

Capacity and consent

At any one time, it is estimated that 2 million people in England and Wales may lack the capacity to make decisions around their healthcare provision. The Mental Capacity Act 2005 (England/Wales) and the Adults with Incapacity Act 2000 (Scotland) were put in place to provide a framework to support adults who lack capacity to make decisions for themselves.

In 2018, NICE released guidance on how to apply the MCA in practice (NG108); we have summarised this guidance here, with additional practical tips from a useful book on this subject, 'Grandpa on a Skateboard' by Tim Farmer.

Where do our responsibilities lie?

As clinicians, we need to be able to assess whether our patient has capacity to consent to, or decline, the treatment we are suggesting for them. GPs are not obliged in the GMS contract to assess capacity for anything other than patient care.

Many capacity decisions fall outside the remit of the MCA (for example, testamentary capacity), so you need to be comfortable that you are familiar with the correct test and how this is applied if considering taking on this work.

NICE outlines our responsibility to support people in making decisions about their care by:

- Providing appropriate, tailored and accessible information about the decision to be made, and adequate time to make the decision.
- Using tools to support this decision-making process where needed.
- Ensuring a person has an independent mental capacity advocate (IMCA) if appropriate.
- Offering information and advice on advance care planning where appropriate.

The Mental Capacity Act 2005

To lack capacity (within the meaning of the Mental Capacity Act 2005), a person must be unable to make a decision because of an impairment or disturbance in the functioning of the mind or brain not due to other factors, for example feeling overwhelmed by the suddenness and seriousness of a decision.

THE FIVE PRINCIPLES OF THE MCA 2005

- The presumption of capacity – every adult has the right to make his or her own decisions, and must be assumed to have capacity to do so unless it is proved otherwise.
- People must be given all appropriate help before anyone concludes that they cannot make their own decisions.
- Individuals retain the right to make what might be seen as eccentric or unwise decisions.
- Anything done for or on behalf of people without capacity must be in their best interests.
- Anything done for or on behalf of people without capacity should be an option that is least restrictive of their basic rights, as long as it is still in their best interests.

Assessing capacity

So, how DO we test this?

Tools like the MMSE and 6-CIT are not designed to assess capacity, though they may provide useful information about cognition, which may be relevant to the decision.

First, you need to define exactly what decision you are trying to make!

Use a question which is as accurate as possible.

For example, "Does this person have capacity to consent to treatment?". The answer is, "To consent to **which specific treatment?**". Consenting to influenza vaccination is different from consenting to a knee replacement, cosmetic surgery or chemotherapy.

Remember: **capacity is time and decision-specific** so the answer might be different depending on the question you are asking!

Take reasonable steps to maximise a person's ability to make decisions:

- Have the discussion at a time when they are most likely to be able to understand and retain the information.
- Provide written or audio information if that will help.
- Allow them to bring a carer or advocate.

We need to establish the answer to the **2-stage test**:

Stage 1

- Is there an impairment of or disturbance in the functioning of the person's mind or brain?
- Is the impairment or disturbance sufficient that the person may lack the capacity to make that particular decision?

If the answer to either of these questions is YES, then GO TO STAGE 2.

Stage 2

The second stage of the test dictates that the person must be able to do ALL the following four things to be assessed as having capacity to make a decision:

- Understand information about the decision to be made.
- Retain that information in their mind for as long as it takes to make the decision.
- Use or weigh-up the information as part of the decision process.
- Communicate their decision.

If a person lacks the ability to do any of these four things, this represents a lack of capacity. In legal terms, making a decision that someone lacks capacity to make a decision is on the 'balance of probabilities'. This means you have to be 51% (!) certain that someone lacks capacity.

BUT how can we tell if someone can understand and retain enough information to make a valid decision?

The CMSL principle

CMSL stands for Concept, Mechanics, Short term and Long term. Each decision can be broken down into these four areas. This then makes it much easier to identify what the person should be expected to understand for each element and how you would expect them to demonstrate it. They only need to retain and demonstrate the salient points back to you.

For example: Does my patient have the capacity to refuse to take their medications?

Using the CMSL principle, we can break it down into the following questions/areas of understanding (please note, the questions below are not intended to be definitive):

- Concept: What is the medication? What is it for?
- Mechanics: How do you get your medication? How do you take it?
- Short term: What are the risks and benefits in the short term of not taking the medication? What symptoms might get worse or better?
- Long term: What are the risks and benefits in the long term of not taking your medication? What effect might this have on your prognosis, safety or quality of life?

Make a written record of your decision-making process and share it, where relevant, with the patient or their representative. NICE recommends we document:

- What the person is being asked to decide.
- How the person wishes to be supported to make the decision, and what advice you have taken from paid and unpaid carers to clarify what support would be helpful.
- Steps taken to help the person make the decision.
- Other people involved in supporting the decision.
- Information given to the person.
- Whether, on the balance of probabilities, a person lacks capacity to make a decision.
- Key considerations for the person in making the decision.
- The person's expressed preference and the decision reached.
- Needs or actions identified as a result of the decision.

Managing decision-making for those who lack capacity

For patients who lack capacity, you need to find out if they have made any form of an advance care plan. If not, decisions will be made in their best interests.

Advance care planning

Advance care planning involves helping people plan for future care and support needs to best maintain their autonomy. NICE recommends that advice and support on advance care planning should be offered to anyone at future risk of losing capacity or those with fluctuating capacity. Anyone can initiate an advance decision and they may not always need to involve a clinician. NICE makes recommendations around how to complete advance care decisions and what form the record should take. There are many useful advance care toolkits online and, in practice, most of us would turn to these toolkits to support our patients and provide documentation for these discussions and decisions.

Legally-binding advance care planning. Clinicians must refer to the attorney or deputy to make the decision on behalf of the patient or adhere to the advanced decision to refuse treatment.	
Lasting power of attorney	<p>This allows someone over 18y to appoint one or more 'attorneys' who will have the power to make decisions on their behalf if they lack capacity in the future. There are two types of lasting power of attorney:</p> <ul style="list-style-type: none"> • Health and welfare lasting power of attorney: for decisions such as medical care, moving into a care home, life-sustaining treatment, daily routine. • Property and financial affairs: for decisions such as managing a bank account, paying bills, selling their home, collecting benefits and pension. <p>To make a lasting power of attorney, the person must fill in the required forms and register the lasting power of attorney with the Office of the Public Guardian (https://www.gov.uk/power-of-attorney accessed 26/02/2019).</p>
Court-appointed deputy	<p>If someone has not appointed a lasting power of attorney and now lacks capacity, someone over 18y (usually a close relative or friend) can apply to be their deputy. The person who is applying to be their deputy must fill in the appropriate forms and send them to the Court of Protection. The court can appoint two or more deputies for the same person. There are two types of deputy:</p> <ul style="list-style-type: none"> • Property and financial affairs deputy: to make decisions about things such as paying bills or organising pension. • Personal welfare deputy: to make decisions about medical treatment and how someone is looked after. This is usually only done when there are concerns about whether decisions will be made in the person's best interests, e.g. disagreement in the family about care or decisions about a specific long-term issue such as where someone will live. <p>(https://www.gov.uk/become-deputy accessed 26.02.2019)</p>
Advanced decisions	<p>This is a decision someone can make in advance to refuse specific treatments at some point in the future. It includes decisions to refuse life-sustaining treatments such as CPR and ventilation. It is legally binding as long as:</p> <ul style="list-style-type: none"> • When they made the decision, the person was aged >18y and had the capacity to make, understand and communicate the decision. • The treatments being refused were specified clearly. • The circumstances in which the treatments were to be refused were explained. • If life-sustaining treatments are being refused, the decision must be written down and signed by both the person making the decision and a witness. A statement must also be included to say the advance decision applies even if their life is at risk. • The decision is made without any pressure/coercion from anyone else. • The person has not said or done anything that would contradict the decision since they made it. <p>(https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/ accessed 26/2/2019)</p>
Non-legally-binding advance care planning. Clinicians must be able to show they have given them fair consideration, and justify why they have not adhered to them if that is the case.	
Advanced statements	<p>These are statements about any aspect of future health or social care. They are not legally binding but can be referred to when making decisions for someone who lacks capacity. (https://www.nhs.uk/conditions/end-of-life-care/advance-statement/ accessed 26/02/2019)</p>
Joint crisis planning	<p>This is used for mental health disorders. It is developed by seeking agreement between the patient and mental health team about what to do if they become unwell in the future. NICE</p>

	recommends that joint crisis planning is offered to anyone who has been diagnosed with a mental disorder and has an assessed risk of relapse, and anyone who is in contact with specialist mental health services. The offer should be documented and, if the person accepts it, the plan should be recorded. (NG108)
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Best interests decisions

Most decisions about care or treatment for someone without capacity will be made in their 'best interests'.

A 'best interests' discussion should:

- Encourage the person to take part as far as possible; make every effort to identify the person's own views on the decision.
- Find out the person's prior views, wishes and beliefs, and any advance statements.
- Consult others (family or carers), where appropriate, about the person's views, wishes and beliefs.
- Make an objective assessment of what would be in their 'best interests'.
 - When doing this, explore the least restrictive option and any possible risks.

Best interests decisions should be clearly documented and shared with all relevant parties. We should make clear who is the 'decision-maker' – in medical decisions, this would be the doctor proposing or undertaking the treatment. They should be reviewed if circumstances change. If an agreed decision cannot be reached, the case may need to be referred to the Court of Protection to be resolved.

A power of attorney (POA) for Health and Welfare can make a decision for the person and does not require a best interests process.

Independent mental capacity advocates

For people who do not have any friends or relatives to consult about their prior views, wishes and beliefs, it is more difficult to make decisions in their best interests. For this reason, the Mental Capacity Act 2005 introduced the right for some people who lack capacity to receive support from an independent mental capacity advocate.

Decision-makers in the NHS (e.g. consultant) or local authority (e.g. care manager) have a duty under the Mental Capacity Act to instruct an independent mental capacity advocate for people who meet the eligibility criteria.

Eligibility for support from an independent mental capacity advocate (IMCA)

People over 16y who do not have anyone to support and represent them, and lack capacity to make a decision about one of the following:

- A long-term care move to or from a hospital or care home.
- A serious medical treatment (apart from treatment for a mental disorder in patients detained under the Mental Health Act).
- Adult protection procedures where it is alleged that the person is or has been abused or neglected by another person, or it is alleged the person is abusing or has abused another person. The person has the right to support from an IMCA even if they have friends or family.
- A Care Review.

An independent mental capacity advocate does NOT make the decision. They are independent of the NHS or local authority.

What do independent mental capacity advocates do?

- Find out the views, feelings, wishes, beliefs and values of the person. They must use whichever communication method is preferred by the client. They may look at copies of health and social care records. They will submit a report to the decision-maker and ensure the decision-maker considers the person's views.
- Represent the person, ask questions on their behalf and make sure their rights are upheld.
- Find out information from professionals and people who know the person well. Carry out any research needed in relation to the decision, e.g. other possible options. They may seek a second medical opinion if required.
- Audit the decision-making process – ensure that the decision-maker is acting in accordance with the Mental Capacity Act and that the decision is in the person's best interest. If the IMCA has concerns about the decision that is made, they can challenge the decision informally or formally (including referring the case to the Court of Protection if needed).

(Lee S. OPG606. Making decisions. The Independent Mental Capacity Advocate Service. The Mental Capacity Implementation programme, 2007)

Mental illness and the Mental Capacity Act

Mental illness may affect a patient's capacity to decide about treatment. Patients who lack capacity to decide on treatment for their mental illness may be treated under the Mental Capacity Act or the Mental Health Act. Patients who have capacity but refuse treatment of their mental disorder may still be treated against their will under the Mental Health Act if the necessary criteria are met (BMJ 2008;337:a116).




Deprivation of Liberty Safeguards (DoLS), MCA 2005 (amended 2009)

DoLS regulations set out the processes that must be followed if a health and social care provider believes that they need to deprive someone of their liberty in order to care for them, for example in a care home. It is the responsibility of the care home to apply for the DoLS authorisation. Deprivation of liberty in care homes and hospitals can only be authorised by the local authority, or in some cases the CCG or commissioning body.

Local authorities should have commissioned services to assess capacity as part of their DoLS framework.

DoLS and death

With effect from 3 April 2017, there is no longer a mandatory requirement to refer to the Coroner simply because a person has died while subject to a DoLS authorisation.

	<p>Capacity and consent</p> <ul style="list-style-type: none">• The Mental Capacity Act 2005 sets out the principles of a framework for decision-making for those who lack capacity.• To assess capacity, use the 2-stage test and keep your question specific.• To have capacity, a patient must be able to do ALL of the following:<ul style="list-style-type: none">◦ Understand information about the decision to be made.◦ Retain that information in their mind for the duration of the assessment.◦ Use or weigh-up the information as part of the decision process.◦ Communicate their decision.• NICE recommends advance care planning for all those at risk of future lack of capacity, including those with fluctuating capacity.• For patients who lack capacity, first consider whether they have made any advance care plans, e.g. appointed a lasting power of attorney, made relevant advanced decisions or an advanced statement.• For patients who lack capacity and have not made any advance care plan, decisions are made in their best interests. The patient should be included in the process as much as possible. Information about their previous wishes and beliefs should be gathered, relatives and friends should be consulted where needed and the least restrictive option should be chosen.• Joint crisis planning can be used as a type of advance care plan for patients with mental health problems.• Independent mental capacity advocates provide support to some people who lack capacity, e.g. when they do not have any friends or relatives who can be consulted to establish their previous wishes and beliefs.
	<p>This is really useful for patients AND professionals: https://www.macmillan.org.uk/information-and-support/organising/planning-for-the-future-with-advanced-cancer/advance-care-planning-england-wales/refuse-treatment.html</p>
	

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