

**BMA**

# Mental Capacity Act tool kit

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## About this tool kit

The Mental Capacity Act 2005 provides a legal framework in England and Wales for decision making on behalf of people aged 16 or over who cannot make decisions themselves. It also sets out the law for people who wish to make preparations for a time in the future when they may lack capacity to make decisions.

The purpose of this tool kit is to act as a prompt to doctors when they are providing care and treatment for people who lack, or who may lack, the mental capacity to make decisions on their own behalf. In our view, this is likely to be the majority of doctors. The tool kit consists of a series of cards relating to specific areas of the Act, such as how to assess capacity, the Act's basic principles, advance refusals of treatment, research and Lasting Powers of Attorney (LPAs). Although each of the cards refers to separate areas of the Act, there is inevitably a degree of overlap.

This tool kit is not intended to provide definitive guidance on all the issues surrounding the Mental Capacity Act. Card 1 lists alternative sources of guidance that should be used in conjunction with the cards. In cases of doubt, legal advice should be sought. The tool kit is designed to raise doctors' awareness of the Act, and to provide an aid for good decision making.

This tool kit applies to England and Wales. In Scotland, decision making in this area is covered by the Adults with Incapacity (Scotland) Act 2000. In Northern Ireland, decision making is currently governed by the common law, although at the time of writing change was anticipated.

The tool kit is available on our website. Trusts, medical schools and individual doctors may download and adapt it to suit their own requirements. There are no copyright restrictions on this tool kit – please feel free to make multiple copies.

We welcome feedback on the usefulness of this tool kit. If you have any comments please address them to:

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# Card 1



## Guidance on the Mental Capacity Act

The website of the Social Care Institute for Excellence provides up to date resources on all aspects of the Mental Capacity Act. <http://www.scie.org.uk/publications/mca/>.

In addition the following publications provide more detailed information:

*Assessment of Mental Capacity*, British Medical Association and The Law Society (4th edition).

*Code of Practice: Mental Health Act 1983*, Department of Health. <https://www.gov.uk/government/publications/code-of-practice-mental-health-act-1983>.

*Deprivation of Liberty Safeguards*. British Medical Association. <http://www.bma.org.uk/support-at-work/ethics/mental-capacity/deprivation-of-liberty-safeguards>.

*Medical Ethics Today: The BMA's Handbook of Ethics and Law*, British Medical Association (2012).

*Mental Capacity Act 2005 Code of Practice*, Office of the Public Guardian (2007).  
<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>.

# Card 2

## General information



### 1 The Mental Capacity Act 2005

The Mental Capacity Act 2005 provides a comprehensive framework for decision making on behalf of adults aged 16 and over who lack capacity to make decisions on their own behalf. The Act applies to England and Wales. Scotland has its own legislation, the Adults with Incapacity (Scotland) Act 2000. The approach in Northern Ireland is currently governed by the common law, although at the time of writing, change was anticipated.

The Act applies to all decisions taken on behalf of people who permanently or temporarily lack capacity to make such decisions themselves, including decisions relating to medical treatment. All doctors working with adults who lack, or who may lack, capacity will need to be familiar with both its underlying principles and its basic provisions. This tool kit sets out the main features of the Act in so far as it relates to decisions about medical treatment.

The Act is accompanied by a statutory Code of Practice providing guidance on how it should be used. Certain people have a legal duty to have regard to the guidance in the Code of Practice, including anyone acting in a professional capacity or being paid for their work with people who may lack capacity. It is therefore essential that health professionals are familiar with the Code of Practice.

## 2 What is capacity?

Decision making capacity refers to the everyday ability that individuals possess to make decisions or to take actions that influence their life, from simple decisions about what to have for breakfast, to far reaching decisions about serious medical treatment. In a legal context it refers to a person's ability to do something, including making a decision, which may have legal consequences for the person themselves or for other people.

## 3 When does a person lack capacity?

For the purpose of the Act a person lacks capacity if, at the time the decision needs to be made, he or she is unable to make or communicate the decision because of an 'impairment of, or a disturbance in the functioning of, the mind or brain'. The Act contains a two-stage test of capacity:

- is there an impairment of, or disturbance in the functioning of, the person's mind or brain? If so:
- is the impairment or disturbance sufficient that the person is unable to make that particular decision?

In practice it can be helpful to ask three questions:

1. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?
2. Is the person unable to make a specific decision at the time it needs to be made for one or more of the reasons given in the Act? (See card 5(2))
3. Is the person's inability to make the specific decision at the time it needs to be made *because of* the aforementioned impairment or disturbance in the person's mind or brain?

The assessment of capacity is 'task specific'. It focuses on the specific decision that needs to be made at the specific time the decision is required. It does not matter if the incapacity is temporary, or the person retains the capacity to make other decisions, or if the person's capacity fluctuates. The inability to make a decision, however, *must* be a result of the impairment or disturbance already mentioned.

This could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication. The important point is that the impairment or disturbance renders the individual unable to make the decision in question.

If the impairment is temporary and the decision can realistically be put off until such time as he or she is likely to regain capacity, then it should be deferred. While it is clear that an unconscious patient will lack capacity, most other categories of patient will retain some decision-making capacity, however slight.



# Card 3

## Basic principles

# 3

### 1 What are the Act's basic principles?

The Act sets out a number of basic principles that must govern all decisions made and actions taken under its powers. These are rooted in best practice and the common law and are designed to be fully compliant with the relevant sections of the Human Rights Act. Where confusion arises about how aspects of the Act should be implemented, it can be extremely helpful to refer back to them.

Actions or decisions that clearly conflict with them are unlikely to be lawful, although there may be occasions on which they are in tension with each other, and some balancing will be required. A list of the principles, with brief descriptions, is given below. Further information about best interests comes later in the tool kit.

### 2 A presumption of capacity

It is a fundamental principle of English law that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so, unless it is proven otherwise. The responsibility for proving that an adult lacks capacity falls upon the person who challenges it.

### **3 Maximising decision making capacity**

Closely linked to the presumption of capacity, this states that everything practicable must be done to support individuals to make their own decisions, before it is decided that they lack capacity. For example, advocates and communication support might be necessary, and consideration should be given to whether an individual's capacity is affected by the time of day or medication regimes. The aim is to ensure that individuals who are capable of making decisions for themselves, but may need some support, are not inappropriately assessed as incapacitated.

### **4 The freedom to make unwise decisions**

The fact that an individual makes a rash, unwise or irrational decision, or begins to act out of character, is not itself proof of incapacity. All adults retain the right to make decisions which to others might seem unwise or irrational. Although such actions may raise questions about capacity – where for example they follow a period of illness or an accident – they are in no way determinative. What matters is the ability to make the decision, not the outcome.

### **5 Best interests**

At the heart of the Act lies the principle that where it is determined that individuals lack capacity, any decision or action taken on their behalf must be in their best interests.

Practically speaking, what constitutes an individual's best interests will depend upon the circumstances of each individual case. Particular regard must however be given to any statements of current or prior wishes or feelings expressed or made by the individual.

## 6 The less – restrictive alternative

Whenever a person is making a decision on behalf of an adult who lacks capacity, he or she must consider if it is possible to make the decision in a way that is less restrictive of that individual's fundamental rights or freedoms. There are often several ways to achieve a desired outcome, and where possible the choice must be the one that interferes least with the individual's freedoms while still achieving the necessary goal. The option chosen must, however, be in the person's best interests, which may not in fact be the least restrictive.

# Card 4

## Assessing capacity



### 1 Who should assess capacity?

The Act does not specify who should assess capacity. However, anyone who wishes to carry out an action in connection with the care or treatment of an individual, or who wishes to make a decision on their behalf, must be reasonably satisfied that they lack the requisite capacity. This will require taking appropriate steps to assess their capacity to make the decision. Where consent to medical treatment is required, the health professional proposing the treatment has the responsibility of ensuring that capacity is assessed.

The reasons why capacity is in doubt should be recorded in the medical record, as should details of the assessment process and its findings. The more serious the decision, the more formal the assessment of capacity is likely to be, and, where appropriate, it might be advisable to refer to a psychiatrist or psychologist for a second opinion.

### 2 How do you assess capacity?

The Act makes use of a 'functional' test of capacity, adapted from the common law, which focuses on the decision making process itself. First it must be established that the person being assessed has 'an impairment of, or a disturbance in the functioning of, the mind or brain' which may affect their ability to make the decision in question. Secondly, having identified in

accordance with the points listed below that the person is unable to make the decision in question, it must be established that the inability to make the decision is a result of the aforementioned impairment or disturbance.

Under the Act, a person is regarded as being unable to make a decision if, at the time the decision needs to be made, he or she is unable:

- to understand the information relevant to the decision
- to retain the information relevant to the decision
- to use or weigh the information, or
- to communicate the decision (by any means).

Where an individual fails one or more parts of this test, then they do not have the relevant capacity and the entire test is failed.

In assessing capacity, consideration should be given, where appropriate, to the views of those close to the individual. Family members and close friends may be able to provide valuable background information, although their views about what they might want for the individual must not be allowed to influence the assessment. An assessment that a person lacks the capacity to make a decision must not be discriminatory.

It must not be based simply on:

- age
- appearance
- assumptions about their condition
- any aspect of their behavior.

A person should not be assessed as lacking capacity until all reasonable steps have been taken to assist them to make the decision.

### **3 Uncertainties about capacity**

Difficult judgements will still need to be made, particularly where there is fluctuating capacity, where some capacity is demonstrable but its extent is uncertain or where a level of impairment may interact with a degree of coercion or duress from those close to the individual. This four-stage test is nevertheless well established, and more detailed advice on practical procedures for assessing capacity is available from other sources. The Act requires that any decision that a person lacks capacity must be based on a 'reasonable belief' backed by objective reasons.

Where there are disputes about whether a person lacks capacity that cannot be resolved using more informal methods, the Court of Protection can be asked for a judgment.

### **4 What do you do when an individual refuses to be assessed?**

Occasionally an individual whose capacity is in doubt may refuse to be assessed. In most cases, a sensitive explanation of the potential consequences of such a refusal, such as the possibility that any decision they may make will be challenged at a later date, will be sufficient for them to agree. However, if the individual flatly refuses, in most cases no one can be required to undergo an assessment.

# Card 5

## Best interests

# 5

### 1 What does the Act mean by best interests?

All decisions taken on behalf of someone who lacks capacity must be taken in his or her best interests. The Act provides a checklist of common factors that must be taken into account when making a best interests judgement. Subsequent case law has established that when assessing an individual's best interests, decision makers must look at their welfare in the broadest sense. This must extend beyond medical factors to incorporate social and psychological dimensions of wellbeing. As part of the assessment process the courts have made it clear that the decision maker must also make a reasonable effort to put themselves in the place of the patient and ask what their attitude to the proposed treatment would be.

### 2 What should you take into account when assessing best interests?

Lacking capacity to make a decision should not exclude an individual from participating in the decision-making process as far as is possible. The decision maker must also take into account the likelihood that the person will regain capacity. A decision should be delayed if it can reasonably be left until he or she regains the capacity to make it. Other relevant factors are likely to include:

- the person's past and present wishes and feelings, including any relevant written statement made when she or he had capacity – this would include general

- statements of wishes, beliefs or values where they would have an impact on the decision
- other factors the person would have considered if able to do so – such as the effect of the decision on other people.

A crucial part of any best interests judgment will involve a discussion with those close to the individual, including family, friends or carers, where it is practical or appropriate to do so, bearing in mind the duty of confidentiality. (For more on information sharing, see card 16). It should also include anyone previously nominated by the person as someone to be consulted. Where an individual appointed to act under a Lasting Power of Attorney or a deputy appointed to make decisions by the Court of Protection has the authority to make the decision, they should be provided with as much information as is necessary for them to make the decision in question. Further information about attorneys and court-appointed deputies is given later in the tool kit (see cards 11 and 12).

### **3 Are there any exceptions to the best interests principle?**

There are two circumstances when the best interests principle will not apply. The first is where someone has previously made an advance decision to refuse medical treatment while they had capacity. Where the advance decision is valid and applicable, it should be respected, even if others think that the decision is not in his or her best interests (for more information on advance decisions, see card 9).

The second exception relates to the enrolment of incapacitated adults in certain forms of research. This is covered in more detail in card 10.



# Card 6

# 6

## Acts in connection with care or treatment

### 1 What powers does the Act give to health professionals?

An action or intervention will be lawful – i.e. health professionals will enjoy protection from liability – where the decision maker has a *reasonable belief* both that the individual lacks capacity to consent to what is proposed, and that the action or decision is in his or her best interests. (See card 5 on how to assess someone's best interests). It applies to anyone making a decision on behalf of another, irrespective of whether they have a professional relationship with the incapacitated individual. It could include, for example, taking an incapacitated stranger by the arm to assist them cross a road. In relation to medical treatment, it is applicable not only to an episode of treatment itself, but also to those necessary ancillary procedures such as conveying a person to hospital.

### 2 How far do these powers extend?

There are limits to these powers. A valid advance decision, and a valid decision by an attorney or a court appointed deputy, would take precedence. The Act also sets limits to the extent to which the freedom of movement of an incapacitated person can be restricted. An incapacitated person can only be restrained where there is a reasonable belief that it is necessary to prevent harm to the incapacitated person. Any restraint must be proportionate to the risk and of the minimum

level necessary to protect the incapacitated person. (For more information about restraint, see card 7).

The onus is on the person wishing to act to justify as objectively as possible his or her belief that the person being cared for is likely to be harmed unless some sort of physical intervention or other restraining action is taken. Although reasonable use of restraint may be lawful, the Act makes it clear that it will never be lawful to deprive a person of his or her liberty within the meaning of Article 5(1) of the European Convention on Human Rights without appropriate authorisation. (See cards 7 and 8 for more information on deprivation of liberty).

### **3 When is court approval required?**

Before the Act came into force, the courts had decided that some decisions were so serious that each case should be taken to court so that a declaration of lawfulness could be made. Under the Act, the following cases should continue to go before the court:

- proposals to withdraw or withhold artificial nutrition and hydration from patients in a persistent vegetative state or a minimally-conscious state
- cases involving organ or bone marrow donation by a person lacking the capacity to consent
- proposals for non-therapeutic sterilization
- some termination of pregnancy cases
- cases where there is a doubt or dispute that cannot be resolved locally about whether a particular treatment will be in a person's best interests. (Case law has emphasized that the Act must not be used to suppress legitimate disagreements about an individual's best interests).
- cases involving ethical dilemmas in untested areas.

# Card 7

## Restraint



### 1 What is restraint?

There may be occasions when health professionals need to consider the use of restraint in treating an individual lacking capacity. The Act states that restraint is the use or threat of force, to make someone do something they are resisting, or restricting a person's freedom of movement, whether they are resisting or not. The Act only refers to restraint to prevent harm to the patient. Health professionals have a common law right to use restraint to prevent harm to others.

### 2 Types of restraint

Restraint can be overt, such as the use of bed rails. It can also be covert and indirect such as doors that are heavy and difficult to open or putting patients in low chairs from which they find it difficult to move. Restraint may be:

- physical – holding by one or more persons
- mechanical – the use of equipment such as bed rails or mittens to stop patients removing nasogastric tubes or catheters
- chemical – involving medication, for example sedation
- psychological – telling patients that they are not allowed to do something, or taking away aids necessary for them to do what they want, for example spectacles or walking aids.

### 3 When is restraint lawful?

Restrictive measures should be a last resort and alternatives to restraint must always be considered. Anybody proposing to use restraint must have objective reasons to justify that it is necessary. They must also be able to show that the patient is likely to suffer harm unless proportionate restraint is used. A proportionate response means using the least intrusive type and the minimum amount of restraint to achieve the objective, in the best interests of the patient lacking capacity. If these conditions are met, it is permissible to restrain a patient to provide necessary treatment. It also follows that in such circumstances there would be no liability for assault. The restraint must not amount to a deprivation of liberty and if it is considered necessary to go so far as to deprive someone of their liberty in order to safeguard their interests, special safeguards must be employed. (For further information on deprivation of liberty, see card 8).

# Card 8

## Care and treatment amounting to deprivation of liberty



### 1 Deprivation of liberty

The Act makes it clear that people who lack the ability to consent to treatment should be cared for in accordance with the 'less-restrictive principle' (see card 3). As outlined in card 7, there will be times when this might involve imposing restrictions on a person's liberty. There will be circumstances however in which appropriate and necessary care or treatment that is in an individual's best interests can only be provided in circumstances that will amount to a 'deprivation of liberty.' Any such deprivation of liberty will only be lawful if it is authorised in accordance with procedures set out in the Deprivation of Liberty Safeguards (DoLS) which were added to the Mental Capacity Act by amendments introduced by the Mental Health Act (MHA) 2007.

This card gives a brief outline of relevant factors to take into account when assessing whether an individual is or might be deprived of liberty and outlines the procedure for seeking authorisation. Although individuals may be deprived of their liberty in a variety of settings, including domestic ones, this card focusses on deprivation of liberty in hospitals and care homes.

This is a complex area of law and practice and where doctors identify individuals who may be, or who may need to be, deprived of their liberty they should refer to local

protocols, consult the more-detailed guidance listed earlier in this toolkit, or take appropriate legal advice.

### **Key points for health professionals**

- The fact that care or treatment amounts to a deprivation of liberty does not mean that it is inappropriate. It means only that it reaches a certain threshold of restriction such that authorisation is required.
- Identifying and authorising a deprivation of liberty should not substitute for or impede the delivery of the highest standard of care.
- The focus of decision making must remain the best interests of the patient.
- Nothing in the Act or DoLS is designed to prevent the provision of timely and appropriate medical treatment. In an emergency, treatment must not be delayed for the purposes of identifying whether a deprivation of liberty has taken place, or seeking its subsequent authorisation.
- An authorisation for a deprivation of liberty does not provide legal authority for treatment. Treatment for adults unable to consent must be given on the basis of an assessment of their best interests or in accordance with another legal provision of the Act.

### **When might it be appropriate to deprive a patient of their liberty?**

The Mental Capacity Act Deprivation of Liberty code of practice states that depriving a patient of liberty may be justifiable if:

- it is in their best interests to protect them from harm
- it is a proportional response when compared with the harm faced by the person
- there is no less-restrictive alternative.

## What constitutes a deprivation of liberty?

The concept of 'deprivation of liberty' is not straightforward. The Act does not provide a definition of 'deprivation of liberty', but refers instead to the meaning of Article 5 of the European Convention on Human Rights.

The Supreme Court judgment in *Cheshire West* in 2014 introduced an 'acid test' for what constitutes a deprivation of liberty for the purposes of Article 5. When considering whether an individual may be deprived of their liberty, health professionals should ask three key questions.

- Is the person subject to 'continuous supervision and control'?
- Is the person 'free to leave'?
- Does the person lack the capacity to consent to their care and treatment in those circumstances?

If the person is under continuous supervision and control *and* is not free to leave and lacks the capacity to consent to their care and treatment in those circumstances then the acid test is met. The individual is therefore deemed to be deprived of liberty under Article 5 and authorisation for the deprivation must be sought.

### *Continuous and complete supervision and control*

When considering whether an individual is subject to 'continuous and complete supervision and control', it can be helpful to ask whether there is a care plan in place that means that those looking after the individual will be aware at any time:

- where the individual is
- what the individual will be doing, and
- what steps they will take if they cannot establish the above.

### *Non-negligible period of time*

Case law has also established that for the purposes of Article 5 any deprivation of liberty must be for a 'non-negligible' period of time. There is no definition of a 'non-negligible' period of time, but in general the more intense the measures of restraint and the greater the resistance or resentment of the individual, the shorter will be the period. The courts have regarded as little as forty minutes of intense restraint as amounting to a deprivation of liberty.

### *Free to leave*

Whether a person is 'free to leave' will depend on whether he or she is free to come and go or to decide to live elsewhere or whether he or she would require permission. If permission is required, it is likely that he or she is not free to leave and therefore this part of the deprivation of liberty test has been satisfied.

### *Does the person have capacity to consent to that deprivation of liberty?*

In addressing this question the attention has to be on the specific circumstances of the individual's care and treatment. The question must be: does the individual have the capacity to consent to the specified care and treatment in the concrete circumstances that are proposed or in place?

### *Factors not relevant to a deprivation of liberty*

The purposes for which care and treatment are being provided are not relevant to whether a person is being deprived of their liberty, nor are the nature of any disabilities they may have. Similarly, a person's compliance or lack of objection are not relevant, nor is the agreement of family or carers, the appropriateness or 'normality' of the treatment or the lack of an alternative safe place for treatment.



## How do you authorise a deprivation of liberty?

Where it is identified that an individual may be deprived of liberty in a care home or hospital and lacks the capacity to consent, that deprivation of liberty must be authorised under the Deprivation of Liberty Safeguards (DoLS). To do this the 'managing authority' of the hospital or care home has to apply to a 'supervisory body' – usually the local authority where the person lives.

There are two types of DoLS authorisation, standard and urgent.

### *Standard authorisation*

After receiving an application for a standard authorisation, the supervisory body has to decide within 21 days whether the person can be deprived of their liberty. If the conditions are met, the supervisory body must authorise the deprivation of liberty and inform the person and managing authority in writing. It can be authorised for up to one year.

The person does not have to be deprived of liberty for the period of authorisation. The restrictions should stop as soon as they are no longer necessary.

### *Urgent authorisations*

There will be times when a person may need to be deprived of their liberty before a standard authorisation can be provided. In these situations the managing authority can itself issue urgent authorisation which can last up to seven days, with an option to extend it for a further seven days if the supervisory body is in agreement. When issuing an urgent authorisation the managing authority must also request a standard authorisation.

# Card 9

## Advance decisions refusing treatment



### 1 What is an advance decision?

The Act makes it clear that somebody who is aged 18 or over and has the necessary mental capacity can refuse specified medical treatment for a time in the future when he or she may lose the capacity to make the decision. This is known as an advance decision. The Act's powers are restricted explicitly to advance decisions to refuse treatment. An advance refusal of treatment is binding if:

- the person making the decision was 18 or older when it was made, and had the necessary mental capacity
- it specifies, in lay terms if necessary, the specific treatment to be refused and the particular circumstances in which the refusal is to apply
- the person making the decision has not withdrawn the decision at a time when he or she had the capacity to do so
- the person making the decision has not appointed, after the decision was made, an attorney to make the specified decision
- the person making the decision has not done anything clearly inconsistent with the decision remaining a fixed decision.

## 2 Can advance decisions extend to refusing life-sustaining treatment?

Although advance decisions can be oral or in writing, an advance refusal will *only* apply to life-sustaining treatment where it is in writing, is signed and witnessed, and contains a statement that it is to apply even where life is at risk. In our view advance decisions cannot be used to refuse basic care, which includes warmth, shelter and hygiene measures to maintain body cleanliness. This also includes the offer of oral food and water, but not artificial nutrition and hydration.

In an emergency or where there is doubt about the existence or validity of an advance decision, doctors can provide treatment that is immediately necessary to stabilize or to prevent a deterioration in the patient until the existence, and the validity and applicability, of the advance decision can be established.

## 3 Do advance decisions apply to individuals subject to compulsory mental health legislation?

Where a patient is subject to compulsory treatment under mental health legislation, an advance refusal relating to treatment provided for the mental disorder for which compulsory powers have been invoked will not be binding, save in the case of electro-convulsive treatment (ECT) although the treating professional should take such a decision into account. This could include, for example, considering whether there are any other treatment options available that are less restrictive. An agreed advance treatment plan for mental health conditions can be helpful and would represent a kind of advance statement, although it would not be binding during periods of compulsion.

# Card 10

## Research

# 10

### **Can patients who lack capacity participate in research?**

Yes. Under the Act it is lawful to involve adults who lack capacity in research – excepting clinical trials which are separately regulated – provided it is related to the condition, or treatment for the condition, from which they are suffering. The research must be approved by an appropriately established research ethics committee, or, in Wales, its equivalent. It must not be possible to conduct the research involving individuals who have the capacity to consent it.

Where the research is 'therapeutic' and is expected to benefit the individual directly, the risks must not be excessive in relation to the anticipated benefits. Where the research is not expected to deliver direct benefit to the patients but is intended to investigate the condition from which they suffer, the risk to individuals must be negligible and any restriction on liberty or intrusion must be kept to a minimum.

[Clinical trials into pharmaceutical products are regulated by the Medicines for Human Use (Clinical Trials) Regulations 2004. In April 2014, the EU adopted the Clinical Trials Regulations 2014 that repeal the earlier Directive on which the 2004 Regulations are based. It is unlikely that these Regulations will come into force prior to May 2017. Research on anonymised medical information or tissue is regulated separately by either the Data Protection Act 1998 or the Human Tissue Act 2004.]

## What safeguards exist for individuals who lack capacity?

Before an incapacitated adult can be involved in research, the researcher must make reasonable efforts to identify someone who is close to them – although not in a professional capacity – who is willing to be consulted about the appropriateness of their involvement. This will ordinarily be a family member. It could also be an attorney or court-appointed deputy. In the absence of such a person, the researcher must nominate somebody who is independent of the research in accordance with guidance set out in 2008 by the Department of Health and Welsh Assembly.

The following additional safeguards are provided under the Act once the research has started.

- Nothing should be done to incapacitated adults as part of the research to which they appear to object, unless it is intended to protect them from harm or to reduce or prevent pain or discomfort.
- Where incapacitated individuals show signs of distress or resistance, or indicate by any means the wish not to continue in the research, they must be withdrawn.
- The interests of individuals must outweigh the interests of medical science and society.
- Nothing must be done that is contrary to any advance decision or statement, or prior statement of wishes or preferences – provided those statements or decisions have not subsequently been withdrawn.

Where an adult is withdrawn from research he or she may continue to receive any treatment they had received as part of the research where there are good grounds to believe that its withdrawal would pose a significant risk to the individual's health.

## Can research take place in an emergency situation where the patient lacks capacity?

In December 2006, an amendment to the 2004 Clinical Trials Regulations introduced provisions enabling patients to be enrolled in clinical trials of pharmaceutical products without prior consent in emergency situations provided the research is approved by an appropriate research ethics committee. Where research falls outside the Clinical Trials Regulations it would need to be lawful under the terms of the Mental Capacity Act.

## Innovative treatment

Doctors have always modified methods of investigation and treatment in light of experience and so innovative therapy is a standard feature of good care. There are occasions however where innovative treatment may involve exposing patients to unknown or significant risks.

Where adults lack the capacity to consent to innovative treatment, any such treatment must be governed by the Act, in particular it must be in the incapacitated person's best interests.

Where any proposed treatment differs significantly from existing practice and involves unknown or significant risk, considerable care must be taken as innovation can give rise to legal and ethical uncertainty. In these circumstances, it is advisable to seek both expert clinical scrutiny and legal advice.

# Card 11



## Lasting powers of attorney

The Act replaced the Enduring Power of Attorney (EPA) with a new form of power of attorney, a Lasting Power of Attorney (LPA). An LPA allows the individual (the donor) to give authority to someone else (the attorney) to make decisions on the donor's behalf. The donor decides who the attorney should be and how wide ranging the power should be. More than one attorney can be appointed and they may be appointed to make some decisions jointly (i.e. together) and some decisions jointly and severally (i.e. independently). If the LPA does not specify this then the attorneys must act jointly.

There are two types of LPA, the property and affairs LPA and the health and welfare LPA. The health and welfare LPA covers personal, welfare and health care decisions, including decisions relating to medical treatment. Although an LPA in relation to property and affairs can be used by the attorney even when the donor still has capacity, an LPA dealing with health and welfare can only operate if the individual lacks capacity in relation to the issue in question.

### **1 Requirements of an LPA**

The Act allows an individual aged 18 or over who has capacity to appoint an attorney under a health and welfare LPA, to make decisions on their behalf once they lose capacity. In order for it to be valid a specific form must be used for an LPA. This must be in writing and include:

- information about the nature and extent of the LPA
- a statement signed by the donor stating that they have read and understood the information and that they want the health and welfare LPA to apply when they lose capacity
- the names of anyone (other than the attorney(s)) who should be told about an application to register the LPA
- a statement signed by the attorney(s) stating that they have read the information and understand the duties, in particular the duty to act in the donor's best interests
- a certificate completed by a third party, confirming that, in their opinion, the donor understands the nature and purpose of the LPA and that no fraud or pressure has been used to create the LPA. Registered health care professionals can be certificate providers and, GPs in particular, may find they are asked by patients to fulfil this role.

## 2 Registration of an LPA

An LPA must be registered with Office of the Public Guardian (OPG) before it can be used. It does not give the attorney any legal power to make decisions before it is registered. OPG maintains a register of LPAs and, where there is doubt as to the existence of an LPA, anyone can apply to search the register.



### 3 Powers of an LPA

The powers granted to an attorney will depend entirely on the wording of the LPA. If a health and welfare LPA has been registered, the attorney will have no authority to make decisions about the donor's finances or property. On the other hand, if a property and affairs LPA has been registered, the attorney will have no power to make any decisions about the medical treatment of the donor. The donor may also have included specific restrictions on the attorney's powers. It is therefore important that health care professionals carefully check the wording of the LPA. Even where a health and welfare LPA has been created and no restrictions have been imposed by the donor, an attorney cannot:

- make treatment decisions if the donor has capacity
- consent to a specific treatment if the donor has made a valid and applicable advance decision to refuse that treatment after the creation of the LPA
- consent to or refuse life-sustaining treatment unless this is expressly authorised by the LPA
- consent to or refuse treatment for a mental disorder where a patient is detained under mental health legislation
- demand specific treatment that health professionals consider is not necessary or appropriate for the donor's particular condition.

Where an attorney is acting under a health and welfare LPA and they are making decisions in relation to medical treatment, they must act in the donor's best interests. If there is any doubt about this and it cannot be resolved locally an application can be made to the Court of Protection (see also card 12).

## 4 LPA versus EPA

The fundamental difference is that EPAs cover decisions relating to property and financial affairs only, whereas there are two types of LPA, one to deal with financial affairs and one to deal with personal welfare and medical treatment decisions. Although no new EPAs can be made, any that were made before 1 October 2007 and are registered remain legally effective. LPAs will eventually replace the existing system of EPA, but this will inevitably take some years during which time the two systems will coexist.

# Card 12

# 12

## Court of Protection and court appointed deputies

### 1 Court of Protection

The Act established a new Court of Protection to oversee the proper functioning of the legislation. The Court has the power to rule on the validity of LPAs as well as to determine their meaning or effect. It also has the power to rule on cases where there is doubt or dispute as to whether a particular treatment is in the best interests of an incapacitated individual, and to make a declaration as to whether an individual has or lacks capacity to make decisions. In addition, court approval is required for the following:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from patients in a persistent vegetative state or a minimally conscious state
- cases involving organ or bone marrow donation by a person who lacks capacity
- cases involving proposed non-therapeutic sterilization of a person who lacks capacity
- cases involving ethical dilemmas in untested areas
- some termination of pregnancy cases
- cases where there is a doubt or dispute that cannot be resolved locally about whether a particular treatment will be in a person's best interests.

The Court of Protection has the same authority as the High Court and appeals can be made against its decisions, with permission, to the Court of Appeal.

## 2 Court-appointed deputies

The Court of Protection is able to appoint deputies as substitute decision makers where a person loses capacity and has not appointed an attorney under an LPA. Deputies replace and extend the previous role of a receiver.

Deputies can be appointed to make decisions on health and welfare as well as financial matters. They are likely to be appointed where an ongoing series of decisions is needed to resolve an issue, rather than a single decision of the court. In the majority of cases, the deputy is likely to be a family member or someone who knows the patient well. However, the Court may sometimes appoint a deputy who is independent of the family, if, for example, there is a history of serious family dispute or the individual's health and care needs are very complex.

As with attorneys appointed under an LPA, deputies have to make decisions in the individual's best interests and must allow the individual to make any decisions for which they have capacity. Deputies cannot refuse life-sustaining treatment.

Deputies should inform the health professional with whom they are dealing that the Court has appointed them as a deputy.

Deputies will have been provided with official documentation in relation to their appointment. Health professionals should review the documentation in order to confirm the extent and scope of the authority given by the Court.

# Card 13

## Independent Mental Capacity Advocates

# 13

### 1 What is an Independent Mental Capacity Advocate (IMCA)?

IMCAs support and represent particularly vulnerable adults who lack capacity to make certain decisions where there are no family members or friends available or willing to be consulted about those decisions. An IMCA is independent of the health care professional making the decision and represents the patient in discussions about whether the proposed decision is in the patient's best interests. An IMCA can also raise questions or challenge decisions which appear not to be in the patient's best interests.

### 2 When should an IMCA be instructed?

An IMCA must be instructed in relation to individuals who lack capacity and who have no family or friends whom it is appropriate to consult when:

- an NHS body is proposing to provide, withhold or stop 'serious medical treatment', or
- an NHS body or local authority is proposing to arrange accommodation (or a change in accommodation) in a hospital or care home, and the stay in hospital will be more than 28 days, or the stay in the care home more than 8 weeks.

Whilst it is not compulsory, IMCAs may also be instructed in a care review of arrangements for accommodation or an adult protection case involving a vulnerable individual, whether or not family members are involved.

An IMCA cannot be instructed if an individual has previously named a person who should be consulted about decisions that affect them, and that person is willing to assist, or they have appointed an attorney under a health and welfare LPA or the Court of Protection has appointed a welfare deputy to act on the patient's behalf. There is also no duty to instruct an IMCA where there is a need to make an urgent decision, for example, to save a patient's life. If a patient requires treatment whilst a report is awaited from an IMCA, this can be provided in the patient's best interests. It is also not necessary to instruct an IMCA for patients detained under mental health legislation.

Responsibility for instructing an IMCA lies with the NHS body or local authority providing the treatment or accommodation.

### **3 What is 'serious medical treatment'?**

Serious medical treatment is defined as treatment which involves providing, withdrawing or withholding treatment where:

- in the case of a single treatment being proposed, there is a fine balance between its benefits to the patient and the burdens and risks it is likely to entail
- in the case where there is a choice of treatments, a decision as to which one to use is finely balanced, or
- what is proposed would be likely to involve serious consequences for the patient.

Examples of serious medical treatment might include chemotherapy and surgery for cancer, therapeutic sterilisation, major surgery, withholding or stopping artificial nutrition and hydration and termination of pregnancy. Where it is proposed to

withdraw or withhold artificial nutrition and hydration from a patient in a persistent vegetative state, or a minimally-conscious state, an application must be made to the Court of Protection (see card 12).

#### **4 What are the powers of an IMCA?**

In order to provide necessary support to the incapacitated individual an IMCA will have powers to:

- examine health records which are relevant and necessary to deal with the issue
- consult other persons who may be in a position to comment on the incapacitated individual's wishes, feelings and beliefs
- ascertain what alternative courses, actions and options may be available to the incapacitated individual
- obtain an alternative medical opinion.

An IMCA is required to write a report to the NHS body or local authority responsible for the individual's treatment or care. The IMCA's report must be taken into account before the final decision is made.

# Card 14

# 14

## Relationship with the Mental Health Act

The relationship between the Mental Capacity Act (MCA) and the Mental Health Act (MHA) is a key issue for health professionals.

### 1 When is the MHA applicable?

The MHA code of practice contains detailed practical guidance on decisions concerning whether to use the MCA or the MHA. In general, health professionals should consider using the MHA to detain and treat people where:

- the treatment cannot be given under the MCA e.g. because of a valid advance decision
- restraint in a way that is not permitted by the MCA is required
- assessment or treatment cannot be undertaken safely and effectively other than on a compulsory basis
- the individual lacks capacity in respect of some parts of the treatment but has capacity in respect of other parts and refuses a key element
- the person objects to being kept in a hospital or to being given mental health treatments
- there is another reason why the individual may not receive treatment and as a result the individual or someone else may suffer harm.



## 2 The MCA/MHA interface

As stated previously, except in the case of ECT, advance decisions relating to compulsory treatment under the MHA will not be binding. On the other hand, a valid and applicable advance decision for treatment for conditions that are not covered by the compulsory powers of the MHA will be lawful. Similarly, where an incapacitated adult is subject to compulsory powers, all other decisions relating to the general care and treatment of the individual will be covered by the MCA.

There may be circumstances in which either legal framework may apply and the question as to which act applies will be for the judgement of the health professional. However, as a rule of thumb if the patient retains capacity the MCA cannot be used. If the treatment is for a physical condition, then the MHA is irrelevant. If the treatment is for a mental disorder and the patient retains capacity, the MCA cannot be used. Where detention is deemed necessary, the MHA must be used provided the relevant grounds are met.

# Card 15

## Dispute resolution

# 15

There may be occasions in relation to the care and treatment of a person who may be incapacitated where disagreements arise.

These may relate to:

- whether an individual retains the capacity to make a decision
- whether a proposed decision or intervention is in an incapacitated person's best interests
- whether the decision or the intervention is the most suitable of the available options.

It is clearly in everybody's interests that disagreements are resolved as soon as possible, and with as much consensus as possible. Broadly speaking, disputes can be resolved either informally or formally. Some disputes will be so serious that they may have to be referred to the Court of Protection. This card sets out briefly the different options available for resolving disputes in relation to incapacitated adults.

### 1 Good communication

Many disputes can either be avoided, or settled rapidly, by using good communication and involving all relevant individuals. Where health professionals are involved in a dispute with those close to an incapacitated person it is a good idea to:

- set out the different options in a way that can be clearly understood

- invite a colleague to talk the matter over and offer a second opinion
- consider enrolling the services of an advocate
- arrange a meeting to discuss the matter in detail.

## **2 Mediation**

Where the methods outlined above do not successfully resolve the dispute, it may be a good idea to involve a mediator. Any dispute that is likely to be settled by negotiation is probably suitable for mediation.

A mediator is an independent facilitator. It is not the role of a mediator to make decisions or to impose solutions. The mediator will seek to facilitate a decision that is acceptable to all parties in the dispute.

## **3 Patient complaints**

It may be that as part of the dispute resolution process, those acting on behalf of an incapacitated adult might wish to lodge a complaint about the services he or she has received. Health professionals should be able to provide information about which complaint procedures would be appropriate in the circumstances. Initially the Patient Advice and Liaison Service (PALS) may be able to deal with the problem informally. PALS does not investigate complaints but they can, where appropriate, direct people to the formal NHS complaints process.

## **4 The Court of Protection**

The Court of Protection is the final arbiter in relation to matters arising under the Act. The Court can make decisions about whether an individual has the capacity to make a specific decision. Where disputes have arisen that cannot be resolved in any other way, it may be necessary to make an application to the Court of Protection. Cases involving any of the following

decisions should always be brought before the Court:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from patients in a persistent vegetative state or a minimally-conscious state
- cases involving organ or bone marrow donation by a person who lacks capacity
- cases involving proposed non-therapeutic sterilization of a person who lacks capacity
- cases involving ethical dilemmas in untested areas
- some termination of pregnancy cases
- all other cases where there is disagreement that cannot be resolved by other means as to whether a particular treatment will be in a person's best interests.

Information about making an application to the Court of Protection can be found here:

<http://www.scie.org.uk/publications/guides/guide42/how.asp>

# Card 16

# 16

## Confidentiality and informing sharing

Health professionals have the same duty of confidentiality to all their patients regardless of age or disability. Patients with mental health problems or learning disabilities should not automatically be regarded as lacking capacity to give or withhold their consent to the disclosure of confidential information. In the case of health information, health professionals may only disclose information on the basis of the incapacitated patient's best interests.

Where patients lack mental capacity to consent to disclosure it is usually reasonable to assume that they would want people close to them to be given information about their illness, prognosis and treatment unless there is evidence to the contrary. However, where there is evidence that the patient did not want information shared, this must be respected. Those close to the patient who lacks capacity have an important role to play in decision making whether they have a formal role as a proxy decision maker (attorney or deputy), or more informally in terms of helping the health care team to assess the patient's best interests. It therefore might not be possible to carry out these roles without some information being provided about the medical condition of the patient.

### **1 Proxy decision makers and IMCAs**

Welfare attorneys and court appointed deputies whose authority extends to medical decisions have the right to give or withhold consent to treatment and

so must be involved in treatment decisions, although where emergency treatment is required this may not always be possible or practicable. Where a patient lacks capacity and has no relatives or friends who can be consulted, the Act requires an Independent Mental Capacity Advocate (IMCA) to be appointed and consulted about all decisions about 'serious medical treatment', or place of residence (see also card 13). The health team must provide the attorney, deputy or IMCA with all the relevant information including the risks, benefits, side effects, likelihood of success and level of anticipated improvement if treatment is to be given, the likely outcome if treatment is withheld and any alternatives that might be considered. While it will therefore be necessary for attorneys, deputies and IMCAs to have information that will enable them to act or make decisions on behalf of the patient, it does not mean that they will always need to have access to all the patient's records. Only information relevant to the issue in question should be disclosed.

## **2 Relatives, carers and friends**

If a patient lacks capacity, health professionals may need to share information with relatives, friends or carers to enable them to assess the patient's best interests. Where a patient is seriously ill and lacks capacity, it would be unreasonable always to refuse to provide any information to those close to the patient on the basis that they have not given explicit consent. This does not however mean that all information should be routinely shared and where the information is particularly sensitive, a judgement will be needed about how much information the patient is likely to want to be shared and with whom. Where there is evidence that the patient did not want information shared, this must be respected.

### 3 Next of kin

Despite the widespread use of the phrase 'next of kin' this is neither defined, nor does it have formal legal status. A next of kin has no rights of access to a patient's medical records or to information on a patient's medical condition. On the other hand, if, prior to losing capacity, a patient nominates a next of kin and gives authority to discuss their condition with them, they can provide valuable information to the staff looking after the patient. There are no rules about who can and cannot be a next of kin. A patient may nominate their spouse, partner, member of their family or friend. A patient's family cannot argue who should be the next of kin if the patient has not made a nomination as there is no legal status attached to it. It is important not to confuse the concept of next of kin with the role of 'nearest relative' under the Mental Health Act. The individual authorised to undertake that role is subject to the statutory rules under that Act which is wholly distinct from any nomination of next of kin.

### 4 Office of the Public Guardian

The MCA gives the Public Guardian a right of access to patients' health records. Office of the Public Guardian (OPG), or a Court of Protection visitor acting on the instructions of OPG, may therefore ask a GP to see a patient's records while it is investigating the actions of a deputy or attorney. For example, OPG may want to establish the mental capacity of a patient at a particular time. If GPs can release this information promptly it can help ensure these investigations are completed as quickly as possible.

# Card 17

# 17

## Useful names and addresses

### **British Medical Association**

Medical Ethics Department  
BMA House, Tavistock Square,  
London WC1H 9JP  
Tel: 020 7383 6286  
Email [ethics@bma.org.uk](mailto:ethics@bma.org.uk)  
Web: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

### **Court of Protection**

PO Box 70185  
First Avenue House  
42-49 High Holborn  
London WC1A 9JA  
Tel: 0300 456 4600  
Email: [courtofprotectionenquiries@hmcts.gsi.gov.uk](mailto:courtofprotectionenquiries@hmcts.gsi.gov.uk)

### **Department of Health**

Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Tel: 020 7972 2000  
Web: [www.gov.uk/government/organisations/  
department-of-health](http://www.gov.uk/government/organisations/department-of-health)

### **General Medical Council**

<http://www.gmc-uk.org/about/contactus/london.asp>.  
Tel: 0161 923 6602  
Email: [gmc@gmc-uk.org](mailto:gmc@gmc-uk.org)



**Northern Ireland Department of Health,  
Social Services and Public Safety**

Information Office

Castle Buildings C5.20

Stormont, Belfast BT4 3SQ

Tel: 028 9052 0500

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**Office of the Public Guardian**

PO Box 16185

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Email [customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk).

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