Central and North West London NHS
NHS Foundation Trust

MND: Managing risk in the MDT – safeguarding and capacity assessments

September 2022

Betsey Lau-Robinson
Head of Safeguarding, the Mental Capacity Act and Prevent
University College London Hospitals NHSFT

Jonathan Martin
Consultant in Palliative Medicine
Central & North West London NHSFT
National Hospital for Neurology & Neurosurgery,
University College London Hospitals NHSFT

Objectives

By the end of the session participants will:

- be aware of possible signs which indicate a safeguarding issue
- know how to raise safeguarding concerns
- have received an explanation of mental capacity and its implication for practice – with reference to the NICE NG42 as appropriate
- have been introduced to the process for getting a mental capacity assessment/judgment
- have been introduced to the concept of positive risk taking.


CASES

Mrs T

- 64 year old lady diagnosed with MND 18 months ago.
- Few bulbar symptoms but poor mobility, uses a wheelchair, hospital bed at home and has a QDS PoC.
- She communicates well, but you have noticed increasing emotional lability, with some disinhibition and apathy.
- You are concerned about her cognition and her worsening weight loss, which you think is due to poor intake, although you will assess her swallow.
- She is declining CANH, but you worry that she may not have the mental capacity for this decision.

Mr M

- Mr M is a 42 man admitted to hospital in respiratory failure, requiring admission to ITU and intubation.
- He has subsequently been diagnosed with a bulbar-onset MND.
- He and his family are reeling from the news.
- He is failing the ventilation weaning plan.
- A decision needs to be made about whether a tracheostomy should be performed, or whether a one-way extubation is the right thing to do.

NICE Guidance: NG42

The MCA appears in this guideline in multiple places, e.g.:

Recommendations:

- 15 – Care must be in line with the MCA
- 76 – Decisions about clinically assisted nutrition and hydration in those with MND with FTD
- 123 – Staff should have up to date knowledge of the MCA


HEALTHCARE AND THE LAW

Legal basics of our "contract"

1. Patients do not have the right to demand a "medically useless or futile" treatment.
   - But Lady Hale also said: *"…health professionals must take account of a patient's wishes when making treatment decisions".*

     (*Aintree University NHS Trust v James* [2013] UKSC 67)
2. Healthcare professionals do not have the right to force a patient with mental capacity to undergo a treatment they do not want.
   - Lord Philips: patients have the right to refuse but not to demand treatments

     (*Burke v the General Medical Council* [2005] EWCA Civ 1003)
   - i.e. The right to refuse means that the principle of the sanctity of life gives way to the principle of self-determination

Consent

- This lies at the heart of the clinician-patient contract.
  - With few exceptions, to do something to someone without their consent is a form of trespass.
- From common law, we know that ‘valid’ consent requires three elements:
  - Adequate information
  - Freedom of decision making (freedom from coercion)
  - Mental capacity
- For the person who lacks mental capacity (for a particular decision at particular time), consent must be ‘constructed’

THE MENTAL CAPACITY ACT IN CONTEXT

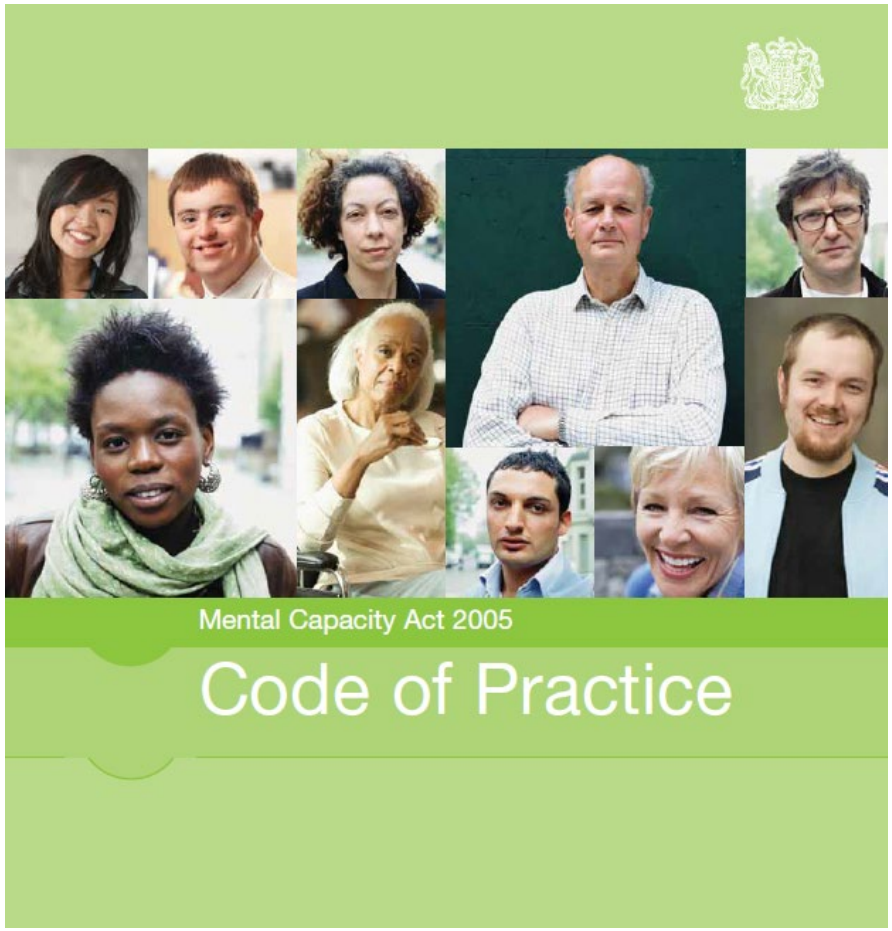
Mental Capacity Act 2005

CHAPTER 9

CONTENTS

PART 1

PERSONS WHO LACK CAPACITY



Certain categories of people are legally required to ‘have regard to’ relevant guidance in the Code of Practice, including healthcare professionals

Why be interested in the MCA?

Three reasons why you should be very keen to understand and apply the MCA correctly:

1. It confers rights that your patients are entitled to.
2. You are only protected by the provisions of the MCA if you follow the legal duties within it.
3. Your views regarding a person's capacity matter.

Things to know

- The MCA applies to all citizens
- Capacity decisions should be made by the person who is "directly concerned" eg delivering the care (this could be any citizen)
  - But note the role of MDT in healthcare
- You must have a "reasonable belief" that the person lacks capacity to be able to act on this conclusion (Code of Practice s4.44)
  - A reasonable belief is one based on information, defendable
  - The civil standard applies to the capacity assessment

Principles of MCA

1. A person must be assumed to have capacity unless it is established that he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Further points

- Adults have the right to make decisions on their own behalf and are assumed to have the capacity to do so, *unless it is proven otherwise*
  - The responsibility for proving that an adult lacks capacity falls upon the person who challenges it
  - But, if there are signs that a person may not have relevant mental capacity, you cannot rely on Principle 1 to protect you because you also have a duty of care

Decision making hierarchy

The MCA clarifies the hierarchy of decision making within the law.

Highest to lowest:

- The person themselves (“P”)
- Advance Decision to Refuse Treatment (if valid and applicable)
- Lasting Power of Attorney
- Court of Protection
- Court Appointed Deputy
- Best Interests Decision Maker

What is mental capacity?

- It is the ability (as defined by the test of capacity in the MCA) to take a particular decision for oneself at a particular time
- The MCA covers most decisions, include all healthcare decisions
- Unwise decisions
  - We all make unwise decisions despite having capacity, so capacity is not a judgement about the *outcome* of a decision, only about the cognitive processes involved in reaching the decision


HOW TO MAKE AN
ASSESSMENT OF CACPACITY

When should we assess capacity

- The Code of Practice gives little guidance about this, although sometimes it will be obvious that a person may lack capacity.
- It does give guidance about the borderline position of **unwise decisions**. Although a person may choose to make an unwise decision, certain factors raise the concern that they may not have relevant capacity:
  - repeatedly makes unwise decisions that put them at significant risk of harm or exploitation, or
  - makes a particular unwise decision that is obviously irrational or out of character.

(Code of Practice s2.11)

Who should assess mental capacity?

- The person "directly concerned" with the patient
- If a healthcare professional proposes a treatment or procedure, it is this person who is responsible for assessing capacity to consent (c.f. it would be a lawyer for a will)
  - May be delegated (the authority to assess, but not the responsibility)
- For more complex decisions other professionals may be brought in to advise eg psychiatry, palliative care, but it remains the responsibility of the person who intends to carry out the action, not the professional who is advising

What is a lack of capacity?

"A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment, or a disturbance in the functioning of, the mind or brain" MCA 2005 s. 2(1)

This means that a person lacks capacity if:

1. They have an impairment or disturbance (e.g. a disability, condition or trauma) that affects the way the mind or brain works (the "diagnostic test"), *and*
2. This impairment or disturbance means they are unable to make a specific decision at the time it needs to be made (the "functional test").
   - (1) must be the cause of (2).

The functional test of capacity

Four components, all need to be intact to have capacity:

- Understand the relevant information
- Retain the information
- Use and/or weigh the information in the balance to make a decision
- Communicate their decision by any means

Never judge a book….

An assessment that a person lacks capacity to make a decision must not be discriminatory. It must not be based simply on a person's:

- Age
- Appearance
- Assumptions about their condition
- Any aspect of their behaviour
- Any 'unwise' decision

Capacity assessment in practice

- MND is a condition that will usually satisfy the diagnostic test
  - Note that if capacity is in question the functional test should only be carried out when the individual is at their 'best' (most supported), if decision urgency allows
- At their best, consider:
  - Can the decision wait to a better time?
  - Who is present?
  - Time of day?
  - Communication support?
  - Other factors such as symptoms?

Capacity assessment in practice

What does this look like:

- Understand the relevant information
  - "What would happen if you said 'Yes', or 'No', or do not decide?"
- Retain
  - For long enough to make a decision
- Use or weigh in the balance to make a decision
  - "Tell me your rationale for that answer."
- Unable to communicate it by any means

Capacity assessment in practice

- In someone who communicates well (albeit with support), such as Mrs T, applying this approach is relatively straight forward
- But what someone like Mr M whose communication is limited?
  - You need to try to agree a system of Yes and No e.g. blinking, eye movements, finger movements
  - If shakes and nods are possible, this is the preference because such movements are so culturally embedded that their use does not add a cognitive step and therefore make communication harder.

Capacity assessment in practice

- In circumstances of using only Yes or No, questions need to be framed such that a Yes to one question equates to a No to another. For example:
  - Would you like to go home?
  - Would you like to stay in hospital?
- This allows you to be sure that the person understands and is not just agreeing with you.
- At the same time, you need to be aware of the influence of your own body language e.g. small nods of your own head
  - SLT communication support is often essential

Capacity assessment in practice

- Assessing the question of whether the person is **using and/or weighing** the information is especially difficult
  - With the help of family, you may be able to guess at a person's rationale and put these ideas to them using Yes/No questions and their related reverse questions
  - Here I think you are reaching the limits of adequate communication; it is possible that this does not bear fruit and the person may fail the communication aspect of the capacity assessment
  - Clearly this is a slow and painstaking process
- This does not need to be done alone; indeed, an MDT approach is often useful

The standard to be applied

- The MCA is law that mostly applies in the civil, not criminal, courts.
- The standard of proof of whether someone has the mental capacity for a specific decision and the time the decision is needed is therefore ‘On the balance of probabilities’, not ‘Certainty’.
  - If, on the balance of probabilities, the person does not have capacity, then this is the proof that underpins your reasonable belief of the same.

Other terms

In the draft new Code of Practice 2022

- "Insight"
  - This is usually a mental health term. A lack of insight into a diagnosis does not necessarily entail a lack of mental capacity
- "Executive function"
  - This is more usually used in the context of neuropsychological assessments. Here it means a repeated mismatch between what a person say they will do and their actual ability to carry it out. If the person does not understand that there is a mismatch or cannot use or weight this information in a decision, then they lack relevant capacity

Other terms

- "Fluctuating capacity"
  - This is not a new term, but the section on it has been expanded in the draft new Code
  - It refers to temporary loss of capacity, either due to a reversible problem such as an infection, or where capacity waxes and wanes
  - For one-off decisions that can wait, you should do so until capacity has returned
  - For a repeating decision you should ask the person their wishes when they do have capacity for when they do not, and apply this when they do not
  - This is true even though this may be said to go against the spirit of the need to make time-specific decisions


BEST INTERESTS

What is “best interests”

- No single definition because it depends on the person. Instead we are given a procedure by which to determine best interests:
  - In short, this is mostly about a person’s previously expressed wishes and feelings
  - But it also includes identifying all relevant circumstances and incorporating these into the decision
- You need to a “reasonably belief” that something is in the person’s best interests to act on it
- Best interests is irrelevant if there is a valid and applicable advance decision to refuse treatment

Who decides best interests?

- Rule of thumb: the person *doing the care* in question is the person who must determine best interests.
- In practice: for most *everyday decisions* it will be the MDT who reaches an agreement as to what is in the best interests of the patient
- For *serious decisions* it may be a case-conference decision (in line with the Code of Practice):
  - It is then up to the person delivering that aspect of the care to be sure that they agree with the decision.
- In general, the more momentous the decision, the more formality is needed

Best interests decision making

- Review the benefits and risks of the proposed intervention, any alternatives and of doing nothing.
- Collate the views of carers, family, friends, Independent Mental Capacity Advocate, others.
- Hold a ‘best interests decision-making meeting’.
  - Consider the medical, social, welfare, emotional and ethical issues
  - Review all of the evidence eg written statements (ACP)
  - Decision maker to ensure that the decision is recorded and communicated to all key people in a timely manner (NB confidentiality)

Compulsory minimum checklist

- Anyone caring for, or interested in the welfare of, the pt?
- Lasting Power of Attorney?
- Court Appointed Deputy?
- Regain capacity?
- Participate?
- Evidence re pt's past and present wishes and feelings?
- Beliefs and values?
- Other factors (relevant circumstances)?
- Anyone named to be consulted?


DIGNITY OF RISK

Autonomy v welfare

- Much healthcare law is an attempt to balance a respect for a person's autonomy (R4A) with their welfare.
- If you have mental capacity then the fulcrum of this balance is well over to the R4A side.
- The MCA attempts to replicate this for those lacking capacity but there is inevitably some shift towards welfare.

The problem of allowing higher risk

- We see the impact of risk on our thinking in a number of ways:
  - A worry that we will be criticised if we do not assess the capacity of someone making an unwise decision that puts them at risk
  - A worry that we will be criticised if we reach a best interests (BI) decision to 'allow' a greater degree of risk than we could potentially achieve
    - But note that this is part of taking a less restrictive approach (Principle 5)
  - We are probably less worried about the person's freedom in such circumstances than perhaps we ought to be.

The problem of allowing higher risk

- The courts have recognised the temptation, in someone who has very risky behaviour, to find that they lack capacity for this reason
  - But they warn against this: assessment of capacity is about the process not the outcome
- In terms of BI, the courts are mixed as to whether they agree that a 'risky' outcome is in a person's BI or not:
  - This is to be expected because BI is person-specific
  - In some ways it seems easier to agree that the stopping of a treatment that leads to death is in someone's BI than it is, say, to allow someone to go home unsupervised who is at risk of harm

Court of Protection

- We may also feel that these higher-risk BI decisions are better taken by a judge
  - Indeed, the Court of Protection is there is help us with the more difficult decisions: it takes an inquisitorial approach, not an adversarial one
  - Perhaps we should be using this court more often
  - Or at the least, seek legal advice

Positive risk taking

- Despite all this, we are required to consider any less restrictive options that are still in someone's BI
  - And this may include allowing additional risk
- "Risk enablement" is a balancing of the benefits of taking risks against the harms arising from preventing risks (which maybe psychological) (DoH 2010 *"Nothing Ventured, Nothing Gained", Risk Guidance for People with Dementia*)
  - Preventing risk taking may also have physical health benefits e.g. reduction of injury, but these will not be 'experienced' by the person
- Careful BI decisions with a wide group (family, friends, professionals) is the safest approach


CONCLUSION

Conclusion

- The fundamentals of the MCA are reasonably straight forward and are based on longstanding healthcare law on autonomy and consent
- Unwise decisions may prompt us to assess capacity but do not, in themselves, indicate a lack of capacity
- Things may be tricky, however, in particular when communication is very impaired
- Best interests is the key to managing risk in those who lack capacity
- Following due process is the most protective approach, both for your patient and for you
- Do not be slow to seek advice as necessary