the capacity or not
- final decisions about what would be in your best interests; for instance, deciding which type of accommodation would be in your best interests
- resolving disagreement about the suitability of the person you appointed to make future decisions for you when you made a Lasting Power of Attorney. For instance, if there is disagreement about the attorney's own capacity, or if the attorney hasn't been acting in your best interests, the court can decide whether the attorney should be removed
- appointing a deputy to make ongoing decisions if you lack the capacity to do so (see section on deputies below).

The court will be based at its Central Registry in Archway, north London and this is where applications to the court should be made; however, the court's hearings will take place in key regional locations across England and Wales. Not all applications to the court will go to a regional hearing; this will depend upon the nature of the application.

Deputies

Deputies will be appointed by the Court of Protection when there is a need to make ongoing decisions about property and affairs for a person who lacks capacity. The court will also be able to appoint deputies to deal with personal welfare decisions.

The court will specify the decisions that can be made by the deputy, as well as how long the deputy will have the power to make these decisions. Deputies will only have the power to make decisions for which you are deemed not to have capacity and they will be supervised and supported by the Office of the Public Guardian. The court will also be able to send 'visitors' who will check on your welfare and report back to the court. A deputy may be someone who knows you in a personal or professional capacity - a family member, friend, solicitor, accountant or existing appointee are some examples of who the court may appoint.

Protection from ill-treatment or wilful neglect

The introduction of the *Mental Capacity Act* (Section 44) makes it a criminal offence to wilfully neglect or ill-treat someone who lacks capacity. Anyone who is responsible for the care of a person who lacks capacity, or is their attorney or deputy, and mistreats, neglects or abuses that person can face criminal charges that can lead to a fine or imprisonment. If you, or anyone around you, think you are being ill-treated or neglected, the police or social services should be notified immediately.

Research

Research is often carried out to help us understand why people lose capacity, and have changing treatment, care and needs. The *Mental Capacity Act* protects people who take part in research projects but who do not have the capacity to make a decision about their involvement. Anyone carrying out research must ensure that the research complies with provisions set out in the Act and follow the guidance laid out in the Code of Practice.

You should be assumed to have capacity unless it is proven otherwise and the normal tests of capacity should be applied. Someone who is interested in your welfare such as family members, friends or carers (except professional/paid care workers) must be consulted. If there is no one appropriate to consult, the researcher must nominate someone following relevant guidance. If you lacked capacity and a decision was being made about your involvement in research, your interests are to be considered more important than the interests of science or society. Any objections you make about your involvement in the research must be respected.

What does the *Mental Capacity Act* mean for carers and family of a person with an autism spectrum disorder?

As well as providing protection to a person who lacks mental capacity, the *Mental Capacity Act* sets out a clear framework for parents and carers to use when making decisions on behalf of someone who lacks capacity, and also provides protection to those making these decisions if they have followed the Act properly

The types of decisions that are covered by the Act start with the very basic, like whether to have tea or coffee to drink, right through to decisions about life-saving treatment. The person/s involved in making decisions will vary according to the complexity of the decision and its outcomes. Even for those decisions where a medical professional, for example, is making the decision, the Act says that anyone with a caring responsibility for the person (for example parents and carers) should be consulted in the decision-making process where appropriate.

If someone you are caring for has an autism spectrum disorder (ASD), it is possible that they may lack the capacity to make some decisions. Without knowing an individual, it is difficult to say exactly which decisions a person is going to be capable or incapable of making, but it is important to remember that a diagnosis of autism, ASD, Asperger syndrome or any other diagnosis, behaviour or characteristic, does not automatically mean a person lacks capacity to make a decision. You should always assume that a person has capacity to make the decision unless it is demonstrated otherwise. Before deciding someone doesn't have the capacity to make a decision, all reasonable efforts should have been made to help the person make and communicate their decision.

For somebody on the autism spectrum, this may mean that they will need visual supports to help them understand the information, and support in ensuring they have communicated their preference. You may need to be very clear about the outcomes of a potential decision and how it may affect them in the future, to ensure they fully understand the decision they are making.

Helping a person on the autism spectrum to communicate their decisions

- Think about the environment – keep noise and distractions to a minimum.
- Do they need more time to take account of the information and convey their decision?
- Use written information or visual supports – brochures and leaflets containing relevant information or visual communication systems.
- What is that person's usual form of communication? Use alternative communication methods where necessary.
- Who is the best person to help them communicate?
- Think about the language you are using – be direct and clear.

The following example from the Code of Practice illustrates how providing information in the right way can help someone make a decision:

Scenario: providing relevant information in an appropriate format

Mr Leslie has learning disabilities and has developed an irregular heartbeat. He has been prescribed medication for this, but is anxious about having regular blood tests to check his medication levels. His doctor gives him a leaflet to explain:

- the reason for the tests
- what a blood test involves
- the risks in having or not having the tests
- that he has the right to decide whether or not to have the test.

The leaflet uses simple language and photographs to explain these things. Mr Leslie's carer helps him read the leaflet over the next few days and checks that he understands it.

Mr Leslie goes back to tell the doctor that, even though he is scared of needles, he will agree to the blood tests so that he can get the right medication. He is able to pick out the equipment needed to do the blood test. So the doctor concludes that Mr Leslie can understand, retain and use the relevant information and therefore has the capacity to make the decision to have the test.

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As a parent or carer of somebody on the autism spectrum, the types of decisions you will usually need to make will be around everyday care. The Code of Practice states that for these day-to-day decisions, assessments of capacity do not need to be recorded formally. However, such evidence would always help in case of any disputes.

Decisions that are made for a person who lacks capacity must be made in their best interests. This means taking into account the wishes and feelings of the person, including things they have said or done in the past; their beliefs or values, such as religious beliefs; as well as any other circumstance or information that is relevant to the decision. As a parent or carer of a person, you should be consulted when someone is deciding what is in the person's best interests; your knowledge of their wishes, feelings, beliefs and previous actions, among many other things, is invaluable in helping the decision maker make the best decision for that person. Best interests are looked at in more detail earlier, so please refer back to this for more detailed guidance.

A Code of Practice accompanies the Act and will provide informal (non-paid) carers with a source of assistance and guidance.

Applying to be a deputy

As a parent or carer of someone who lacks capacity, you could become a deputy to make certain decisions on their behalf. If the person has lost capacity, it is too late for them to appoint an attorney. However, the court may appoint a deputy for them instead. This would mean that you can make decisions in the person's best interests regarding their financial affairs or welfare.

You would need to apply to the Court of Protection using the application form that is available from the Office of the Public Guardian. You can apply to become a deputy if you are over the age of 18; the court will then decide on whether a deputy is needed to make the decision and whether you are suitable as a deputy. This decision may not actually require you to go to the court but can often be made on the basis of the information provided in the form. There will be a charge for doing this; the Office of the Public Guardian will be able to provide you with up-to-date costs.

If you are appointed as a deputy, you will receive supervision from the Office of the Public Guardian.

Protection from ill-treatment or wilful neglect

If you are concerned about the treatment of a person who lacks capacity, for example unreasonable use of restraint, inadequate care or any type of abuse, you need to contact the police or social services. The *Mental Capacity Act* makes it a criminal offence to ill-treat or wilfully neglect a person who lacks capacity and a conviction of this offence can result in imprisonment or a fine.

As well as providing protection to the person that lacks capacity, the Act also protects parents and carers from liability if you have a reasonable belief that the person lacks capacity and that you have taken the action that is in their best interests.

As a parent or carer you need to be clear about the decisions you have made and the reasons for these decisions. If there is any dispute or disagreement about what is actually in a person's best interests, it can be helpful to keep a note of what you decided and why.

Further reading

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

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

Making decisions. An easy read guide.

All of the titles listed above are published by the Mental Capacity Implementation Programme, (C) Crown Copyright 2006.

They are available from www.dca.gov.uk/legal-policy/mental-capacity/publications.htm or call 023 80 878036 or 023 80 878038.

Bartlett, P. (2005). ***Blackstone's guide to the Mental Capacity Act (Blackstone's Guide)***. Oxford University Press.

Department for Constitutional Affairs (2007). ***Mental Capacity Act Code of Practice.***

Richards, S. and Mughal, A. (2006) ***Working with the Mental Capacity Act 2005***. Matrix Training Associates.

Weeraratne, A. and Burnham, U. (2007). ***Mental Capacity Act 2005 (Butterworths New Law Guides)***. Butterworths Law.

Resources

To view a copy of the *Mental Capacity Act 2005* visit:
www.opsi.gov.uk/acts/acts2005/20050009.htm

For an easy read summary of the Act and Code of Practice visit:
www.dca.gov.uk/legal-policy/mental-capacity/links.htm

The Department of Health website provides up-to-date information and guidance on the Act
www.dh.gov.uk/mentalcapacityact

Rethink – Mental Illness Website
www.rethink.org/living_with_mental_illness/rights_and_laws/laws_you_need_to_know_about/mental_capacity.html

Office of the Public Guardian (available from October 2007)
www.publicguardian.gov.uk

Where to go for more advice

For more advice about the *Mental Capacity Act 2005*, speak to your GP, social worker, a solicitor or contact:

Community Legal Service – can help you find a solicitor and provide advice about making decisions on behalf of someone lacking capacity
Tel: 0845 345 4 345
Website: www.clsdirect.org.uk

Disability Law Service
Tel: 020 7791 9800
Website: www.dls.org.uk

Law Society
Tel: 0870 606 2555 (for help finding a solicitor)
Website: www.lawsociety.org.uk

Public Guardianship Office
Tel: 0854 330 200
Website: www.guardianship.gov.uk

In Scotland, another law applies.

The *Adults with Incapacity (Scotland) Act 2000* exists to safeguard the welfare and finances of people who lack capacity.

You can read more about this Act at
www.scotland.gov.uk/Topics/Justice/Civil/awi

The National Autistic Society is the UK's leading charity for people affected by autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

Together, we are going to change this.

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Julia Butcher


Your autism charity