Child and Young Person's Advance Care Plan Collaborative

Association for Paediatric Palliative Medicine

Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLS) resource-guidance

Please note this guidance only covers England and Wales. All other UK nations are advised to consider this document alongside their own national guidance.

We have created this guidance as a way of bringing together resources on the Mental Capacity Act and Deprivation of Liberty Safeguards, with a focus on children and young people. The first section has links to resources, with a short summary of what can be found at each link. The second section has some worked examples, which should help understanding of the MCA in practice.

Section One

Mental Capacity Act resources

BMA Best interests' decision-making for adults who lack capacity.
https://www.bma.org.uk/media/1850/bma-best-interests-toolkit-2019.pdf

- England and Wales
- Contains a helpful Mental Capacity Assessment Template
- Aged 16 years and over. For 16-18 years, also use the CYP ethics toolkit

BMA Children and Young People ethics toolkit
https://www.bma.org.uk/media/swsfdkbw/children-and-young-people2024.pdf

- All people aged 16 and over are presumed in law to be competent to give their consent to medical treatment
- Parental responsibility may be exercised until a young person reaches 18 years
- Section 7: 16 & 17 year olds who lack mental capacity

GMC 0-18 years: guidance for all doctors
https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---0-18-years---english-20200211_pdf-48903188.pdf

- Guidance summarising how to assess capacity and best interests from 0-18 years

NHS England: Guidance to support implementation of the Mental Capacity Act in acute trusts for adults with a learning disability
https://www.england.nhs.uk/long-read/guidance-to-support-implementation-of-the-mental-capacity-act-in-acute-trusts-for-adults-with-a-learning-disability/#appendix-2-checklist-for-preparing-to-assess-the-mental-capacity-of-someone-with-a-learning-disability

- Very clear guidance on assessing capacity
- Flowchart to assist decision making
- Includes information on 16 & 17 year olds
- Gives practical information to support people with learning disability and ideas for reasonable adjustments to support assessment of capacity

Mental Capacity Resource Centre
https://www.39essex.com/information-hub/mental-capacity-resource-centre

- Caselaw database, which summaries and comments on mental capacity cases
- Guidance notes on assessing capacity and best interests, written by members of the Court of Protection team

NICE Decision-making and mental capacity
https://www.nice.org.uk/guidance/ng108

- Guidance based on the Mental Capacity Act 2005

GMC Mental Capacity
https://www.gmc-uk.org/professional-standards/ethical-hub/mental-capacity

- Capacity is decision-specific
- Capacity involves being able to make a particular decision at the time it needs to be made

Mental Capacity Act 2005
https://www.legislation.gov.uk/ukpga/2005/9/section/1

- Link to the full text of the Mental Capacity Act 2005

Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice
Larcher V, Craig F, Bhogal K, *et al* (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives of Disease in Childhood* 2015;**100:**s1-s23
https://adc.bmj.com/content/100/Suppl_2/s1

- Decision making framework to help support decisions regarding limiting treatment in life-limiting and life-threatening conditions
- Covers legal and ethical basis
- Discusses the situation where a child with capacity refuses life sustaining treatment

Autonomy Project: Preparing for the Cliff-Edge of 18
https://autonomy.essex.ac.uk/preparing-for-the-cliff-edge-of-18/

- Presentation from the National Mental Capacity Forum webinar
- Myth busting guide for parents "My child has reached 18 and can't make their own decision. What should I do?".

My Adult still My Child
https://myadultstillmychild.co.uk

- Advice for young adults, parents, carers and professionals on the process of transitioning to adult services
- Gives easy to read advice on what the law says in areas relevant to transition
- Also includes personal stories

Deprivation of Liberty Safeguards (DoLS) resources

BMA Deprivation of Liberty Safeguards- guidance for doctors
https://www.bma.org.uk/media/3087/bma-deprivation-of-liberty-safeguards-guidance-september-2020.pdf

- Guidance summarising the Deprivation of Liberty Safeguards, with case examples
- DoLS only applies to those who are aged 18 and over

Research in Practice- Practice Guidance: Deprivation of liberty and 16-17 year olds
https://www.researchinpractice.org.uk/media/rurpghvh/joint_deprivation-of-liberty-and-young-people_web.pdf

- Detailed guidance on assessing when a young person may be deprived of their liberty, including examples

39 Essex Chambers- Guidance note: Deprivation of Liberty and those under 18
https://www.39essex.com/sites/default/files/2023-03/Mental-Capacity-Guidance-Note-Deprivation-of-Liberty-and-under-18s.pdf

- Good practice guidance relating to deprivation of liberty in under 18s
- If a young person (16-17 year old) cannot or does not consent to confinement, no one (including parents) can consent on their behalf. If the other limbs of the test are satisfied, a deprivation of liberty arises.
- For children under 16 years, parents can provide consent if that is an appropriate exercise of parental responsibility, therefore no deprivation of liberty will arise.

Section Two

Example one: MCA with different age groups

Assessment of Capacity

Jack has a diagnosis of Angelman Syndrome. He is unable to communicate verbally but uses a communication book (Augmentative and Assisted communication). Jack lives with his parents but is spending time at his local hospice for respite. Jack requires treatment with oral antibiotics for a lower respiratory tract infection but communicates to you that he does not wish to take them. You make an assessment of capacity.

You sit with Jack in the hospice quiet room, accompanied by his parents and a nurse who knows him well. You meet in the morning, as Jack's parents have told you this is when he is best able to focus.

To assess capacity, we have to consider three elements:

1. An inability to make a decision (the functional test)

- To understand the information relevant to the decision
- To retain the information long enough to make the decision
- To use or weigh the information
- To communicate the decision (by any means)

Information Jack should be able to process:

- Reason for needing antibiotics – chest infection
- Why antibiotics are needed- to treat the chest infection
- Risk of not taking the antibiotics- infection getting worse, Jack becoming more unwell

You explain to Jack the diagnosis of chest infection and why this requires treatment with antibiotics. You also explain the risks of not taking the antibiotics. All communication is supported by Jack's parents and the nurse accompanying you. Jack is able to tell you using his communication book that he needs medicine and that he doesn't want it because it tastes bad. When asked what might happen if he doesn't take it, he is unable to answer. You discuss further the risks associated with not taking the antibiotics, but Jack becomes upset and does not wish to talk about it further. You leave Jack to have a break and when you return half an hour later, Jack states he needs medicine, but he doesn't know why. You re-discuss what the antibiotics are for, and the risks associated with not taking them. Jack repeatedly tells you he doesn't want them.

You feel that Jack is unable to fully understand the information and weigh the information to make a decision, particularly in regard to the risks associated with not taking the antibiotics. You consider that Jack does not have the capacity to make the decision whether or not to take the antibiotics.

2. **An impairment of, or a disturbance in the functioning of the mind or brain (the impairment /disturbance test)**

Jack has a diagnosis of Angelman Syndrome, which was diagnosed when he was 20 months old. As a result of the Angelman Syndrome he has a profound communication disorder and is unable to communicate verbally, although he is able to use Augmentative and Assisted communication for basic communication of his needs and feelings. As a result of the Angelman Syndrome, Jack also has a short attention span and a learning disability.

3. **A causal link between the two (in other words, the inability to make a decision must be caused by the impairment)**

It is a direct result of the learning disabilities caused by Jack's diagnosis of Angelman Syndrome that means he is unable to make the decision regarding treatment.

16-17 year olds

If Jack was 16-17 years old, his parents have parental responsibility and can make the decision regarding treatment.

Decision:
In this scenario, doctors have a choice in how to proceed with further treatment. You have decided that Jack lacks capacity. In 16-17 year olds, parental responsibility can still be exercised. Jack's Mum and Dad both hold parental responsibility and agree that Jack should be prescribed oral antibiotics for his chest infection. It remains good practice to assess capacity and consider a best interest's decision in this age group, although parents can formally make the decision, if deemed reasonable by professionals.

Alternatively, the MCA can be used, whilst considering his parents' wishes to make a best interests decision.

MCA in 18 years and older

If Jack was 18 years or older, you should make a best interests' decision regarding his treatment. His parents cannot make the decision for him.

Best interests' decision:
After discussing matters with Jack's parents, and taking into account their views, you reach a conclusion that it is in Jack's best interests to have the antibiotics, as the benefits outweigh the risks.

Example 2: MCA when capacity is not clear

Laura has fluctuating capacity depending on her physical health. She develops a chest infection and needs antibiotic treatment. Laura refuses antibiotic medication because it makes her sick. You question whether her intercurrent illness may have affected her capacity.

How do you assess this further?

Assessment of capacity

To assess capacity, we have to consider three elements:

1. An inability to make a decision (the functional test)
    - To understand the information relevant to the decision
    - To retain the information relevant to the decision
    - To use or weigh the information
    - To communicate the decision (by any means)
2. An impairment of, or a disturbance in the functioning of the mind or brain (the impairment /disturbance test)
3. A causal link between the two (in other words, the inability to make a decision must be caused by the impairment)

Example 2A:
You assess Laura's capacity using the above questions and decide that she has made and communicated a capacitous decision even though it could be considered unwise.

What else might you want to consider?

- Options to address Laura's concerns about taking antibiotics (antiemetic/alternative antibiotic etc)
- Whether Laura's wishes for treatment would change if her condition worsened and she loses capacity
- Decision of person with parental responsibility (if <18 years)

Example 2B:
You decide that Laura does not have capacity. Although you feel antibiotics are in her best interests, she makes it clear she does not want to take the medication.

How can we incorporate her expressed wishes into a best interest decision?

- The MCA states that "so far as is reasonably ascertainable the person's past and present wishes and feelings, the beliefs and values that would be likely to influence his decision if he had capacity" should be considered.
- Consult with family/familiar carers to understand Laura's usual preferences and what she might want if she had capacity
- Laura has expressed concern about antibiotics making her sick – this should be prioritised in her treatment plan.

How do you ensure you are making the least restrictive decisions to enable Laura to regain capacity and decide for herself?

- Argument that effectively treating infection will allow Laura to regain capacity
- Plan regular review of treatment decision and Laura's capacity.

Are there additional things to consider when thinking about practical ways to ensure Laura gets the treatment?

- If Laura is actively refusing the treatment there may be risks to herself or staff from continuing it (e.g. pulling out cannulae, spitting out medicine).
- An MDT approach should be taken to balance the risks and benefits of continuing treatment.

Example 3: Best interests' decisions when YP and parents' views differ

Tom is 18. He has capacity and wants to record that he would not want cardiopulmonary resuscitation (i.e. neither compressions nor ventilation) in the event of cardiopulmonary arrest. His parents do not agree with him.

How do the legal and ethical guidelines help with this if they are >18 years?

All people aged 18 and over are presumed in law to have capacity to give their consent and to refuse medical treatment. If Tom has capacity to make this decision then his parents cannot override this decision.

How do the legal and ethical guidelines help with this if they are if they are 16-17 years?

- In England and Wales people aged 16 and over are presumed to have capacity to consent to treatment but a capacitous refusal of treatment by a patient under 18 may be overruled by a court or by a person with parental responsibility. In these circumstances, the views of the young person should still be given due weight in determining their best interest.
- Tom's request should trigger a detailed assessment of his understanding of his situation and the impact of his decision, and of his parents' views. If consensus cannot be reached, healthcare professionals who are faced with an informed refusal of a treatment they believe to be in the patient's best interests should seek ethical or legal advice.

Example 4: Transition

Louise has delayed processing and is non-verbal due to a learning disability. She relies on augmentative and assisted communication (AAC) and always attends appointments with a parent to support her communication. She is reaching adulthood, and her parents are anxious about how decisions will be made when they no longer have parental responsibility.

How can you reassure them?

What options might be open to them if Louise is unlikely to ever have capacity to make significant treatment decisions?

- Consider whether Louise has capacity to appoint her parents as Lasting Power of Attorney even if she does not have capacity to make treatment decisions.
- Her parents should be reassured that their opinions should always be considered as part of a best interest's decision for Louise.
- An application could be made to the Court of Protection by her parents to be appointed her welfare deputy, although they would have to have specific evidence that this appointment is in her best interests.

You feel Louise has capacity for some decisions and want to ensure she is supported to participate in decision-making wherever possible. What steps can you take to support this?

- The MCA states that a best interests' decision should "so far as is reasonably practicable, permit and encourage the person to participate or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him"
- Contact the learning disability team for Louise's local hospital to see what support they can give.

- Consider using a hospital passport or similar document to outline Louise's communication needs and ways she can be supported to participate in decisions
- Encourage Louise to participate in advance care planning so that she can be supported to take part in decision-making and record her wishes when she is well and has time to understand her choices.

The parents tell you that Louise wishes to make them Lasting Power of Attorney for Health and Welfare. How can you assess her capacity to make this decision, and ensure her wishes are genuinely heard?

The Lasting Power of Attorney application requires an impartial person to confirm that the donor understands what they are doing and is not being pressurised (Certificate provider). Although this does not have to be a professional, if Louise's capacity is in question it would be advisable to ask a social worker, solicitor, doctor or independent mental capacity advisor to be the Certificate provider as they will be more experienced in assessing her capacity.

Example 5: Respite care & DoLS

A hospice for CYP offers respite for some over 18s who are not able to give consent to being cared for in the hospice.

What steps need to be in place to ensure the hospice is adhering to the Mental Capacity Act?

- A process should be in place to ensure that a patient's capacity to consent to a respite stay in the hospice is assessed each stay
- If a patient cannot consent and would not be free to leave if they wanted, then a DOLS application should be made (England and Wales).
- A hospice can apply for a standard DOLS authorisation 28 days ahead of a planned stay. The application should go to the local authority for the area where they normally live. The local authority will make arrangements to assess the person and make a decision within 3 weeks.
- A standard authorisation can be valid for 1 year, so may cover several hospice stays if each stay is sufficiently long that it can be said that the patient is a 'detained resident' at the hospice throughout the year. If the patient's needs have not changed a request for a further authorisation can be made up to 28 days in advance. This is a shorter form and fewer assessments are required.
- If more urgent authorisation is needed due to an unplanned admission or loss of capacity, a separate application form can be used which provides authorisation for 7 days while awaiting assessment.

Dorothy is 25 years old and determined to leave the hospice. She is not judged to have capacity to make this decision or to be safe to leave on her own.

What practical options might be appropriate to keep Dorothy safe?

- Consider the least restrictive options to support Dorothy including reassurance and finding out what would make staying in the hospice more acceptable to her.
- If she attempts to leave, consider:
  - Supervision and redirection when trying to leave
  - Accompanying her for short trips outside the hospice
  - Having a friend/family member present
  - Close/1-to-1 or video-monitoring
  - Door locks/codes

What is the legal framework to support these measures and ensure they are proportionate?

The above measures intend to prevent Dorothy from leaving and can therefore be classed as a restriction or deprivation of her liberty. The Deprivation of Liberty safeguards provide a framework to do this legally.

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We hope you find this information useful. If you have any feedback, we would be delighted to hear it admin@appm.org.uk