

**THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE**

# **USING THE MENTAL CAPACITY ACT TO IMPROVE CARE & CHOICE**

**Simon Chapman**

Ethics Advisor

The National Council for Palliative Care

**YORSHIRE & HUMBER AREA CONFERENCE**

**22 JANUARY 2009**

**s.chapman@ncpc.org.uk**

**[www.ncpc.org.uk](http://www.ncpc.org.uk)**

## 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 & enable people to express and protect choices**
- Set the MCA in the **current policy and practical context**, for example:
  - End of Life Care Strategy
  - Advance care planning

# POLICY: THE END OF LIFE CARE STRATEGY

- Launched on 16 July 2008
- First ever national comprehensive end of life care strategy in 60 years of the cradle-to-grave NHS
- Covers all conditions & settings
- Builds on existing good practice, e.g.:
  - Experience of hospices & specialist palliative care
  - Gold Standards Framework; Liverpool Care Pathway; Preferred Priorities for Care
  - Mare Curie's Delivering Choice programme
- Needs to be linked to the Dementia & other strategies

# EoLC STRATEGY OBJECTIVES

To 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 THEMES INCLUDE...

**An end of life care pathway.** 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

**Raising public awareness:**

- Everybody: patients; families; carers; professionals; commissioners...

# THE END OF LIFE CARE STRATEGY

*“The most important objective is to ensure that people’s individual needs, their priorities, their preferences for end of life care are identified, they are documented, they are reviewed, they are respected and acted upon wherever possible. Now that message has to go out everywhere within the NHS and I think that’s the important starting point for everything else...”*

Alan Johnson, Secretary of State for Health, speaking on Radio 4’s *Today* programme at the launch of the End of Life Care strategy, on 16 July 2008

# MENTAL CAPACITY ACT

- In force since 2007
- Broad objectives:
  - To support adults with impaired capacity so that they can make decisions for themselves wherever possible
  - Where they cannot take decisions, to provide a protective framework for decision-making
  - To provide a framework for those who have to take and implement decisions
- Much attention has focussed on implementation and compliance
- Intended by government to deliver cultural change
- How to use the MCA proactively and creatively to deliver better care and decision-making?

## EXAMPLES OF PEOPLE FOR WHOM CAPACITY CAN BE AN ISSUE

- People living with **dementia**
- People living with **neurological conditions**
- 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**

## MCA & CULTURAL CHANGE

- Lack of capacity is a determination of last resort
- Supporting people and maximising their capacity is the first priority
- Legal obligation to act in best interests
- Emphasis on **person-centred care** and on valuing people's choices
- Decisions and assessments must be based on **evidence not assumptions**
- **Challenging paternalism**
- To deliver the MCA will require focus on excellent **communication, and good record-keeping**
- This will improve the **quality of decision-making** and hence the **quality of care**

## 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 to have regard
- **Deprivation of Liberty Safeguards** – new Code from April 2009
- **New Court of Protection & Public Guardian**
- **Criminal offences**: wilful neglect & ill-treatment
- New provisions relating to **research**

**MCA:  
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

## 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

## STATUTORY CHECKLIST FOR BEST INTERESTS

- **Not** merely by reference to age, appearance, condition, or aspect of behaviour, **BUT**
- Consider all relevant circumstances; **AND**
- Consider whether and when the person might gain capacity
- Permit and encourage the person to participate
- For life-sustaining treatment, must **NOT** be motivated by a desire to bring about death
- Consider, so far as is reasonably ascertainable:
  - Person's past & present wishes & feelings (including any written statement)
  - Person's beliefs & 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
- **Preferred Priorities of Care** is a tool that can capture this

## SOME POSSIBLE EXAMPLES

- *“If I am being washed, I prefer showers to baths*
- *I am allergic to lanolin; please don't put me in lambswool clothes or give me hand cream with lanolin in it*
- *I hate boiled eggs, and I love Bovril*
- *I want to stay at home as long as I can*
- *I don't like EastEnders. Never have. Never will.*
- *I like the Rolling Stones. And I like The Archers*
- *I love dogs*
- *I am frightened of injections and needles*
- *Please could my grandson look after the cat?”*

## 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, for a fee. Will be stamped when registered
  - cannot be done informally
- Can cover different activities, and be given to different people
- **Donees** of LPA **will need support** – but how much information can they be given?
- **Challenge for professionals** – working with a proxy decision-maker
- Low take-up at present, but for how long?

## 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**
- Voluntary sector hospices do not need to consult an IMCA for patients not funded by the NHS

## NEW FRAMEWORK FOR ADVANCE DECISIONS TO REFUSE TREATMENT

- Will be **legally binding** if meet the requirements of the MCA:
  - Valid
  - Applicable
  - Special formalities for advance decisions refusing **life-sustaining treatment**
- **Impact on CPR & DNAR**
  - BMA/RCN/Resuscitation Council Guidelines 2007
  - New guidance: [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk) (NCPC & the End of Life Care Programme) launched 2 September 2008

## 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 & 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: whose canvas is it?
  - 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 & 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

## 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
- A new litigation risk?
- Is a futile attempt at CPR “ill-treatment”?

# THE MENTAL CAPACITY ACT PROVIDES LEVERAGE

- It is the law. It must be complied with. Criminal sanctions exist
- To deliver it:
  - Good communication
  - Advance care planning
  - GSF; Preferred Priorities for Care; LCP
- Staff require training & support. ACP & EoLCare tools will help deliver the strategy & comply with the MCA
- Access to Code of Practice
- Must be able to demonstrate:
  - What has been done to support people
  - That decisions are in best interests
- Need for good documentation and audit trails
- Better care and decision-making

## NCPC MCA-RELATED WORK

- *The Mental Capacity Act in Practice: Guidance for End of Life Care*
- *Good decision-making* (summary introductory guidance)  
Published this month
- *Guidance on Advance Decisions to Refuse Treatment*  
(with EoLC Programme)
- Patient Information Leaflets (being piloted, due 2009)
- *Advanced Care Planning: A Guide for Health & Social Care Staff*
- 10 area events in England ([www.ncpc.org.uk](http://www.ncpc.org.uk))

[www.ncpc.org.uk/publications](http://www.ncpc.org.uk/publications)