Best Interests decision-making

Who decides and how?

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The Problem

- Patients who lack mental capacity to decide for themselves
  - Are treated on the basis of their ‘best interests’ (BI)
- There may be widely differing views
  - On where those best interests lie
- Families and clinical teams
  - May come into conflict
    - In their attempts to do what is right for the patient

- The Mental Capacity Act 2005 (England and Wales)
  - Sets out the legal framework for BI Decision-making
    - in patients > 16 years
  - Came into force April 2007
    - Still working out how to implement it
RCP Guidelines

Prolonged Disorders of Consciousness

- Published December 2013
  - Highlighted a poor understanding of the MCA
    - Amongst clinicians and public

Objectives

- Reminder of the MCA and its provisions
  - Responsibility of clinicians
- Practical advice for clinicians at the coal face
Ethical and medico-legal issues

- Describes the Mental Capacity Act 2005
  - Provisions to support patients
    - Who lack capacity to make decisions about their care
  - Key roles in decision-making
    - Lasting Power of Attorney, Welfare Deputy
    - Advance Decisions to Refuse Treatment
    - Procedures to establish Best Interests

- Ethical Challenges
  - Decisions regarding life-sustaining treatments
    - When it may be appropriate to consider
      - Application to the Court for withdrawal of
      - Clinically Assisted Nutrition and Hydration (CANH)
Considering ceiling of care

- In patients with VS/MCS
  - Life sustaining treatment is given in early stages
    - Against the hope/expectation of recovery
  - When diagnosed as in permanent VS/MCS
    - Recovery from that state is deemed highly improbable
    - Appropriate to consider
      - Whether further treatment is in the patient’s best interests

- Decisions regarding ceiling of care
  - DNACPR decisions (Do Not Attempt Cardiopulmonary Resuscitation)
  - Responsibilities of clinicians
    - Provides advice on informing families at the appropriate time
    - Normalising discussion about DNACPR
      - And other life-sustaining treatments (eg antibiotics etc)
End of life issues

- Withdrawal of CANH
  - Operational procedures for application to the Court
    - Who should apply
    - How to go about it

- Care of the dying patient
  - After withdrawal of CANH

- Detailed palliative care regimens
  - Appropriate use and escalation of sedation / analgesia
The Mental Capacity Act
2005
The MCA 2005 introduces

- **Statutory principles**
  - For making decisions on behalf of patients
    - Lacking the capacity to decide for themselves
  - Weighing up best interests
    - Balance of benefits and harms

- **The two-stage test for mental capacity**

- **Provisions to support decision-making**
  - Allow the individual to influence decisions made on their behalf
    - In the event that they might lose capacity
Who decides what?

Doctors decide what treatment options are available

- A patient (who has mental capacity) can decide
  - whether to accept this or not

- Before losing capacity:
  - People can plan ahead:
    - Advance Decision to Refuse Treatment (ADRT)
    - Lasting Power of Attorney – Heath & Welfare

- Or after losing capacity
  - The Court can appoint a Welfare Deputy
    - To make decisions on behalf of a patient
  - For people who have no intimate support network
    - An Independent Mental Capacity Advocate (IMCA)

If none of the above are applicable:

- Responsibility for BI Decision-making
  - Ultimately lies with the senior clinician on the treating team (i.e., consultant)
Futile treatments

- Grounds for with-holding/withdrawing treatment
  - ‘Futile’ medical care
    - A medical intervention that does not lead to improvement in the patient’s prognosis
      - Comfort, well-being
      - general state of health

- All treatments can cause harm
  - Futile treatment has no benefits

- A patient or their family
  - Cannot demand treatment that is not on offer..
    - They cannot force a doctor to deliver treatment
      - for which the harms outweigh the benefits

- Court of Protection can decide
  - ‘It would not be unlawful to with-hold’ a certain treatment – especially if ‘futile’
    - Grounds for futility may be challenged in Court
Two-part test of capacity

The diagnostic test

- Is there an impairment of the mind or brain?
  - Or a disturbance in the functioning of it?

The functional test

- If so, does the impairment make the person unable to
  - Understand information relevant to the decision
  - Retain that information
  - Use or weigh it up to make a decision
  - Communicate that decision (by any means)

- Failure on any one of these criteria
  - Means that the person lacks capacity
Advance Decision to Refuse Treatment

- If an ADRT is in place
  - And is valid and applicable for the decision at hand
    - This trumps everything else
      - (Except withdrawal of artificial nutrition and hydration)

- If no ADRT:
  - BI decision-making regarding care and treatment
    - the responsibility of the senior clinician
  - When determining best interests
    - Must take account of the views of
      - Anyone engaged in caring for the person
        - Or interested in his/her welfare
      - And the reasonably ascertainable views of the patient
Health and Welfare LPA

- **Someone who has capacity**
  - Can appoint one or more LPA
    - To make decisions on about their H&W
      - When the person no longer has capacity
  - **Restrictions on an LPA’s authority**
    - Cannot override a valid and applicable ADRT
    - **Does** extend to giving/refusing treatment
      - May authorise giving refusing consent to life-saving treatment
        - But only if LPA document explicitly says so

- **If a Welfare LPA has been appointed**
  - They **must** be involved in decisions about care and treatment
Court-appointed Welfare Deputy

- Appointed by the Court of Protection
  - After the person loses capacity
    - To make treatment decisions
      - In respect of which the person lacks capacity
  - Welfare Deputy’s authority is restricted
    - Extent of their powers delineated by the Court on appointment
    - May relate to just a single treatment decision
      - Or a wider range of treatment and welfare issues
    - A deputy can never refuse consent
      - To carrying out/continuing life sustaining treatment
Deputy and Decision-making

- If a Welfare Deputy has been appointed
  - To make decisions on behalf of the patient
  - It is the Deputy who decides
    - not the treating team
      - So long as it complies with the terms of their appointment

- The treating team
  - Should ask to see a copy of the order
    - To confirm the scope of the Deputy’s authority

- Deputy’s powers extend to deciding whether to accept
  - Treatment considered by the treating team to be an option
    - The Deputy does not decide what the options are
Independent Mental Capacity Advocate

If a person >16 lacks capacity
– And does not have appropriate family / friends
  - To advocate on their behalf
– Has a right to an IMCA for certain decisions eg
  - Accommodation
  - Serious medical treatments

IMCA’s role
– Gathers information from all parties
  - What is known about the persons prior wishes / beliefs
  - Views of people involved in caring for the patient
  - Prepares an independent report
    – Must be taken in to account in BI decision-making
– (Turn-around time – 1-3 days)
Legal execution

- Disputes under the MCA
  - Adjudicated by the Court of Protection

- Judges in the Court of Protection
  - Empowered to make best interests decisions
    - And to declare that a proposed course of action
      - by a health professional will be lawful

- Office of the Public Guardian
  - Administrative arm of the Court of Protection

- The Official Solicitor
  - Appointed to represent the person lacking capacity
    - As their ‘Litigation Friend’ in Court
Practical application for the clinician at the coal-face
Key features of MCA

- Mental capacity judged on each decision
  - Formal consideration and documentation
    - Assumed to have capacity unless shown not to
    - Must be supported to be involved in decision
      - So far as they are able

- Patient who lacks capacity
  - Treated on the basis of Best Interests
    - Balance of benefits and harms
      - Taking into account what the patient would have wanted
        - So far as this can be established
        - Only the family/friends can give insight into this
          - Based on their previous beliefs and values
Role of family

The role

- The family is best placed to know patient
  - Prior beliefs and values
    - What they might have wanted if they could say
  - The question to them is:
    - In your opinion would he/she want to accept
      - The proffered treatment?

Not in the role:

- To indicate what they want for the patient
- Cannot demand treatment that is not on offer
Next of Kin (NoK)

People often assume
- ‘Next of Kin’ has deciding powers

No such concept in law
- NoK is simply a convenient route for communication
  - In health and social settings only

When determining best interests
- NoK has no more deciding power
  - Than any other family members
- Must hear the views
  - of any family / close friends who want to be involved
Must ask the family

Technically difficult
- Asking their opinion about
  - what the pt would have wanted
- Not what they want for the patient

Families often misunderstand this
- Feel they are being asked to make the decision
  - Or sometimes want to make the decision
Key decisions

- To give a certain treatment (eg operation)
  - Weigh up balance sheet
    - Benefits vs harms

- To withdraw / withhold treatment
  - Can be more emotive
    - Especially when life-sustaining treatment or eg
      - Cardiopulmonary resuscitation (DNACPR)
  - If the decision involves withdrawal of artificial nutrition and hydration
    - Must _always_ be referred the Court of Protection
DNACPR decisions

- CPR can be harmful
  - Fractured ribs, damage to internal organs
  - Hypoxic brain damage

- Outcomes – following in-patient cardiac arrest
  - 15-20% survive to discharge
  - 3-7% return to previous functional capacity
  - In severely brain injured patients – highly likely to lead to
    - Worse brain damage
    - Prolonged ITU stay

- Prolonged CPR attempts almost always contra-indicated
  - Ceiling of care decisions are appropriate
On the other hand…

- Calling the CPR team
  - May be the only way to get rapid help
    - Blocked tracheostomy tube
    - Transient arrhythmia

- DNACPR sends a message to on-call teams
  - Not for active medical care

- Short resuscitation procedures may be appropriate
  - But prolonged support (e.g., ITU ventilation etc.) is not

- Can make explicit instruction for this
GMC guidelines on End of life care

- DNA CPR decisions in patients who lack capacity
  - Must be discussed with the family

- Problems
  - Ceiling of care established early during admission
  - Seems like ‘giving up’ on the patient
  - Family often already highly distressed

- Clinicians reluctant to add to their burden
  - Take the easy way out – do not complete DNA CPR form
    - Exposing the patient to treatment
      - against their best interests
Recommendations

- Find out if any of the following is in place
  - An ADRT,
  - A health & welfare LPA
  - A Welfare deputy

  If yes - ask to see documentation
  - To clarify the scope of their powers

- If not – identify key family members
  - ‘Family’ in the broad sense
    - Important others – people involved in their recovery
    - Not confined to genetic or legal relationships

- Normalise discussion
  - Routinely hold formal Best Interests meetings
    - At an early stage in admission
    - Inviting all ‘family’ members
Best interests meetings

- Explain lines of responsibility for BI decision-making
  - Make clear what the role of the family is
  - Leaflet available
    - [http://www.rcplondon.ac.uk/sites/default/files/information_for_families_about_medical_decisions_0.pdf](http://www.rcplondon.ac.uk/sites/default/files/information_for_families_about_medical_decisions_0.pdf)
    - [http://www.rcplondon.ac.uk/sites/default/files/annex_4b_role_of_family_and_friends_in_medical_decisions.pdf](http://www.rcplondon.ac.uk/sites/default/files/annex_4b_role_of_family_and_friends_in_medical_decisions.pdf)

- Explain treatments that are on offer
  - Eg antibiotics, symptom relief, supporting care etc
  - Discuss whether, in their view, the patient would want these

- Explain why CPR is not on offer
  - Balance of benefits and harms

- Document meetings / decision-making process carefully
  - Including all views from different members of family (especially if conflicting)
  - Seek second opinion if contentious
Summary so far..

- The MCA
  - Provides a useful framework for BI decision making
  - Not fool-proof
    - If we cannot come up with the right answers
      - The law is unlikely to help
      - Certain questions **must** be addressed through the Courts

- Best approach
  - Open and honest discussion with Family
    - Introduce BI concepts early on and maintain dialogue
      - Patients families will normally get there eventually
      - May require some time and patience
Withdrawal of CANH

Artificial nutrition and hydration (ANH)
- Seen as medical treatment
  - GMC – clinically-assisted nutrition and hydration (CANH)

Can be withdrawn – if futile
- But will inevitably lead to death
  - Within 2-3 weeks

Bland case – Hillsborough disaster
- Vegetative state – totally unaware
  - No positive state against which to count benefits
    - Balance sheet is not applicable - all negative
  - ‘Would not be unlawful to discontinue ANH’
Anomalies in the Law

Since the case of Bland 1994
- Withdrawal of CANH in cases of permanent VS
  - Requires an application to the Court of Protection
  - If diagnosis of PVS is verified – further treatment is considered futile
    - Not in the patient’s best interests to continue life sustaining treatment

There have now been over 50 cases – all approved
- Arguably, if the diagnosis can be verified
  - The Court procedure adds little benefit but causes long delay (mean 9 months)
  - Unacceptable delay – effectively assault
  - Family distress
  - Huge cost to the NHS – circa £122,000 per case (Formby et al 2015)
    - £53,000 legal costs
    - £69,000 care costs
Fast Track CoP Application

- CoP Practice direction 9e - application for CANH withdrawal

- Working group convened - To work with CoP Rules committee
  - Develop a fast track process for application
  - For CANH withdrawal in undisputed cases of Permanent VS

- Would still need to go before a judge
  - But could at least avoid a full hearing
  - Quicker
    - Reduced legal costs
    - Alleviates family distress
  - Reserve Court time for more complex cases
Fast Track Criteria

- Undisputed applications
  - All parties agreed on
    - Diagnosis of Permanent VS
    - Best interests
      - taking into account the patient’s own likely wishes

- Completed full expert PDOC assessment
  - including at least 2 standardised tools
  - over appropriate time scale

- Independent expert in agreement (Official Solicitor)

- Established application form
  - set of supporting documentation
Guidelines generally helpful

- Many recent court cases have relied on them
- Open to misinterpretation
  - Some judges have mis-quoted the guidelines
    - Then becomes law!
  - Confusion about to whom they should apply
    - Permanent VS is an entity of profound brain injury
      - Not for end-stage dementia or other degenerative conditions
  - Who is responsible for bringing the application?
    - Should be the CCG – ultimate responsibility for the patient
    - Recent case brought by a Trust
      - Dropped once the patient no longer the Trust’s responsibility

GDG will be reconvened shortly
- To provide further clarification and more specific guidance
Questions and discussion