



Lancashire and South Cumbria
Cancer Network

Welcome back: Conference Outline for the afternoon


<i>Time</i>	
13:30	Capacity and Consent <i>(Julie Foster, EoL Lead, LSCCN)</i>
14:15	Debates <i>Debate 1 – No Fixed Abode (Classroom 1)</i> <i>Debate 2 – Cultural Issues (Classroom 2)</i> <i>Debate 3 – Dementia (Conference room 1)</i> <i>Debate 4 – Learning Disabilities (Conference room 2)</i>
15:15	COFFEE AND MARKETPLACE
15:45	Plenary Session
16:15	Chair's Closing Remarks
16:30	CLOSE

 Connecting Communicating Improving


Cumbria and Lancashire
End of Life Care Network

Capacity and Consent – Challenge or Change?

Julie Foster, Cumbria and
Lancashire End of Life Network

 End of Life
Network



Lancashire and South Cumbria
Cancer Network

Julie Foster

EoL Lead, EoL Network

Julie is the End of Life Care Lead with the Cumbria and Lancashire EoLC Network. She has over 30 years experience within the NHS and was appointed strategic lead for the Network due to her background in the mental capacity act, learning disabilities and PPC advance care planning tool.



Connecting Communicating Improving

Plan of Session

- Why we needed the Act and who it affects
- The Mental Capacity Act principles
- Assessing capacity
- Best interests

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

Cont.....

- 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

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. He has been losing 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.

You recognise that John is dying and phone his daughter, she states that she does not want come but wants you to call for an ambulance to admit him to the hospital.

- What do you 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:

Option i - Admit to hospital

Option i benefits

- Medical care would be on hand

Option i risks

- John may have an undignified death
- John might die in transit
- Nursing and medical staff do not know John
- John would be in strange surroundings
- Hospital admission areas are often busy, noisy environments; John's needs may not be prioritised
- John may become disturbed as in previous admissions
- John's life may be prolonged by active medical intervention until his notes are received
- Prolonging life may cause more discomfort
- No chance of a positive outcome (i.e. preserving life)

Option i - NOT to Admit to hospital

<p><u>Option ii benefits</u></p> <ul style="list-style-type: none"> • John can die in his own bed, in his own room • staff around John know him well • John may remain comfortable in his last few hours • John's care will continue as outlined by the GP and district nurse • John will be able to have a dignified death in peaceful surroundings 	<p><u>Option ii risks</u></p>
---	-------------------------------

Admit to Hospital		Not to admit to Hospital	
<p><u>Option i benefits</u></p> <ul style="list-style-type: none"> • Medical care would be on hand 	<p><u>Option i risks</u></p> <ul style="list-style-type: none"> • John may have an undignified death • John might die in transit • Nursing and medical staff do not know John • John would be in strange surroundings • Hospital admission areas are often busy, noisy environments; John's needs may not be prioritised • John may become disturbed as in previous admissions • John's life may be prolonged by active medical intervention until his notes are received • Prolonging life may cause more discomfort • No chance of a positive outcome (i.e. preserving life) 	<p><u>Option ii benefits</u></p> <ul style="list-style-type: none"> • John can die in his own bed, in his own room • staff around John know him well • John may remain comfortable in his last few hours • John's care will continue as outlined by the GP and district nurse • John will be able to have a dignified death in peaceful surroundings 	<p><u>Option ii risks</u></p>

Outcome:

- The decision maker determined that it would be in the 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 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

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

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

The Independent Mental Capacity Advocate (IMCA)

- Extra safeguard for particularly vulnerable people in specific situations (April 2007)
- Who? - People with no-one to consult (other than paid carers) or if conflict with carers
- When? – serious medical treatment; care home moves

An IMCA will:

- Support a person who lacks capacity
- Obtain and evaluate relevant information on persons behalf
- Not be a substitute decision maker, for LA/NHS
- Will not give opinions
- Ascertain the persons wishes and feelings
- Investigate if the person has an advance decision.
- Ascertain alternative course of action, and present this information to decision maker.
- Obtain further medical opinion when necessary.

IMCA

- Statutory function
- No choice but to refer
- Know and understand the criteria
- Non instructed advocacy
- Can access records
- Right to meet in private room with person
- Reactive service 'decision makers' make referrals.
- Time and issue specific work

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