Advance Care Planning and the Mental Capacity Act (2005)

Julie Foster
End of Life Care Champion
Why We Needed the Act and Who It Affects

• Mental capacity issues potentially affect everyone
• Over 2 million people in England and Wales lack mental capacity to make some decisions for themselves, for example, people with:
  – dementia
  – learning disabilities
  – mental health problems
  – stroke and head injuries
Up to 6 million family and unpaid carers, and people involved in health and social care who may provide care or treatment for them

Previous common law lacked consistency

People’s autonomy not always respected

People can be written off as incapable because of diagnosis

No clear legal authority for people who act on behalf of a person lacking mental capacity
Cont’d....

• Limited options for people who want to plan ahead for loss of mental capacity

• No right for relatives and carers to be consulted

• Enduring Powers of attorney seen as open to abuse
Principles of the Act

- Assume a person has capacity unless proved otherwise
- Do not treat people as incapable of making a decision unless you have tried all practicable steps to help them
- Do not treat someone as incapable of making a decision because their decision may seem unwise
- Do things or take decisions for people without capacity in their best interests
- Before doing something to someone or making a decision on their behalf, consider whether you could achieve the outcome in a less restrictive way
Assumption of Capacity and Supported Decision Making

- Act sets out an assumption of capacity
- Obligation to take all practicable steps to help the person take his or her own decision
- Act makes it clear that a person’s age, appearance, condition or behaviour does not by itself establish a lack of mental capacity
- Must give information in a clear and easy way to understand
- Must help the person who lacks capacity to communicate
Assessing Capacity

• Act sets out the best practice approach to determining capacity - whether an individual is able, at a particular time of making a particular decision

• Decision specific

• Detail on what is involved in assessing capacity is covered in the Code of Practice
What proof of lack of capacity does the Act require?

Two-stage test:

🌟 Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?
Examples may include:

- people with dementia
- people with significant learning disabilities
- the long-term effects of brain damage
- People who are experiencing delirium or confusion
- concussion following a head injury
- people who are under the influence of drugs or alcohol
- people who are imminently dying and who no longer have full mental capacity
Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?
A person is unable to make a decision if they cannot:

1. understand information about the decision to be made (the Act calls this ‘relevant information’)
2. retain that information in their mind
3. use or weigh that information as part of the decision-making process, or
4. Communicate their decision (by talking, using sign language or any other means)
Case Study: Margaret

68 year old woman with LD. Has been poorly and now needs a ‘whipples Resection’. How would you:

- Help her understand the information about the decision to be made
- Check that she could retain that information
- Check that she could use or weigh that information as part of the decision-making process
- Help her Communicate her decision
Best Interests at End of Life

Practical Guidance for Best Interests, Decision Making and Care Planning at End of Life
(relating to the Mental Capacity Act 2005 England and Wales)

Christine Hutchinson
Julie Foster
May 2008
What does the Act mean when it talks about ‘best interests’?
Best Interests

- All decisions must be made in the best interests of the person who lacks capacity
- It is the key principle that governs all decisions made for people who lack capacity
- Must consider all relevant circumstances
Best Interests cont’d…. 

- Act doesn’t define best interests but does give a checklist:
  - Must involve the person who lacks capacity
  - Have regard for past and present wishes and feelings
  - Consult with others who are involved in the care of the person
  - There can be no discrimination
  - Least restrictive alternative/intervention
What to consider

- **Medical** – not just the outcome, but what will be the burden and benefit of the treatment.
- **Welfare** – How will this impact (for better or worse) on the way the person lives their life?
- **Social** – What will this do to the person’s relationships etc?
- **Emotional** – How will this person feel, react?
**Case Study: John**

John is an 85 year old with end stage dementia living in a care home. He has been loosing weight over the last 6 months and is now just 6 stone. He has been hospitalised twice recently with chest infections. He is now very poorly and not taking very much food or fluids. John’s GP has prescribed nutritional drinks and has advised the care staff on making John comfortable in his last few days. Additionally, members of the district nursing team visit regularly in relation to end of life care.
The care home manager recognises that John is dying and phone his daughter, she states that she does not want come but wants her to call for an ambulance to admit him to the hospital.

- What should she do?
- Who is the decision maker?
- Assessment of capacity – 2 stage test
- Determination of capacity
- Best Interests process
**Admission to hospital.** The following options were listed:

<table>
<thead>
<tr>
<th>Option i - Admit to hospital</th>
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</thead>
<tbody>
<tr>
<td><strong>Option i benefits</strong></td>
</tr>
<tr>
<td>• Medical care would be on hand</td>
</tr>
<tr>
<td><strong>Option i risks</strong></td>
</tr>
<tr>
<td>• John may have an undignified death</td>
</tr>
<tr>
<td>• John might die in transit</td>
</tr>
<tr>
<td>• Nursing and medical staff do not know John</td>
</tr>
<tr>
<td>• John would be in strange surroundings</td>
</tr>
<tr>
<td>• Hospital admission areas are often busy, noisy environments; John’s needs may not be prioritised</td>
</tr>
<tr>
<td>• John may become disturbed as in previous admissions</td>
</tr>
<tr>
<td>• John’s life may be prolonged by active medical intervention until his notes are received</td>
</tr>
<tr>
<td>• Prolonging life may cause more discomfort</td>
</tr>
<tr>
<td>• No chance of a positive outcome (i.e. preserving life)</td>
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</table>
Option i - NOT to Admit to hospital

<table>
<thead>
<tr>
<th>Option ii benefits</th>
<th>Option ii risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>• John can die in his own bed, in his own room</td>
<td></td>
</tr>
<tr>
<td>• staff around John know him well</td>
<td></td>
</tr>
<tr>
<td>• John may remain comfortable in his last few hours</td>
<td></td>
</tr>
<tr>
<td>• John’s care will continue as outlined by the GP and district nurse</td>
<td></td>
</tr>
<tr>
<td>• John will be able to have a dignified death in peaceful surroundings</td>
<td></td>
</tr>
<tr>
<td>Admit to Hospital</td>
<td>Not to admit to Hospital</td>
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Outcome:

- The decision maker determined that it would be in John’s best interests to remain within the care home until he died.
- The decision maker contacted John’s daughter to explain her decision and the reasons why.
- A copy of the BI decision process she had followed was placed in John’s notes and faxed to the GP and DN Team.
Planning ahead: for a time when a person might lack capacity

- The Act provides new and clearer defined ways of planning ahead:
  - 1. Lasting Powers of Attorney (LPA’s)
  - 2. Advance decisions to refuse treatment
  - 3. Making your wishes and feelings known
Lasting power of attorney – property and financial affairs

About this lasting power of attorney

This lasting power of attorney allows you to choose people to act on your behalf (as an attorney) and make decisions about your property and financial affairs, when you are unable to make decisions for yourself. If you also want someone to make decisions about your health and welfare, you will need a separate form (downloadable from our website or call 0300 456 0300).

Who can fill it in?

Anyone aged 18 or over, who has the mental capacity to do so.

Before you fill in the lasting power of attorney:

1. Please read the guidance available at direct.gov.uk/mentalcapacity or by calling 0300 456 0300. See, for example, the Guidance for people who want to make a lasting power of attorney for property and financial affairs or other relevant guidance booklets which are all available online or by post.
2. Make sure you understand the purpose of this lasting power of attorney and the extent of the authority you are giving your attorneys.
3. Read the separate information sheet to understand all the people involved, and how the three parts of the form should be filled in.
4. Make sure you, your certificate provider(s), and your attorney(s) have read the section on page 2 called information you must read before filling in their relevant part.

This lasting power of attorney could be rejected at registration if it contains any errors.

Helpline 0300 456 0300
direct.gov.uk/mentalcapacity

Lasting power of attorney for health and welfare

About this lasting power of attorney

This lasting power of attorney allows you to choose people to act on your behalf (as an attorney) and make decisions about your health and personal welfare, when you are unable to make decisions for yourself. This can include decisions about your healthcare and medical treatment, decisions about where you live and day-to-day decisions about your personal welfare, such as your diet, dress or daily routine.

Who can fill it in?

Anyone aged 18 or over, who has the mental capacity to do so.

Before you fill in the lasting power of attorney:

1. Please read the guidance available at direct.gov.uk/mentalcapacity or by calling 0300 456 0300. See, for example, the Lasting power of attorney creation pack or other relevant guidance booklets which are all available online or by post.
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Lasting Powers of Attorney (LPA)

- Enables people to appoint someone they know and trust to make decisions for them
- Two types of LPA
  - ‘Property and affairs’ which replaces EPA
  - ‘Personal welfare’ which is a new way to appoint someone to make health and welfare decisions
- Must be made whilst the person has capacity
Lasting Powers of Attorney (LPA) cont’d…. 

- Must be registered with the Public Guardian

- Chosen attorneys can only make decisions in the persons best interests
My Advance Decision to Refuse Treatment

My Name

Any distinguishing features in the event of unconsciousness

Address

Date of Birth

Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify in advance which treatments I don’t want in the future. These are my decisions about my healthcare, in the event that I have lost mental capacity and cannot consent to or refuse treatment. This advance decision replaces any previous advance decision I have made.

Advice to the reader

I have written this document to identify my advance decision. I would expect any healthcare professionals reading this document in the event I have lost capacity to check that my advance decision is valid and applicable, in the circumstances that exist at the time.

Please check

Please do not assume I have lost capacity before any actions are taken. I might need help and time to communicate.

If I have lost capacity please check the validity and applicability of this advance decision.

This advance decision becomes legally binding and must be followed if professionals are satisfied it is valid and applicable. Please help to share this information with people who are involved in my treatment and care and need to know about this.

Please also check if I have made any other statements about my preferences or decisions that might be relevant to my advance decision.

This advance decision does not refuse the offer and or provision of basic care, support and comfort.
Advance Decisions to Refuse Treatment

- Allows the person to refuse specified medical treatment in advance
- Are legally binding but Act gives greater safeguards
- Must be made when you have capacity and comes into effect if you lack capacity
- Must be clear about which treatment it applies to and when and must be in writing and witnessed if it applies to life-sustaining treatment
- Doctors can provide treatment if they have any doubt that the advance decision is valid and applicable
Have you thought about what is important to you at the end of your life?

- Do you have a long term illness, or a condition that can’t be cured?
- Do you want to discuss your thoughts or concerns and have your wishes and preferences written down?

The Preferred Priorities for Care process can help you with this.

For more information please take a copy of the guide to preferred priorities for care leaflet or visit www.endoflifeinforadults.nhs.uk
Making wishes and feelings known

• It is important that people are given the opportunity to make their wishes and feelings known

• There is no formal process for this but written statements given to professionals, carers, family or friends are likely to carry weight

• Decision makers will have to consider peoples wishes and feelings when deciding what is in their best interests
For Advance Care Planning and End of Life Conversations
New criminal offences of ill-treatment or wilful neglect

- New offences apply to:-
  - People who have the care of a person who lacks capacity
  - An attorney under LPA or EPA
  - A deputy appointed by the court

Criminal offences can result in a fine and/or a sentence of imprisonment of up to five years