Decision-making support for inpatients with learning disabilities

In this article...

- The Mental Capacity Act 2005 and how it relates to people with learning disabilities in acute settings
- How to support people with learning disabilities in making healthcare decisions
- Assessing patients’ capacity to make their own decisions
- Carrying out best-interests decisions on behalf of patients

People with learning disabilities may need support to make healthcare decisions. Nurses can use the Mental Capacity Act to ensure decisions are made in patients’ best interests.

Author Alison Picton was Mental Capacity Act project manager, the Social Care Institute for Excellence, London.


Many people with learning disabilities are able to make their own healthcare decisions, but some lack the mental capacity to do so. This article discusses how the Mental Capacity Act can be used to guide decision-making for people with learning disabilities in hospital, and ensure all decisions are made in the patient’s best interests.

People with learning disabilities have a legal right to the same quality of healthcare as the rest of the population. However, recent studies, such as Mencap’s (2007) Death by Indifference, have shown these rights are not always respected. This report contained case studies of six people with learning disabilities who died unnecessarily after receiving a lower standard of care than people without learning disabilities. The subsequent investigation by the Parliamentary and Health Service Ombudsman and Local Government Ombudsman found considerable failures in services, leading to people with learning disabilities receiving poorer treatment (Local Government Ombudsman, Parliamentary and Health Service Ombudsman, 2009).

The Department of Health (2010) recently published a report on progress to improve healthcare for people with learning disabilities. One of its major concerns was the failure of health services to comply with the Mental Capacity Act (MCA) for healthcare decision making (DH, 2005).

This article explores the requirements of the MCA regarding people who may lack capacity to make their own healthcare decisions. This includes unconscious patients, those with dementia or mental health needs, patients who are confused because of an infection, and people with learning disabilities.

This article focuses on how the MCA relates to people with learning disabilities in acute healthcare settings.

Mental Capacity Act

The MCA has five key principles (Box 1) and a code of practice that should be followed by all healthcare staff (Department for Constitutional Affairs, 2007).

The five principles must inform all healthcare decisions involving people who may or may not be able to make decisions themselves.

5 key points

1 The principles of the Mental Capacity Act 2005 should be followed by all staff caring for people who may lack capacity to make healthcare decisions

2 Many people with learning disabilities can make healthcare decisions with support, such as the use of simple language and pictures, to communicate

3 A mental capacity assessment must be carried out to determine whether individuals have the capacity to make a decision, and before any decisions can be made on their behalf

4 The nurse or doctor is usually responsible for best-interests decisions, with input from patients’ families and carers

5 Health professionals should try to limit restrictions on patients’ rights and freedoms by avoiding any form of restraint, unless it is in the patient’s best interests.
Assume capacity
All health professionals should assume patients can make their own treatment decisions. This is known as having mental capacity. Patients with mental capacity are able to make their own healthcare decisions based on the options explained to them.

If there are concerns about individual patients’ decision-making abilities, they should be supported as much as possible by health professionals to help them make a decision. Any decision made on behalf of a patient must be in the patient’s best interests.

Supporting patients to make decisions
Many people with learning disabilities are able to make their own healthcare decisions if given the right support. Advice may need to be taken about the best way to communicate, which may involve avoiding complex language and using pictures or symbols, such as those supplied by Makaton (www.makaton.org).

It should be assumed that patients are able to make their own decisions, which includes respecting their right to confidentiality by asking them whether they are happy for their carer to be present. However, involving family and carers in discussions can help staff better understand patients’ wants and needs. If a patient with learning disabilities is with a carer, talk to the patient, not the carer.

Assessing capacity
Patients must be assessed before it is decided they lack the capacity to make a decision and before any decisions can be made on their behalf.

Sometimes it will be clear if a patient lacks capacity, for example if he or she is unconscious or has profound learning disabilities with no clear way of communicating. Where patients’ capacity to make a particular decision is less clear, a more formal process is required before any decisions can be made in their best interests. This is done in two stages.

Stage 1: Underlying reason
The underlying reason why a patient may have difficulty making decisions must be established. According to the MCA, this may be “an impairment of, or disturbance in the functioning, of a person’s mind or brain”.

Having a learning disability would satisfy this criteria, as would a diagnosis of dementia or mental illness. It would also be met if a patient was under the influence of alcohol at the time, or if there was evidence of an infection causing confusion.

Stage 2: Impact of the impairment
The second stage is to work out the impact of the impairment or disturbance on the patient’s capacity to make a decision. This means talking to the patient to see whether he or she:

- Understands relevant information;
- Is able to remember the information long enough to make a decision;
- Can weigh up the risks and benefits of different options;
- Is able to communicate decisions.

Patients who are unable to do at least one of these things will lack capacity to make the decision, and treatment must be given in their best interests. The outcome of the assessment should be recorded in patients’ notes, including the reasons why they have been found to lack capacity, in case this is challenged at a later date.

CASE STUDY 1. APPLYING TO THE COURT OF PROTECTION
Patricia Carter* was 55 years old and had a learning disability. She was diagnosed with cancer of the uterus, but lacked capacity to make decisions about her treatment.

Her doctors recommended that to prevent her death she needed to undergo a hysterectomy and have her fallopian tubes and ovaries removed. The need for surgery was explained to Ms Carter and she agreed to have the operation. However, when the time came she refused to go to the hospital. It was concluded that special arrangements needed to be made to ensure Ms Carter had the operation and then remained in hospital to recover. The healthcare staff proposed that an anaesthetist would travel with the ambulance crew to her home and, should she refuse to go to the hospital, administer a sedative. It was recognised that she may also have to be sedated after the operation to prevent her from leaving.

The views of a community nurse who had built up a good relationship with Ms Carter and her family were sought, and they agreed this was in her best interests.

The Court of Protection agreed that the proposed treatment was in Ms Carter’s best interests, as was the use of sedation if necessary to take her to hospital or to keep her in hospital to recover.

*The patient’s name has been changed

Assume capacity: the expectation should be that patients can make their own healthcare treatment decisions
Provide all possible support for people to make their own decisions: take time to make information accessible and explain the treatment options, including potential risks and benefits. Use plain English, real objects, photographs and symbols

People can make unwise decisions: patients who have capacity may go against the advice of doctors and nurses
Decisions must be made in a person’s best interests: nurses and doctors are required to provide treatment in the best interests of patients who they have assessed as being unable to make specific healthcare decisions
Limit restrictions on a person’s rights and freedoms: where possible, avoid using restraint or sedation when providing treatment to a patient who lacks capacity

Assessing mental capacity assessments can be undertaken by nurses, doctors or other members of staff, such as a health professional who has worked with the patient concerned outside the hospital and understands how to communicate with them.

The assessment can be done as a short conversation by the patient’s bedside. It can sometimes take longer, especially if the outcome of the assessment could have serious consequences for the patient’s health – for example, if a person with learning disabilities is resisting treatment that doctors believe would extend their life.

It can be difficult to decide whether patients can make their own healthcare decisions, and different people may come to different conclusions; the person responsible for the final decision is usually the nurse or doctor providing treatment.

Where disputes about a person’s capacity cannot be

BOX 1. KEY PRINCIPLES OF THE MENTAL CAPACITY ACT

- Assume capacity: the expectation should be that patients can make their own healthcare treatment decisions
- Provide all possible support for people to make their own decisions: take time to make information accessible and explain the treatment options, including potential risks and benefits. Use plain English, real objects, photographs and symbols

- People can make unwise decisions: patients who have capacity may go against the advice of doctors and nurses
- Decisions must be made in a person’s best interests: nurses and doctors are required to provide treatment in the best interests of patients who they have assessed as being unable to make specific healthcare decisions
- Limit restrictions on a person’s rights and freedoms: where possible, avoid using restraint or sedation when providing treatment to a patient who lacks capacity

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Kinta Beaver
CASE STUDY 2: APPOINTING AN INDEPENDENT MENTAL CAPACITY ADVOCATE

Mohammed Akbar,* aged 35, had Down’s syndrome. He was diagnosed with chronic heart failure and was recovering from a stroke.

He had been assessed by the healthcare team as lacking capacity to make decisions about his treatment. The ward manager made a referral for an independent mental capacity advocate (IMCA) because no family or friends could be identified.

The IMCA spent time with Mr Akbar to find out his views about treatment. She also spoke to care workers who supported him where he lived. She learnt that Mr Akbar knew he was sick and was expecting to stay in hospital until he was better, but he was keen to get back to his volunteer job in a cafe. She also learnt that he was very tolerant of treatment.

This information, which she provided in a report, supported the healthcare team’s decision to perform valve replacement surgery.

While accessing Mr Akbar’s healthcare records, the IMCA noticed the file was headed DNAR (do not attempt resuscitation). She raised concerns with the healthcare staff that this serious treatment decision had been made without the involvement of an IMCA. With input from the IMCA, the DNAR was reviewed and reversed.

*The patient’s name has been changed

resolved, either informally or through a complaints process, the trust may have to make an application to the Court of Protection (Case study 1). This provides a legal safeguard for patients and some decisions, such as whether non-therapeutic sterilisation should be carried out, can only be made by the Court of Protection.

Best-interests decisions
Once it has been decided a patient lacks the capacity to make their own decisions, the responsibility for best-interests decisions usually lies with the nurse or doctor providing treatment.

It is illegal for family members to make decisions on an adult patient’s behalf unless they are the patient’s attorney or deputy. Attorneys are appointed by patients to make decisions on their behalf if they lose capacity, while deputies perform a similar role but are appointed by the Court of Protection.

Non-urgent best-interests decisions should not be made if it is possible the patient may regain capacity, for example by regaining consciousness.

When a decision is being made on behalf of a patient, the patient’s views must be sought where possible, and the people who know the patient best – such as family members, carers and friends – should be consulted. They may be able to help identify the patient’s wishes, and how to manage any treatment proposed.

Independent mental capacity advocates
Where no family or friends are available to consult on individual patients’ best interests, the law requires that they have the support of a special advocate for serious treatment decisions.

These are known as independent mental capacity advocates (IMCAs) and their role is to make sure the patient’s views and wishes are central to decisions made by the healthcare team (Case Study 2). IMCAs have a legal right to access relevant healthcare records and must provide a report. Ward staff should have contact details of their local IMCA service so they can make referrals if necessary.

Limiting restrictions
When making best-interests decisions, the MCA says health professionals should try to limit restrictions on patients’ rights and freedoms. This means avoiding the use of any form of restraint unless it is in the patient’s best interests.

Examples of restraint that may be appropriate include:

- Firmly holding a patient;
- Giving a patient a sedative;
- Using bedrails to stop a patient falling out of bed.

There are limits to how much restraint can be used in the best interests of a patient before additional safeguards are required – for example, if a patient is physically prevented from leaving the ward on an ongoing basis. These safeguards come under the MCA and are called the deprivation of liberty safeguards.

Pain management
One critical best-interests decision for many people with learning disabilities concerns pain management. When patients with learning disabilities do not ask for pain relief, healthcare staff often assume they do not need it. The disability distress assessment tool (DISDAT) supports health professionals in identifying distress cues in patients whose ability to communicate is severely limited (www.disdat.co.uk).

Conclusion
Nurses need to make the right decisions when providing treatment to people with learning disabilities, whether they are supporting patients to make their own decisions or involved in best-interests decision making.

People with learning disabilities are likely to have had lifelong difficulties in making their own decisions and are therefore unlikely to have been able to take advantage of opportunities under the MCA to make plans for a time when they lack capacity. These could include giving another person the authority to make healthcare decisions for them and making advance decisions to refuse treatment (www.adrtnhs.co.uk).

The Care Quality Commission will be looking at compliance with the MCA as part of its inspection regime. Details of how outcomes in this area will be monitored can be found at www.cqc.org.uk.

References

The symbols used on this week’s cover are Makaton symbols. Makaton uses signs, symbols and speech to help people to communicate. Today over 100,000 children and adults use Makaton symbols and signs, either as their main method of communication or as a way to support speech. www.makaton.org

In next week’s online-only issue: decisions about sex and people with learning disabilities

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