

**THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**

ADVANCE CARE PLANNING & THE MENTAL CAPACITY ACT

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PIECING IT TOGETHER
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THIS PRESENTATION WILL...

- Consider the relationship between:
 - Advance Care Planning (practice)
 - The End of Life Care strategy (policy)
 - The Mental Capacity Act (legislation)
- Identify how these can be used to improve patient care & enable people to express and protect choices

ADVANCE CARE PLANNING: A DEFINITION

“ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual’s agreement, this discussion should be documented, regularly reviewed, and communicated to key persons involved in their care. An ACP discussion might include:

- the individual’s concerns,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences for types of care or treatment that may be beneficial in the future and the availability of these

The difference between ACP and care planning more generally is that the process of ACP will usually take place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.”

Advance Care Planning: A guide for health and social care staff
End of Life Care Programme (2007)

ADVANCE CARE PLANNING IS...

- A means by which a person's priorities and preferences can be identified and recorded to inform those who will have to make decisions in their best interests should they lose capacity
- Distinct from more general care planning
- A continuing process (whilst the person has capacity)
- Voluntary
- Likely to form an important part of the End of Life Care strategy
- Not "Advanced" Care Planning, but staff will need training

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 likely to 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

MENTAL CAPACITY ACT & ADVANCE CARE PLANNING

- Statutory processes:
 - to assess capacity
 - to determine best interests
- Duty to consult next of kin about best interests
- People's priorities and preferences must be recorded and taken into account when assessing their best interests— therefore Advance Care Planning has legal status
- Statutory framework for advance decisions to refuse treatment
- New proxy decision-making – Lasting Powers of Attorney
- Ability to nominate someone to be consulted (or not!)

MCA & CULTURAL CHANGE

- 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**

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?

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)

SOME EXAMPLES

- MND patient in West London. Severe communication difficulties. Clear view about which of 4 hospitals he would wish to be taken to in an emergency. Identified in a written document, signed and supported by his GP and palliative medicine consultant
- “I would like to continue to be cared for in the Nursing Home, where I have been resident since July 2004. I DO NOT WANT TO BE ADMITTED TO HOSPITAL. I want to be cared for by people I know.”
- 60 year old lady with diabetes & limited mobility. Made it clear that she wanted to go home to live as best she could at the end of her life. When approached about filling in the PPC she was very pleased as she had the opportunity to record her wishes. In the section asking about power of attorney she did not list her husband, much to his dismay. When he asked her why she replied that he would send her in to hospital to undergo dialysis, against her wishes. This lady used the PPC to open up the discussion with her husband and make sure her wishes were recorded and acted upon.

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 & 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 AND 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 & communicate
- **Determining best interests:** still involve the person; speak to family, friends and informal carers
- **Obtaining written statements** about priorities & 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 & communication amongst staff

ACP 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
- **Tools**: Preferred Priorities for Care; Gold Standards Framework; Liverpool Care Pathway
- **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 and using ACP tools 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