

# **Ethics Toolkit**

Mental capacity in Northern Ireland



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### **About this toolkit**

**British Medical Association** 

Although the Mental Capacity Act (Northern Ireland) 2016 (MCA(NI)) was enacted by the Northern Ireland Assembly in May 2016, currently only the sections relating to research, money and valuables, and to deprivation of liberty are in force. Apart from these provisions, the care and treatment of adults lacking capacity in Northern Ireland remains largely governed by the common law (or, in some cases, the Mental Health (Northern Ireland) Order 1986), with serious interventions potentially requiring High Court Declaratory Orders.

The purpose of this toolkit is to act as a prompt to doctors providing care and treatment for people in Northern Ireland who lack, or who may lack, the capacity to make decisions on their own behalf. In our view, this is a situation which most doctors are likely to encounter.

The toolkit contains a series of sections relating to specific areas of the common law relating to medical treatment, such as the basic principles, how to assess capacity, and advance refusals of treatment, and outlines the specific provisions relating to deprivation of liberty and research under the MCA(NI). Although each section refers to separate areas of the law, there is inevitably a degree of overlap.

This toolkit is not intended to provide definitive guidance on all issues in respect of mental capacity. Each section lists additional resources that should be used in conjunction with this toolkit. In cases of doubt, legal advice should be sought. The toolkit is designed to raise doctors' awareness of the law on mental capacity, and to provide an aid for good decision making. This toolkit applies to Northern Ireland; the BMA has separate guidance on decision making for patients who lack capacity in England and Wales and in Scotland.

This toolkit is available on the BMA's website and individual Trusts, medical schools, and individual healthcare professionals may download it and make copies. We welcome feedback on its usefulness. If you have any comments, please address them to:

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#### Introduction

The Mental Capacity Act (Northern Ireland) 2016 (MCA(NI)) was enacted by the Northern Ireland Assembly in May 2016, but currently only the sections relating to research, money and valuables, and to deprivation of liberty are in force. Apart from these provisions, the care and treatment of adults lacking capacity in Northern Ireland remains largely governed by the common law, (or, in some cases, the Mental Health (Northern Ireland) Order 1986) with serious interventions potentially requiring High Court Declaratory Orders. This means that some of the general provisions (such as those relating to basic principles, assessing capacity, best interests, and emergency provisions) are 'live' when applied to deprivations of liberty and research, but not for general treatment decisions, where the common law continues to apply. This guidance is aimed at helping doctors to find their way through this complicated legal situation, by setting out clearly which decisions are subject to the rules and tests set out in the common law and which are subject to the statutory rules in the MCA(NI).

Most of the day-to-day decisions doctors make will be covered by the common law and so this forms the majority of this guidance. For decisions relating to deprivations of liberty, or research, where the MCA(NI) applies, the statutory rules and principles are set out in detail in those sections. Although the common law and the MCA(NI) are very similar, it is essential that the correct tests are used when making decisions. Once the MCA(NI) is fully implemented, this guidance will be reissued to reflect those changes.

Under the common law in Northern Ireland, an action or intervention will be lawful (that is, healthcare professionals will enjoy protection from liability) where the decision maker has a reasonable belief that the individual lacks capacity to consent to what is proposed, and the action or decision is in their best interests. In relation to medical treatment, it is applicable not only to an episode of treatment, but also to those necessary ancillary procedures such as conveying a person to hospital.

There are limits to these powers. A valid and effective advance refusal of treatment, for example, is likely to be binding under the common law (and this status will be placed on a statutory footing when the Act is fully in force). There are also limits on the extent to which the freedom of movement of an adult who lacks capacity can be restricted. An adult who lacks capacity can only be restrained where there is a reasonable belief that it is necessary to protect them from harm and the proposed action is proportionate to the risk; where any restriction amounts to a deprivation of liberty, the MCA(NI) must be followed and the action will only be lawful when the appropriate authorisation is in place.

Codes of Practice have been issued for those parts of the MCA(NI) that are currently in force. This includes codes on the deprivation of liberty, and on money and valuables & research. It is essential that healthcare professionals who are making decisions in these areas of practice are familiar with these Codes of Practice.







### **Key resources**

BMA – Treating 16 and 17-year-olds in England, Wales, and Northern Ireland

DHNI – <u>Deprivation of Liberty Code of Practice 2019</u>

DHNI – MCA Useful Information and Contacts

DHNI – Mental Capacity Act (Northern Ireland) 2016 (resources)

DHNI – Money and Valuables & Research Code of Practice 2019

Mental Capacity Act (Northern Ireland) 2016



## **Capacity and incapacity**

#### What is capacity?

Decision-making capacity refers to the everyday ability we possess to make decisions or to take actions that influence our lives, from simple decisions about what to have for breakfast, to complex 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 themselves or for other people.

#### When does a person lack capacity under the common law?

Under the common law in Northern Ireland (set out in the Appeal Court case of Re MB), a person lacks capacity if:

'some impairment or disturbance of mental functioning renders the person unable to make a decision whether to consent or to refuse treatment'.

An impairment or disturbance of mental functioning could be the result of a variety of factors, including mental illness, learning disability, dementia, brain damage, or intoxication.

An individual lacks the capacity to make a decision if, at the time the decision needs to be made, they are unable to:

- understand the information relevant to the decision;
- retain the information;
- use or weigh the information as part of the process of making a decision;
   or
- communicate the decision.

The assessment of capacity is 'task specific'. It focusses 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 MCA(NI) provides a statutory definition of what it means to lack capacity to consent to a deprivation of liberty (section 11) or participation in research (section 12); see the relevant sections of this guidance when making decisions on those issues.





## **Basic principles**

#### What are the basic principles of the common law?

The basic principles that apply to decision making for patients who lack capacity are rooted in best practice and the common law and are designed to be compliant with the Human Rights Act. Actions or decisions that clearly conflict with these principles are unlikely to be lawful, although there may be occasions where they are in tension, and some balancing will be required. A list of the basic common law principles, with brief descriptions, is given below:

#### A presumption of capacity

In Northern Ireland, no one should be treated as lacking capacity unless it has been established that they lack the capacity to make the decision in question. Decision making in this area therefore starts from the position that adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so. This means that it is never for an adult to prove their own capacity. Where a person intends to take steps on the basis that the adult lacks capacity to make the relevant decision, that person must be able to explain why they consider that they are allowed to do so, including why the adult can be said to lack capacity.

#### The freedom to make an unwise decision

No assumptions about the individual's capacity should be made merely because they are making what others consider to be an unwise decision. Making a rash, unwise or irrational decision, or acting out of character, is not in and of itself proof of incapacity. All adults retain the right to make decisions which seem unwise or irrational to others. Although such actions may raise questions about capacity which require further exploration — where for example they follow a period of illness or an accident — they are not determinative of capacity. What matters is the ability to make the decision, not the content of the decision per se. This means that while an unwise decision might be a reason to consider whether the person has capacity, it cannot be the basis on which they are found to lack capacity.

#### **Necessity and best interests**

Under the common law, where individuals lack capacity, no one else, including family members, has the legal authority to consent on their behalf. (There are provisions in the MCA(NI) for individuals to appoint an attorney to make health and welfare decisions on their behalf if they lose capacity, but these have not yet come into force.) Treatment can, however, be provided when it is both necessary to intervene, and the intervention is in the individual's best interests. When assessing an individual's best interests, special regard should be given to statements of current or prior wishes or feelings expressed or made by the individual, and to what is known about the individual's beliefs and values. A determination of what is in the best interests of a person who lacks capacity must not be based solely on the person's age, appearance, or any other characteristic, including any condition. Rather all relevant circumstances must be considered.

For more information about assessing a patient's best interests see section 5. The BMA also has a separate toolkit on best interests decision making for adults who lack capacity; although this is based on the legislation in England and Wales, much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland (see key resources).





#### The less restrictive alternative

Any decisions must be made in compliance with the Human Rights Act 1998. Therefore, 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.



#### **Key resources**

BMA – Best Interests decision-making for adults who lack capacity. Although this is based on the law in England and Wales, the practical information may also be useful for doctors working in Northern Ireland.





### **Assessing capacity**

#### Who should assess capacity?

The law does not specify who should assess capacity where a patient's ability to make a decision has been called into question (but see section 11 for guidance on assessing capacity for a deprivation of liberty). However, anyone who wishes to carry out an action in connection with the care or treatment of an individual, in their best interests, must have a reasonable belief that they lack the requisite capacity. In its guidance on decision making and consent at paragraph 82 the GMC states:

'Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (eg by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision.'

If you believe that the patient may lack the capacity to make a specific decision, then you must assess their capacity to make the decision in question, as set out below. Where consent to medical treatment is required, the healthcare professional proposing the treatment is responsible for ensuring that the patient has the capacity to consent before proceeding, otherwise, under the common law, they would not be able to rely upon the defence of necessity to justify their actions. If the patient lacks the requisite capacity, the person carrying out the treatment must be satisfied that it is necessary and in the patient's best interests or, again, they could not rely on the defence of necessity to justify their actions.

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.

If there is doubt about whether the patient has the capacity to make a specific decision, it can be helpful to seek support from someone who knows the patient well, for example, another member of the healthcare team or someone close to the patient. Although assessing capacity is a core clinical skill, in complex cases, where there is doubt about whether the patient has the requisite capacity, you should seek specialist input from colleagues such as psychiatrists or psychologists. You should also seek specialist input if the patient or someone close to them disagrees with your assessment.

#### How do you assess capacity?

When assessing an individual's capacity to make a specific treatment decision, doctors should ensure, as far as possible, that any factors likely to affect the patient's ability to decide for themselves are addressed beforehand. These may include medication, medical condition, pain, time of day, fatigue, or mood. Any information must be given as clearly and plainly as possible with communication aids used where appropriate. Those assessing a patient's capacity are also under an obligation to enhance their capacity as far as reasonably possible. This will involve seeking to ensure that patients are engaged in decision making when they are best able to participate and are encouraged to participate in decision making to the greatest extent they are able.



In relation to medical treatment, doctors should follow the common law which states that a person lacks capacity 'if an impairment or disturbance of mental functioning renders them unable to make a decision'. That inability to make a decision occurs when they are unable to:

- understand the information relevant to the decision;
- retain the information;
- use or weight that information as part of the process of making the decision; or
- communicate the decision.

Where an individual fails one or more parts of this test, they do not have the relevant capacity. Difficult judgements will still need to be made, particularly where capacity fluctuates; where some capacity is demonstrable but its extent is uncertain; or where the impairment – which does not require a formal diagnosis – may interact with coercion or duress from those close to the individual.

If the incapacity is temporary and the decision can reasonably be put off until such time as the patient is likely to regain capacity, then it should be deferred.

While it is clear that an unconscious patient will lack capacity, most other patients will retain some decision-making capacity, however slight. In assessing capacity, family members and close friends may be able to provide valuable background information about the individual to assist with the assessment of capacity, although their views about what they might want for the individual must not be allowed to influence the assessment of capacity.

#### What do you do if 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 later, 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. In these circumstances, doctors should document the refusal in the medical record, make a decision about capacity based on the information they have available, and document the decision reached and the reasons for it; where the question of capacity cannot be resolved on the basis of existing information, legal advice should be sought.

If there are reasonable grounds to believe that the refusal of assessment results from coercion by a third party, legal advice should be sought (see key resources).



#### **Key resources**

BMA and The Law Society – <u>Assessment of Mental Capacity. A practical guide for doctors and lawyers (5th edition)</u>. Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.

GMC – Decision making and consent



#### **Best interests**

#### What is meant by best interests?

All decisions taken on behalf of someone who lacks capacity in Northern Ireland must be taken in their best interests. Case law, including common law 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 Supreme Court applying the English Mental Capacity Act has made it clear that the decision maker must make a reasonable effort to put themselves in the place of the patient and ask what their attitude to the proposed treatment would be. We consider that this approach applies equally to a decision maker applying the common law in Northern Ireland in relation to medical treatment. The focus should therefore be on determining what decision the individual would make if they had the capacity to choose. (See also section 6 on supported decision making.)

#### What should you consider 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 possible. The decision maker must consider whether the person is likely to regain capacity and, if so, whether the decision can reasonably be left until they regain the capacity to make it.

When determining whether an intervention would be in the best interests of an adult who lacks capacity, assumptions must not be made merely on the basis of the individual's age or appearance, their medical condition, or any disability, or an aspect of their behaviour — this is the principle of equal consideration and non-discrimination.

In most circumstances it will be clear where the individual's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming – but this is not always the case. Whether to provide analgesics for someone in pain is likely to be a straightforward question; a decision about whether to continue providing life-sustaining treatment is less so. Where a decision is likely to have grave consequences for a person it will require greater consideration, wider consultation with those close to the patient, and more detailed documented evidence about the decision reached and the reasons for it.

Relevant factors to consider are likely to include (so far as they are reasonably ascertainable):

- the person's past and present wishes and feelings and, in particular, any written statements made when they had capacity;
- their wishes, beliefs, and values; and
- other factors the person would have considered if able to do so, such as the effect of the decision on other people.

For significant decisions, a crucial part of best interests assessments involves discussion with those close to an individual who lacks capacity, including family, friends, or carers, where it is practical or appropriate to do so, bearing in mind the duty of confidentiality (see section 14 on information sharing). The BMA has a best interests decision making toolkit which, although based on the legislation in England and Wales, contains a lot of practical information and guidance that may be helpful for those practising in Northern Ireland (see key resources).



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

There are two circumstances in which the best interests principle will not apply. The first is where someone has previously made an advance decision to refuse treatment (ADRT) while they had capacity. Where the advance decision is valid and effective, it should be respected, even if others think that the decision is not in their best interests. For more information on advance decisions see section 7. The second exception relates to the enrolment of adults who lack capacity in certain forms of research - see section 12.



#### **Key resources**

**British Medical Association** 

BMA – <u>Best Interests decision-making for adults who lack capacity toolkit</u>. Although this is based on the law in England and Wales, the practical information may also be useful for doctors working in Northern Ireland.





## Supported decision making

#### What does 'supported decision making' mean?

In 2009, the UK ratified the United Nations Convention on the Rights of People with Disabilities (CRPD). Although not incorporated into UK law, and so not part of the law in Northern Ireland, the CRPD has ushered in something of a sea-change regarding the care and treatment of people who may lack capacity to make certain decisions. The focus of the CRPD is on *supported* rather than *substitute* decision making. In this section we set out ways in which doctors can draw on aspects of this approach to complement their obligations under the common law.

#### Is there a difference between mental and legal capacity under the CRPD?

Yes. Although mental and legal capacity are treated similarly under mental capacity law, the CRPD relies on a distinction between mental and legal capacity. Legal capacity refers to the formal ability to hold and exercise rights and duties. Under the CRPD, these are universal and cannot be lost. Mental capacity refers to decision-making skills and abilities and these clearly vary from individual to individual.

#### What does 'supported decision making' mean under the CRPD?

As interpreted by the UN treaty body responsible for the CRPD, the Convention uses the concept of supported decision making in a particular sense. It requires ensuring that people receive the support they need and want to make and express decisions where this is possible. If it is not possible, decisions must be taken in a way that reflects the person's 'will and preferences.' Where their will and preferences are unclear, it is permissible to act according to a 'best interpretation of will and preferences.' This approach now guides decisions made by the Court of Protection in England and Wales (which courts in Northern Ireland are likely to look to when considering cases), and the Supreme Court (whose decisions form case law in Northern Ireland). The key difference is that the focus is increasingly on determining what the individual would want — and consider to be in their best interests — in the circumstances, rather than what others believe objectively to be in their best interests.

#### What measures can enhance supported decision making?

These measures can include:

- exploring with the person how best they can be supported to make decisions;
- identifying, as far as possible, the wishes and feelings of those unable to make decisions. Such wishes and feelings should be complied with when making best interests decisions unless there are compelling reasons to set them aside;
- ensuring facilities are available in healthcare services where assessments
  of capacity are frequent to ensure the proper support of those being
  assessed, including an environment conducive to their maximal
  involvement in decision making; and
- facilitating, as appropriate, the involvement of those close to the individual to support their decision making.

#### Who is responsible for ensuring appropriate support?

The obligation to take appropriate steps to support the person to make a decision falls largely on those responsible for assessing the individual's mental capacity. This will include ensuring a conducive environment and ensuring information is provided in an accessible form.





# Advance decisions to refuse treatment

#### Are advance decisions to refuse treatment legally binding?

When the MCA(NI) is fully enacted it will provide a statutory foundation for advance decisions to refuse treatment (ADRT), such that where there is a valid and effective ADRT made by an adult, this will be legally binding. Currently, however, there is no legislation in force covering ADRTs in Northern Ireland. The Department of Health's review of the law relating to ADRTs (see key resources) says that 'Valid and effective advance decisions to refuse treatment have the same legal status as decisions made by people with capacity'. It states that before healthcare professionals apply an ADRT there must be proof that:

- 'a. The decision exists (this is more likely to be apparent if the decision is in writing);
- b. The decision applies to the existing circumstances;
- c. The person had capacity to make the decision at the time it was made;
- d. The person making the decision understood the consequences of refusing treatment; and
- e. The person making the decision was not under the undue influence of a third party.'

It goes on to state that in order to establish whether an ADRT is valid and effective, healthcare professionals must try to ascertain whether the person making it:

- `a. Has done anything that clearly goes against their advance decision;
- b. Has withdrawn their decision;
- c. Has subsequently conferred the power to make that decision on an attorney; or
- d. Would have changed their decision if they had known more about the current circumstances.'

When assessing the validity of an ADRT it is important to remember the principle that no one should be treated as lacking capacity unless it has been established that they lack the capacity to make the decision in question (see section 3). Doctors should therefore start from the presumption that a person who has made an advance decision had the capacity to make it, unless there are reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it. In cases of genuine doubt about the existence or validity of an advance decision, doctors can provide treatment that is immediately necessary to stabilise or to prevent a deterioration in the patient's condition until the existence, and the validity and effectiveness, of the advance decision can be established. If doubts cannot be resolved locally, and time permits, legal advice should be sought about applying to the court for a declaration.

Advance requests for future treatment, or statements about matters other than medical treatment, are not legally binding, although they can be a very useful indication of a patient's wishes and feelings when making best interests decisions.





#### Are there limits to advance decisions to refuse treatment?

Although any written or oral statements of patients' future wishes are clearly a vital part of decision making, there are limits to patients' ability to influence their future care. Nobody can authorise or refuse in advance procedures they could not authorise or refuse contemporaneously. They cannot, for example, insist upon treatment that is not clinically indicated. In the BMA's view, it would also be inappropriate for patients to refuse in advance the provision of all forms of 'basic care' such as hygiene and interventions designed solely for the alleviation of pain or distress. This also includes the offer of oral food and water (but not clinically-assisted nutrition and hydration). An advance decision to refuse treatment cannot be used to nominate someone else to make decisions, or give effect to an unlawful act.

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

Advance decisions to refuse treatment cannot extend to treatment for mental disorders provided under the authority of the Mental Health (Northern Ireland) Order 1986. The Department of Health's policy on advance care planning, however, says: 'When the Mental Capacity Act (Northern Ireland) 2016 is fully commenced it will replace the Mental Health (NI) Order 1986, for everyone aged 16 and over, and will include mental health treatment. The Mental Capacity Act NI 2016 will provide a statutory foundation for an ADRT. It will note that if there is a valid and applicable ADRT, this cannot be overruled by a decision under the Act' (see key resources).

# Is there a specific format for advance decisions to refuse treatment?

The common law does not set out the form in which an advance decision to refuse treatment needs to be made. Oral advance decisions can be binding, particularly when supported by appropriate evidence, although a note should be made of any such oral decision in the medical record. It is worth bearing in mind that advance decisions can also be recorded, for example on smart phones, although patients have to take appropriate steps to ensure relevant people are made aware of their existence.

Patients wishing to make an advance decision that is likely to have serious consequences for them, including any decision relating to life-sustaining treatment, should ideally put their wishes in writing. (It is worth noting that the Mental Capacity Act for England and Wales requires any decision relating to life-sustaining treatment to be in writing, signed and witnessed, and to contain a statement that it is to apply even where life is at risk, and this could be considered best practice when patients are drawing up an ADRT).

In the BMA's view, patients making a written advance decision should include the following:

- full details of the person making the advance decision including their name and address:
- the name and address of the person's GP and whether they hold a copy of the document;
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- the signature of the person making it and any person witnessing the signature; and
- the date the document was written or subsequently reviewed.



It is advisable for patients to review their ADRTs regularly, particularly where there are any material changes in the individual's condition or treatment options, and at least every five years.

#### How should advance decisions be stored?

The storage of advance decisions, and the obligation to ensure that relevant healthcare professionals are aware of them, are the responsibility of those who make them. A copy of any written ADRT should be given to the patient's GP for storage in the medical record; a copy of the document should be provided to another healthcare professional involved in the patient's care on request. The patient should also draw it to the attention of hospital staff before an episode of care. It is also good practice for anyone who makes an ADRT to draw it to the attention of anyone who may be called upon to contribute to best interests assessments, such as friends, family, or any advocate.



#### **Key resources**

**British Medical Association** 

DHNI – For now and the future. An advance care planning policy for adults in Northern Ireland

DHNI – Review of the law relating to Advance Decisions to Refuse Treatment



**British Medical Association** 



### Treatment in an emergency

# Can emergency treatment be provided to adults who lack the capacity to consent?

It is clearly established under the common law 'principle of necessity' that, in an emergency, where consent cannot be obtained, doctors should provide treatment that is immediately necessary either to preserve life or to prevent a serious deterioration in the patient's condition. The only exception to this is where there is clear evidence of a valid and effective advance decision refusing the treatment in question (see section 7). Emergency treatment does not have to be restricted to what is immediately necessary. Applying the principles set out above, to consider the person's capacity and best interests, it can also include steps to prevent deterioration in order to ensure that recovery is an option. Where decisions can reasonably be delayed until such time as the adult is likely to regain capacity, or to permit an assessment of capacity and discussion with those close to the patient, then they should be.

# What should you do if, in an emergency, a patient refuses treatment and there is doubt as to their capacity?

Doctors should take whatever steps are necessary to prevent deterioration in the patient's condition, and then consider questions of capacity and consent. If it is clear that a patient has the capacity to refuse treatment, or has a valid and effective advance decision to refuse the treatment, doctors cannot provide the treatment unless authorised under the Mental Health (Northern Ireland) Order 1986. For more information on advance decisions to refuse treatment, see section 7.

# What should I do if emergency treatment amounts to a deprivation of liberty?

The emergency provisions in the MCA(NI) are in force in relation to decisions about deprivation of liberty. Chapter 10 of the Deprivation of Liberty Safeguards (DoLS) Code of Practice (see key resources) explains the process that must be followed in an emergency situation.



#### **Key resources**

DHNI – <u>Deprivation of Liberty Safeguards Code of Practice</u> 2019





# Treatment requiring special safeguards

For most day-to-day healthcare decisions, the procedures and principles set out in the common law and outlined in this guidance are sufficient. There are some treatments, however, that are generally regarded as being more serious or controversial and require either special safeguards, or in the case of the most complex and difficult decisions, referral to court.

#### What treatments may require an application to the court?

In England, case law (including Supreme Court case law) and Court of Protection guidance have made clear that certain categories of cases are ones where legal advice should be sought to determine whether an application to court is required. Given that these are cases where there is doubt or disagreement about the correct course of action, or where it is considered that the proposed treatment would involve serious interference with the person's human rights, the BMA recommends that doctors in Northern Ireland seek legal advice in cases, where:

- at the end of the decision-making process:
  - the decision is finely balanced;
  - there is a difference of medical opinion;
  - there is a doubt or dispute that cannot be resolved locally (see section 13) about whether a particular treatment will be in a person's best interests; or
  - there is a conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed;
- a medical procedure or treatment is for the primary purpose of sterilisation;
- the procedure is for the purpose of donation of an organ, bone marrow, stem cells, tissue, or bodily fluid to another person;
- the action proposed involves a procedure for the covert insertion of a contraceptive device or other means of contraception;
- it is proposed that an experimental or innovative treatment be carried out;
   or
- the case involves a significant ethical question in an untested or controversial area of medicine.

It is also advisable to seek legal advice where the proposed action involves the use of deception to deliver medical treatment (for example covert medication) to the patient on a regular or long-term basis.

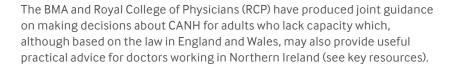
Is Court approval required for decisions relating to the proposed withholding or withdrawal of clinically-assisted nutrition and hydration (CANH) from patients in a persistent vegetative state or a minimally conscious state?

The Supreme Court has made clear that there is no legal obligation to seek Court approval for these decisions unless, at the end of the best interests assessment:

- the way forward is finely balanced;
- there is a difference of medical opinion;
- there is a lack of agreement to a proposed course of action from those with an interest in the patient's welfare; or
- there is a potential conflict of interest on the part of those involved in the decision-making process that cannot be appropriately managed.









#### **Key resources**

Applications relating to medical treatment; guidance authorised by the Honourable Mr Justice Hayden, the Vice-President of the Court of Protection

BMA and RCP — Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in England and Wales. Although this is based on the law in England and Wales, some of the practical information will still be useful for doctors practising in Northern Ireland.





# Restraint and other restrictive practices

#### What is restraint?

There may be occasions when healthcare professionals need to consider the use of restraint in treating an individual lacking capacity. 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. Healthcare professionals have a common law right to use proportionate restraint to prevent the immediate risk of harm to the patient or others.

Any use of restrictive practices, including the use of restraint, should comply with the NI Department of Health's *Regional policy on the use of restrictive practices in health and social care settings* (see key resources). If restraint amounts to a deprivation of liberty, the required legal authority must be in place for the action to be lawful (see section 11).

#### What are the types of restraint?

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

**'Physical Restraint:** Any direct physical contact where the intervener prevents, restricts or subdues movement of the body, or part of the body, of another person.

**Mechanical Restraint:** The use of a device to prevent, restrict or subdue movement of a person's body, or part of the body, for the primary purpose of behavioural control.

**Chemical Restraint:** The use of medication, which is prescribed and administered for the purposes of controlling or subduing acute behavioural disturbance, or for the management of on-going behavioural disturbance.'

#### What other types of restrictive practices are there?

In addition to restraint, restrictive practices are defined in the Regional Policy as including:

**Environmental restrictions:** The use of obstacles, barriers or locks to prevent a person from moving around freely. This could also include the use of electronic monitoring.

**Psychological restrictions:** Depriving a person of choices, controlling them through not permitting them to do something, making them do something or setting limits on what they can do.

**Coercion:** The practice of persuading someone to do something by using force or threats.

**Observation:** A restrictive intervention of varying intensity in which a member of healthcare staff observes and maintains contact with a person to ensure the person's safety and the safety of others.'

Seclusion is defined as 'the confinement of a person in a room or area from which free exit is prevented.'





#### When is the use of restrictive practices permitted?

The Regional Policy sets out the following general principles which must apply to any use of restrictive practices.

- Decisions to use restrictive practices must be supported by robust justification.
- Children and young people should never be subject to seclusion.
- Restrictive interventions, restraint and seclusion should not be used for reasons related to disability.
- Any use of restrictive practices must only be considered as a last resort.
- Initial attempts of restraint should as far as possible be non-physical.
- There must be a real possibility of imminent harm to the person or to staff, the public or others if no action is undertaken.
- Any use of restrictive practice must be most effective and therapeutic intervention possible with regards to reducing behaviours associated with risk and/or their impact.
- The nature of the technique used must be proportionate to the risk of harm and the seriousness of that harm and be the least restrictive option that will meet the need.
- Any restriction should be imposed for no longer than absolutely necessary.
- Restrictive interventions, restraint or seclusion must never be used as
  discipline, to inflict pain or humiliation, or a substitute for the provision of
  proper, person-centred care.
- Use of restraint or seclusion must be considered in the context of the legal authority for its use, and fully compliant with a rights-based approach.'

If these conditions are met, it is permissible to use restrictive practices to provide necessary treatment to an individual. It also follows that in such circumstances there would be no liability for assault. Where, however, the practices amount to a deprivation of liberty (see section 11), the action would be unlawful unless the necessary authorisation has been obtained.



#### **Key resources**

DHNI – Regional policy on the use of restrictive practices in health and social care settings, March 2023





# Care or treatment amounting to a deprivation of liberty – the Deprivation of Liberty Safeguards regime (DoLS)

#### What is a deprivation of liberty?

It may be necessary at times to provide care or treatment to an adult lacking capacity in circumstances that amount to a deprivation of their liberty. The acid test to determine whether what is being done to the person is a deprivation of liberty is that the person is:

- not free to leave; and
- under continuous supervision and control.

The Deprivation of Liberty Safeguards (DoLS) Code of Practice (see key resources) provides guidance as to the meaning of deprivation of liberty and is accompanied by a set of scenarios. Deprivations of liberty can be authorised if they comply with the deprivation of liberty safeguards; these only apply to people who are aged 16 years old or over who are in a place where care or treatment is being provided.

If a person has capacity to consent, they can be subject to any arrangements, including arrangements that are of a similar nature to a deprivation of liberty, on a voluntary basis. However, if he or she, at any time, loses capacity to consent, such arrangements are no longer voluntary. If a person no longer has capacity to consent to the arrangements, all the safeguards of the MCA(NI) must immediately be put in place. The DoLS Code of Practice is clear (at paragraph 2.11) that a 'person who has capacity cannot consent pre-emptively to the deprivation of their liberty for a time in the future when they may no longer have capacity'.

No deprivation of liberty will be deemed to have occurred – and therefore no authorisation will be required – where the person is in hospital being treated for a life-threatening illness and the circumstances of the treatment for the physical illness for the person who lacks capacity is the same as for a person who has capacity.

The DoLS Code of Practice, reflecting case law from England and Wales, clarifies that this situation would apply to:

'a person in intensive care who is chemically restrained due to the physical illness they are being treated for, and thus not free to leave and is subject to continuous supervision and control. However, if the reason for the restraint is the physical illness and not the lack of capacity, the person is not deprived of his or her liberty and the additional safeguards outlined in this Code do not apply.' (paragraph 2.21)

#### What is meant by 'not free to leave'?

The DoLS Code of Practice makes clear that the fact that the individual is unable to leave does not necessarily mean that the individual is being prevented from leaving which would amount to a deprivation of liberty. Examples of the type of situations which would require authorisation include:

- locked doors that are not unlocked on the individual's request;
- physically preventing the individual from leaving;
- the individual not being able to leave the place without supervision; and
- not being free to permanently move residence.



#### What is 'continuous supervision and control'?

The DoLS Code of Practice says that being under 'continuous supervision and control' may include having control over who the patient can have contact with, control over their activities, or supervision over their health and actions. In practical terms, when considering whether an individual is subject to 'continuous 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;
- who the individual will have contact with; and
- what steps they will take if they cannot establish the above.

#### What is the legal basis for a deprivation of liberty?

The MCA(NI) and the Mental Capacity (Deprivation of Liberty) (No. 2) Regulations (Northern Ireland) 2019 set out a process for the authorisation of a deprivation of liberty for those people aged 16 and over lacking capacity to consent to the arrangements. These provisions combined form the Deprivation of Liberty Safeguards (DoLS). The basic features of DoLS are given below to give an overview of the system. Those who are, or are likely to be, required to make or participate in decisions about deprivation of liberty must familiarise themselves with the DoLS Code of Practice and training requirements (see key resources). It is also necessary that they are familiar with the situations under which the Mental Health (Northern Ireland) Order 1986 may apply because, where it does apply, the law is clear that the Order must be used rather than the DoLS framework.

It is very important also to understand that a DoLS authorisation does not give any authority to carry out acts of care and treatment. Care and treatment therefore need to be delivered either on the basis of the person's capacitous consent, or on the basis of the common law approach (see sections 2,3, and 5)

# What principles apply to decisions that include deprivation of liberty?

The principles set out in the MCA(NI) have been 'live' in relation to deprivations of liberty since 2019. It is important that the statutory principles are used, and where necessary are referred to expressly, when making decisions relating to deprivation of liberty.

The statutory principles are as follows:

'Principle 1-A person is not to be treated as lacking capacity unless it is established that the person lacks capacity in relation to the matter in question.

Principle 2- The question if a person is able to make a decision for himself or herself can only be determined by considering the requirements of the Act and no assumptions can be made merely on the basis of any condition that the person has or any other characteristics of the person.

Principle 3 – A person is not to be treated as unable to make a decision for himself or herself unless all practicable help and support to enable the person to make the decision has been given without success.

Principle 4 – A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.

Principle 5 – Any act done, or decision made, must be made in the person's best interests.'



#### What are the deprivation of liberty safeguards?

Before a person can be deprived of their liberty the following safeguards must be in place:

#### **General safeguards**

To be protected from liability when depriving a person of his or her liberty, there must be:

- a reasonable belief of lack of capacity; and
- a reasonable belief of best interests.

#### **Additional safeguards**

Four additional safeguards must also be in place for the deprivation of liberty to be lawful:

- a formal assessment of capacity must be completed;
- the nominated person should be consulted;
- the prevention of serious harm condition must be met; and
- an appropriate authorisation must be in place (see below).

#### What is the test of capacity for deprivation of liberty?

The test of capacity in the MCA(NI) has been 'live' in relation to deprivation of liberty since 2019 and therefore must be used, and where appropriate, explicitly referred to. For the purposes of deprivation of liberty, an individual lacks capacity if they are:

'unable to make a decision for himself or herself about the matter, because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

There are three elements to the assessment of capacity:

- 1. an inability to make a decision (the functional test);
- 2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
- 3. a causal link between the two (ie the inability to make a decision must be caused by the impairment).

All three elements are equally important, and all three elements must be present for the person to lack capacity.

The DoLS Code of Practice states that, under the functional test, an individual lacks the capacity to make a decision if they are unable to do any of the following:

- 'a. understand the information relevant to the decision (which includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision);
- b. retain that information for the time required to make the decision;
- c. appreciate the relevance of that information and use and weigh it as part of the decision making process;
- d. communicate his or her decision.'



# Who can carry out a formal assessment of capacity for a deprivation of liberty?

The DoLS code of practice states that a formal assessment of capacity, and a statement of incapacity, for a deprivation of liberty may be carried out by any of the following people:

- a. social worker;
- b. medical practitioner;
- c. nurse or midwife;
- d. occupational therapist;
- e. speech and language therapist;
- f. dentist:
- g. practitioner psychologist.

In addition, a person carrying out a formal assessment of capacity must:

- have received training on formal capacity assessments approved by the Department of Health within the 36 months immediately prior to the assessment taking place;
- have at least two years' experience in working with persons who lack capacity; and
- must be designated by his or her employer as a person to carry out formal assessments of capacity.

# How are best interests assessed in the case of deprivation of liberty?

The sections of the MCA(NI) that apply to best interests decision making have been 'live' in relation to decisions about deprivation of liberty since 2019. It is important that the statutory provisions are followed when making assessments relating to deprivation of liberty.

The code of practice makes clear that the best interests determination:

'... is more than a clinical or medical best interests test; it is a holistic consideration of all relevant factors that would be reasonable to consider under the circumstances. The best interests is not what the professional would do or agree to if he or she was in the same shoes or what the relatives think they would do. A best interests determination starts with consideration of what decision P would have made if P had capacity to make the decision.' (para 6.3)

Section 7 of the MCA(NI) sets out factors that must be considered as part of the best interests assessment, although this list is not exhaustive and all relevant points must be considered. The statutory checklist includes that the decision maker must:

- give 'special regard' to (as far as they are ascertainable):
  - the person's past and present wishes and feelings (in particular any written statements made when they had capacity);
  - any beliefs and values that are likely to influence their decision if they had capacity; and
  - any other factors that would be likely to influence their decision;
- not make assumptions merely on the basis of the individual's age, appearance, medical condition or any aspect of their behaviour which might lead others to make unjustified assumptions about what might be the individual's best interests;
- consider all the relevant circumstances;
- encourage and help the individual to participate as fully as possible in the determination of what would be their best interests;



- consider whether the individual is likely to have capacity to make the decision in the future and, if so, when that is likely to be;
- so far as it is practicable and appropriate to do so, consult the relevant people, including the 'nominated person', about what would be in the individual's best interests and take into account those views;
- consider whether the same purpose can be as effectively achieved in a way that is less restrictive of the individual's rights and freedom of action; and
- have regard to whether failure to take the action proposed is likely to result in harm to others with resulting harm to the person lacking capacity.

In relation to the point above, the Code of Practice gives the example that 'resulting harm to [the individual] includes indirect harm such as losing contact with people or being subject to the criminal justice system because of harm caused to others'. It is, however, always important to be able to explain why the person, themselves, will be harmed in consequence.

#### Who is the 'nominated person'?

The Act requires a 'nominated person' to be consulted when making best interests assessments in relation to proposed actions that would amount to a deprivation of liberty. The nominated person does not have decision-making powers but must be consulted as part of the assessment process.

- A person over 16 years old who has capacity may appoint, in writing, someone over the age of 16 to be their nominated person.
- A person over 16 years old who has capacity may also specify, in writing, that a particular person is not to be their nominated person.
- In some circumstances, the Review Tribunal (an independent judicial body set up by the Mental Health (Northern Ireland) Order 1986) can appoint a nominated person.
- Where neither the individual nor a Review Tribunal has appointed a nominated person the 'default list' will apply. The person who is highest up the list (see below) is the individual's nominated person unless they are under 16 or have been discounted by the individual or the Review Tribunal.

The default list, in order of hierarchy, is set out in section 73 of the Act, as follows:

- a. carer;
- b. spouse or civil partner;
- c. living with the individual as spouse or civil partner for at least 6 months;
- d. child;
- e. parent;
- f. brother or sister;
- g. grandparent;
- h. grandchild;
- i. aunt or uncle;
- j. niece or nephew;
- k. someone living with the individual for a period of at least 5 years.

More information can be found in the DoLS Code of Practice.





#### How is a deprivation of liberty authorised?

There are two ways of authorising a deprivation of liberty. If a person who lacks capacity is in hospital, a deprivation of liberty — called a short-term detention — can be authorised for the purposes of examination in hospital, or examination followed by treatment and care, on the production of a report from an appropriate healthcare professional, usually an approved social worker, which must include a report from a medical practitioner. The short-term detention can initially be authorised for up to 14 days, then extended for a maximum of a further 14 days.

If a deprivation of liberty happens outside hospital, a panel appointed by the Trust for these purposes must authorise the deprivation. The Trust Panel is made up of three members, one of whom is always a medical practitioner.

Both a short-term detention and a deprivation of liberty authorised by the Trust Panel can be reviewed by the Review Tribunal on the application of the individual or their nominated person.

The DoLS Code of Practice explains the process that must be followed in emergency situations.



#### **Key resources**

DHNI - Deprivation of Liberty Safeguards Code of Practice 2019

DHNI - Mental Capacity Act Training

DHNI – MCA Useful Information and Contacts

Mental Capacity Act (Northern Ireland) 2016

Mental Capacity (Deprivation of Liberty) (No. 2) Regulations

(Northern Ireland) 2019



#### Research

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

Yes. The research provisions of the MCA(NI) have been in force since 2019. It is therefore important that the statutory provisions are used and, where appropriate, expressly referred to when making decisions relating to research in Northern Ireland.

Under the MCA(NI) and the Mental Capacity (Research) Regulations (Northern Ireland) 2019, it is lawful to involve adults who lack capacity in research in some circumstances. (Different rules apply to participation in clinical trials — see below). The Money and Valuables & Research Code of Practice (see key resources) sets out the conditions that must apply:

- 'a. it must be connected with the condition which is the cause or contributed to an impairment of, or a disturbance in the functioning of, the mind or brain ("impairing condition") or its treatment;
- there must be reasonable belief that research of comparable effectiveness cannot be carried out if the project has to be confined, or relate, to persons who have capacity to consent only;
- c. it must have the potential to benefit the individual and that the burden
  of the research project is proportionate to the benefit or be intended to
  provide knowledge of causes or treatment, or care, of persons affected by
  same or similar conditions as the individual;
- d. nothing can be done to the individual to which they appear to be objecting except for where the act is done to prevent harm or to reduce pain or discomfort;
- e. nothing can be done to the individual which is contrary to an effective advance decision to refuse treatment;
- f. nothing can be done to the individual which is contrary to a written statement made by the individual when they had capacity; and
- g. if the individual indicates (in any way) a wish to be withdrawn from the project, they must be withdrawn without delay'

In order for research involving patients who lack capacity to be lawful, the interests of the patient must at all times be assumed to outweigh any benefits to science and society.

Clinical trials under Medicines for Human Use (Clinical Trials) Regulations 2004 are subject to their own rules and regulations and guidance should be sought from professional bodies, and health and social care guidance, before such trials are carried out. (In April 2014, the EU adopted the Clinical Trials Regulations 2014 to repeal the earlier Directive on which the 2004 Regulations are based. However, it had not become applicable in the EU when the UK exited the EU and will therefore only be incorporated into UK law if specific, domestic steps are taken to bring this about.)

# What principles apply to decisions related to research involving patients who lack capacity?

The principles set out in the MCA(NI) came into force in 2019. It is important that the statutory principles are used and, where appropriate, are expressly referred to when making decisions relating to research.



The statutory principles that apply to decisions about research are listed in the Money and Valuables & Research Code of Practice as follows:

- 'Principle 1 A person is not to be treated as lacking capacity unless it
  is established that the person lacks capacity in relation to the matter in
  question.
- Principle 2 The question if a person is able to make a decision for himself or herself can only be determined by considering the requirements of the Act and no assumptions can be made merely on the basis of any condition that the person has or any other characteristics of the person.
- Principle 3 A person is not to be treated as unable to make a decision for himself or herself unless all practicable help and support to enable the person to make the decision has been given without success.
- Principle 4 A person is not to be treated as unable to make a decision merely because the person makes an unwise decision.
- Principle 5 Any act done, or decision made, must be made in the person's best interests.'

#### What is the test of capacity for participation in research?

The test of capacity in the MCA(NI) has been 'live' in relation to research since 2019 and therefore must be used, and where appropriate, explicitly referred to. For the purposes of research, an individual lacks capacity if they are:

'unable to make a decision for himself or herself about the matter, because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

There are three elements to the assessment of capacity:

- 1. an inability to make a decision (the functional test);
- 2. an impairment of, or a disturbance in the functioning of the mind or brain (the impairment/disturbance test); and
- 3. a causal link between the two (ie the inability to make a decision must be caused by the impairment).

All three elements are equally important, and all three elements must be present for the person to lack capacity.

The DoLS Code of Practice states that, under the functional test, an individual lacks the capacity to make a decision if they are unable to do any of the following:

- 'a. understand the information relevant to the decision (which includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision);
- b. retain that information for the time required to make the decision;
- c. appreciate the relevance of that information and use and weigh it as part of the decision making process;
- d. communicate his or her decision.

# What safeguards exist for individuals who lack capacity in research?

For research involving an adult who lacks capacity to be lawful, it must be approved by an appropriate body recognised by the Department of Health, such as the ethics committee of a university or health and social care trust. The current statutory list of appropriate bodies is set out in the Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended) (see key resources).



After receiving approval for a research project, but before commencing the research, the researcher must consult with a person who is engaged in caring for, or is interested in, the patient's welfare on what their wishes and feelings would be if they had capacity. This person cannot be engaged with the patient in a professional capacity. The person can be an attorney under an existing Enduring Power of Attorney, a deputy or the patient's nominated person (see section 11). If the researcher is unable to identify anyone willing to be consulted, they must appoint a person who is prepared to be consulted on the project and has no connections with the research.

If, at any time, the person consulted is of the opinion that the patient no longer wishes to take part in the research, the researcher must withdraw the patient from the research.

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

Any research, including urgent research, must be approved by an appropriate body recognised by the Department of Health (see The Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended)). If the researcher considers it necessary to take action for the purposes of the research, but it is not practicable to consult with others, the researcher can provide the treatment if:

- the researcher has the agreement of a medical practitioner who is not involved in the organisation or conduct of the research project; or
- if it is not practicable to get that agreement, the researcher acts in accordance with a procedure agreed by the appropriate body when the research was approved.

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 where the research is approved by an appropriate research ethics committee.

Given the potential vulnerability of adults lacking capacity who are enrolled in research, it is important that doctors undertaking such research are familiar with the substantial body of guidance reflecting international standards for research involving patients who lack capacity.

# Can doctors provide innovative treatment to patients lacking the capacity to consent to it?

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 significant risk. Where adults lack the capacity to consent to innovative treatment, any such treatment must be governed by the MCA(NI) and, in particular, it must be in the 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.



#### **Key resources**

DHNI – <u>Money and Valuables & Research Code of Practice</u> 2019

The Mental Capacity (Research) Regulations (Northern Ireland) 2019 (as amended)





## **Dispute resolution**

#### When can disputes occur?

There may be occasions in relation to the care and treatment of a person who may lack capacity where disagreements with the relatives and carers of the patient arise. These may relate to:

- whether an individual retains the capacity to make a decision;
- whether a proposed decision or intervention is in the person's best interests; or
- 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 it may be necessary to make an application to court.

#### How should a dispute be approached initially?

Many disputes can either be avoided, or settled rapidly, by using good communication and involving all relevant individuals. Where healthcare professionals are involved in a dispute with those close to a person who lacks capacity 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; and/or
- arrange a meeting to discuss the matter in detail.

#### When should mediation be considered?

Where the methods outlined above do not successfully resolve the dispute, it may be helpful 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.

#### What if a complaint is made?

It may be that as part of the dispute resolution process, those acting on behalf of an adult who lacks capacity might wish to lodge a complaint about the services they have received. Healthcare professionals should be able to provide information about the formal NHS complaints process.

#### What role does the court have?

If agreement cannot be reached in a reasonable period, legal advice should be sought, and it may be necessary to seek a court order. Where this is the case, relatives and carers of the patient, and where possible, the patient, should be informed and advised to seek legal representation.

Going to court can be distressing for those concerned. However, the benefits are that a court can give rulings very quickly when necessary, and it can provide a protective role for both patients and the healthcare team who treat them in cases where there is a disagreement that cannot be resolved.



# **Confidentiality and information sharing**

#### Is a duty of confidentiality owed to patients who lack capacity?

Yes. Healthcare professionals owe the same duty of confidentiality to all their patients whether or not they have capacity. Healthcare professionals may therefore usually only disclose information about an adult who lacks capacity where it is in the patient's best interests.

#### What role do relatives, carers, and friends have?

If a patient lacks capacity, healthcare professionals may need to share information with relatives, friends, or carers to enable them to provide information to help 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 the patient had not given explicit consent. This does not however mean that all information should be routinely shared. 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.

#### Is there a role for 'next of kin'?

Despite the widespread use of the phrase 'next of kin' this is neither defined, nor does it have formal legal status in relation to decision making about medical treatment. 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 an individual and gives authority for their condition to be discussed with them, they can provide valuable information.

There are no rules about who can and cannot be nominated as someone to be consulted. A patient may nominate their spouse, partner, member of their family, or friend. In the absence of a named individual, the healthcare team should consult with people who are close to the patient; depending on the seriousness and implications of the decisions to be made, this may be a group of people rather than one individual.

# When should disclosures be made to protect adults who lack capacity?

In the absence of a legal requirement, where adults lack the capacity to make a decision about whether or not to disclose information relating to harm or abuse, decisions need to be made on their behalf. Healthcare professionals can make a decision based upon an assessment of the individual's best interests. When considering a disclosure of information, any assessment of best interests will ordinarily involve discussion with those close to the individual. However, care must be taken to ensure that anyone consulted who is close to the individual is in fact acting in the person's interests. Healthcare professionals must disclose information to the appropriate authority where there is a belief that an adult lacking capacity is at risk of abuse or other serious harm, unless it is not in the overall best interests of the patient to do so.



#### **Key resources**

BMA – Confidentiality and health records toolkit.

BMA – Best interests decision making for adults who lack capacity toolkit. Although this is based on the legislation in England and Wales much of the practical information and guidance will also be helpful to doctors practising in Northern Ireland.



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