

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

MAKING IT HAPPEN:
*USING THE MENTAL CAPACITY ACT
TO IMPROVE END OF LIFE CARE*

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MAKING IT HAPPEN

- MCA in force since 2007: April (IMCAs & criminal offences) and October (everything else)
- Much attention has focussed on implementation and compliance
- Do not forget that this is intended by government to deliver cultural change
- How to use the MCA proactively and creatively to deliver better care?

EXAMPLES OF PEOPLE FOR WHOM CAPACITY CAN BE AN ISSUE

- People living with **dementia**
- People living with **learning disability**
- Older people experiencing **frailty**
- People who are experiencing **delirium** or **confusion**
- People with **fluctuating consciousness** or capacity
- People on **powerful medication** which causes persistent, transient or fluctuating **cognitive impairment**
- People who are **imminently dying** and who no longer have full mental capacity
- People who are **unconscious**

KEEP THESE PEOPLE IN MIND TODAY

THIS PRESENTATION WILL...

- Give an **overview** of the MCA's impact on end of life care
- Identify how the MCA can be used to **improve patient care**
- Set the MCA in the **current policy and practical context**, for example:
 - End of Life Care Strategy
 - Advance care planning

A NEW CULTURE OF CARE

- Lack of capacity is a determination of last resort
- Supporting people and maximising their capacity is the first priority
- Justify a determination of lack of capacity
- Legal obligation to act in best interests
- Decisions and assessments must be based on **evidence not assumptions**
- To deliver the MCA will require focus on excellent **communication & person-centred care**

THE DISABILITY CONTEXT

- 682 British disabled people have died as a result of 'disability prejudice'
- DRC reports that people with learning disabilities (PWLD) are 4x more likely to die of a treatable illness

CASE STUDY

- A young man with Downs syndrome developed a treatable testicular cancer. Initially the treatment team decided that as he could not 'consent' to treatment he could not be treated.
- An oncology social worker and the man's key worker enabled the man to demonstrate his understanding and consent.
- The team leader was heard to remark 'What a shame to put him through this'

(Thanks to Linda McEnhill, St Christopher's Hospice)

JANE CAMPBELL

I was born with spinal muscular atrophy, a so-called "terminal" condition. I cannot lift my head from the pillow unaided and I need a ventilator to help me breathe at night. I use a powered wheelchair and have a computer on which I type with one finger.

In January 2003 I was hospitalised with severe pneumonia in both lungs. On two separate occasions, doctors told me they assumed that if I fell unconscious I wouldn't want to be given life-saving treatment. I was so frightened of what might happen to me that I kept myself awake for 48 hours. My husband brought in a photo of me in my graduation gown and stuck it on the bed-head to remind the hospital staff that there was more to me than the shrivelled form they saw lying in front of them.

I was lucky: although I could barely breathe, I had an assertive husband insisting to the authorities that I had everything to live for. Imagine what it would be like if you were too weak to communicate. Or your relatives less positive about the quality of your life. (2003)

SOME SPECIFICS

- Statutory tests:
 - to assess capacity
 - to determine best interests
- Emphasis on person-centred care
- Duty to consult next of kin about best interests
- Advance Care Planning has legal status
- Statutory framework for advance decisions
- New proxy decision-making & advocacy
- Code of Practice – statutory duty
- New Court of Protection & Public Guardian
- Criminal offences: wilful neglect & ill-treatment
- New provisions relating to research

FIVE UNDERLYING PRINCIPLES

1. Presumption of capacity
2. Individuals should be supported where possible so that they can make their own decisions
3. People have the right to make decisions that may seem eccentric
4. Decisions should be in a person's best interests
5. Decisions should be as unrestrictive as possible

CODE OF PRACTICE

- There is a new statutory Code of Practice
- All paid carers (including all health and social care professionals) are under a duty to have regard to it
- If you do not follow it, you must be able to explain why
- Unpaid carers should use it for guidance

LACK OF CAPACITY

- Assessed on a decision by decision basis
- **Diagnostic**: an impairment or disturbance of mind or brain...
- **Functional**: ...by reason of which a person cannot understand, retain, use or weigh relevant information, or is unable to communicate by any means
- Must **not** be established merely by reference to age, appearance, condition or aspect of behaviour

BEST INTERESTS 1

The MCA contains a specific process to determine best interests:

- **Not** merely by reference to age, appearance, condition, or aspect of behaviour, BUT
- Consider all relevant circumstances; AND
- Take the following steps...(see next slide)...

BEST INTERESTS 2

- Consider whether and when P might gain capacity
- Permit and encourage P to participate
- Where life-sustaining treatment in issue, do NOT be motivated by a desire to bring about death
- Consider, so far as is reasonably ascertainable:
 - P's past & present wishes and feelings (including any written statement by P whilst he had capacity)
 - P's beliefs and values
 - Any other factors P would consider if able to
- Take account, if practicable, of the views of:
 - Anyone named by P as someone to be consulted
 - Anyone engaged in caring for P or interested in his welfare
 - Any holder of an LPA or any Court Appointed Deputy

BEST INTERESTS & ADVANCE CARE PLANNING

- **Best interests assessment** includes a requirement to consider, so far as is reasonably ascertainable the person's past & present wishes and feelings (including any written statement made whilst he had capacity), beliefs & values, and any other factors the person would consider if able to
- **ACP is a continuing process of discussion between an individual and his care providers.** ACP discussions may include:
 - the individual's concerns
 - his important values or personal goals for care
 - his understanding about their illness and prognosis
 - his preferences for types of care or treatment that may be beneficial in the future and the availability of these
- **EoL Care Programme tools:** Gold Standards Framework, Preferred Priorities of Care; Liverpool Care Pathway

WHO IS RESPONSIBLE FOR THE DECISIONS THAT ARE MADE?

- **Is it the person who:**
 - determines capacity?
 - decides what course of action is in the patient's best interests?
 - implements the decision?
- **Where does responsibility lie in multi-disciplinary teams?**

THIRD PARTY INVOLVEMENT IN DECISION-MAKING

2 new proxies:

- **Lasting Powers of Attorney**
(appointed by P to make decisions on his behalf)
- **Court appointed Deputies**
(appointed to make decisions on P's behalf)

1 advocate:

- **Independent Mental Capacity Advocates**
*(advocate, **not** a decision-maker)*

LASTING POWERS OF ATTORNEY

- Now cover personal welfare as well as property – this means a proxy can be appointed to make health and social care decisions
- It is a formal agency agreement:
 - prescribed form
 - registration required
 - cannot be done informally
- Can cover different activities, and be given to different people

COURT APPOINTED DEPUTIES

- Completely new creation
- Court can only appoint if in P's best interests
- Must be appointed with as limited scope and for as short a time as necessary
- Might be relative or friend, or professional
- Cannot make decisions about life-sustaining treatment

INDEPENDENT MENTAL CAPACITY ADVOCATES

- IMCAs **must** be consulted when:
 - A decision is being made about long-term residence or serious medical treatment; and
 - The decision is being made by an NHS or local authority body; and
 - The person has no friends or family to consult
- IMCAs are NOT decision-makers. There to ensure good process on capacity & best interests.
- Voluntary sector hospices do not need to consult an IMCA

ADVANCE DECISIONS TO REFUSE TREATMENT

- N.B. only advance decisions to **refuse** treatment can be binding
- To be binding must be both **valid** and **applicable**
- “Specific” language required both as to treatment **and** circumstances - if any circumstances are identified
- If not binding, **must still be considered** when assessing best interests
- If binding, patient has taken responsibility for the decision

ADVANCE DECISIONS 2

- **Special rules apply to advance decisions refusing life-sustaining treatment:**
 - The patient must state that the advance decision is to apply to the specified treatment even if his life is at risk as a result
 - The advance decision must be in writing, signed either by the patient or by somebody else on his behalf and at his direction, and signed by a witness.
- **Clarity of language needed:**
 - Instead of “living wills” or “advance directives” use “advance decisions to refuse treatment” or “advance statements”

A QUICK SUMMARY

ASK YOURSELF THE FOLLOWING:

1. **What decision has to be made?**
2. **Does the patient have capacity to make it?**
 - What support is required to help him make it?
3. **If no capacity:**
 - Is there a proxy - LPA or a CAD - to make the decision?
 - If it involves treatment, is there an advance decision refusing it?
4. **In all cases where the patient doesn't have capacity & there is no valid & applicable advance decision refusing treatment, ask:**
5. **WHAT ARE THE PATIENT'S BEST INTERESTS?**

HOW CAN PEOPLE USE THE MCA TO EXPRESS/PROTECT THEIR CHOICES IF INCAPACITATED?

- **Appoint a proxy decision-maker** under an LPA
- **Refuse specific treatments** in advance
- **In anticipation of other people assessing their best interests in the future:**
 - **Nominate** somebody to be consulted (friend/relative)
 - **Identify** who should **not** be consulted
 - **Make written statements** about their values, priorities and preferences – these must be taken into account (Advance Care Planning)

BUT REMEMBER FUTURE PLANNING IS VOLUNTARY

- People are **NOT** required to make advance care plans, or advance decisions refusing treatment, or appoint LPAs
- Risks:
 - asking at inappropriate times or in an inappropriate way
 - forcing people to have discussions they do not want to have – increasing rather than reducing distress
 - painting by numbers
 - quality of care will be judged by numbers of advance care plans. They are a tool not an outcome

INTERESTED FAMILY, FRIENDS & CARERS

- **Protected decision-making** for all professional and informal carers (if they reasonably believed a person lacked capacity and the act was in his/her best interests)
- They must **be consulted** about the person's best interests where practicable
- **Challenge decisions**, if felt not to be in best interests
- Be appointed as a **Lasting Power of Attorney**
- Apply to be **appointed as a Deputy** by the court

MCA: THE IMPORTANCE OF COMMUNICATION

- Individuals should be supported where possible so that they can make their own decisions. Incapacity is a determination of last resort.
- Assessing capacity: need to engage with the person and give support to maximise ability to understand, remember, judge and communicate
- Determining best interests: still involve the person; speak to family, friends and informal carers
- Obtaining written statements about priorities and preferences, or making an advance decision to refuse treatment: good communication is required, to give and receive information
- Need to justify decisions will improve note-keeping, decision-making and communication amongst staff

NEW CRIMINAL OFFENCES

- MCA introduces 2 new criminal offences:
 - Wilful neglect
 - Ill-treatment
- “Neglect” and “ill-treatment” are not defined. The Courts will have to decide what level of misconduct is so serious that there should be a criminal sanction
- Both offences carry possible prison sentences

(1) THE EoLC STRATEGY WILL...

- Cover all conditions and settings
- Build on the experience of hospices and specialist palliative care services
- Build on the existing End of Life Care Programme (e.g. Gold Standards Framework, Liverpool Care Pathway, Preferred Priorities for Care and advance care planning)
- Build on recent experience from the Marie Curie Delivering Choice Programme and other innovative service models

(2) THE EoLC STRATEGY WILL...

Address a number of problems including:

- Clinician difficulty in **initiating discussions** about death and dying
- Inadequate **assessment and care planning**
- Poor **co-ordination of care**
- **Suboptimal services** in hospitals care homes & the community
- Inadequate **involvement & support of carers**
- Lack of **dignity & respect**

EoLC STRATEGY EMERGING THEMES

Six emerging themes, including:

- An end of life care pathway
- Workforce development

The pathway's elements include:

- Initiating discussion
- Assessment and care planning
- Review of people's needs and preferences
- Care in the last days of life
- Support for carers (throughout illness and into bereavement)

Workforce development includes:

- Communication skills; end of life care skills; developing appropriate competencies at all levels

MCA & EoLC STRATEGY LINKS

- **MCA**: values the choices of vulnerable people; emphasises communication & support; commitment to person-centred care
- **MCA**: legal framework for advance care planning: written statements; advance decisions refusing treatment; LPAs
- **Care Pathway**: End of Life Care Programme tools and advance care planning enable people's priorities to be understood and recorded – so best interests decisions can be made
- **Workforce development**: informing colleagues about the MCA is also to have the opportunity to inform them about the end of life care strategy. Communication skills will be key
- **MCA** is the law; it must be complied with. Delivering the EoLC strategy will help you comply with the MCA.

NCPC WORK

- New **publication**: *The Mental Capacity Act in Practice: Guidance for End of Life Care*
- In partnership with EoLC Programme, during 2008:
 - **Guidance** on advance decisions to refuse treatment
 - **Patient information** on ACP & advance decisions
- **Impact Survey** (Specialist units, hospices, care homes)
- **10 Area events** in England (see NCPC website)

Visit www.ncpc.org.uk/publications for:

- *Guidance on Artificial Nutrition & Hydration*
- *Advanced Care Planning: A Guide for Health & Social Care Staff*
- E-learning tool with Help the Hospices