Involving the family & advance care planning

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Vegetative and minimally conscious states:
diagnosis, treatment and end-of-life decisions...
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Building on presentations so far today...focusing on family/friends

Mental Capacity Act 2005 - importance of considering

(a) the person’s past and present wishes and feelings ...
(b) the beliefs and values that would be likely to influence his decision if he had capacity and
(c) the other factors that he would be likely to consider if he were able to do so. [s4(6)] MCA 2005

Consulting family & friends therefore key
Our research

Multi-disciplinary team (see cdoc.org.uk), including close work with healthcare providers

Our research:

• Interviews with family members (who have relatives in PDoC, for a few months to over 30 years)
• Interviews with wide range of staff (e.g. are assistants, Allied Healthcare professionals, neuro-rehab consultants)
• Observation + tracking patient pathways, follow up over time (over up to 10 yrs)
• Case studies of specific cases (through court/clinical best interests for ceilings of treatment)
What we found (in 2010....- & sadly still today)

• Some families tells us their relatives’ past wishes, feelings, beliefs, values have not inform treatment decision.

• Often no formal records of BI decision-making process about CANH in notes - Actions often simply done, without explanation (often for years). Sometimes notes say ‘done in best interests’ or ‘duty of care’, provided treatment ‘because needed’ “Treatment by default”.

• When we support families to ask for best interest reviews, sometimes long delays and gaps in information needed
A key issue & questions for you

Some patients are given on-going life-sustaining treatment, especially Clinically Assisted Nutrition and Hydration... *without* any proper and timely ‘best interests’ consideration taking into account their own wishes.

Is this happening to any patient you are caring for?

Why?
Decision-making in Practice – the Family experience of ‘involvement’

Case Studies
Decision-making in Practice — family experiences: Case 1

see Kitzinger and Kitzinger in International Mental Health and Capacity Law (2017)
PVS for 23 years

• In August 2017 judge sanctioned withdrawal of CANH from a patient who’d been in a vegetative state for 23 years
• Found CANH “overwhelmingly not in his best interests”
• 1994 – hypoxic brain damage after being caught in a machine at work.
• Cared for at home from 1997 with care package from personal injury settlement
• Treatment continued long after clinicians + family had abandoned hope for recovery (“we didn’t know there was any other option”)

• c. 2004 parents initiated discussion of ‘ceilings of treatment’ – asked for no return to hospital and DNACPR (No clinician or case manager responded by suggesting withdrawal of CANH)

• 2016 Parents raised issues of why CANH treatment was continuing, having read magazine article + case then moved slowly towards Court.

• Died following CANH-withdrawal in 2017
“We were going over for a yearly checkup at [the specialist centre]. They’d check “what’s his medicine?, “What’s his weight” …

They probably thought we were in denial and we probably were. But doctors have these seminars – they have research papers come through – shouldn’t they have known?

Shouldn’t they have said something? Why didn’t anyone say anything?” (Father)
Decision making in practice – family experiences
Case no 2 - Recent case

• Recently chaired a best interests meeting in 2019 (at the invitation of the GP, following approach from family)
• Brain haemorrhage mid-2017
• Discharged in a vegetative state with CANH
• Family had stated (unanimously) from outset that patient would not value life if she could not live independently
• Discharge Summary (end 2017) refers to this + advises revisiting this with a best interests discussion about CANH in 1 year from date of collapse (why 1 year?)

• Family requested meeting 1 year from date of collapse – told not necessary. Treatment continued.

• Took several months to arrange meeting, then cancelled due to staff illness

• Finally held BI meeting 21 months after patient collapse – agreed continuing treatment was not in her best interests
Returning to question for you -

Why might some patients be given on-going life-sustaining treatment .... *without* any proper ‘best interests’ consideration taking into account their own past wishes, feelings, beliefs and values?

Is this happening to any patient you are caring for?

Explanations for why this happens?

...and what can be done???
Explanations focused on the family & friends

Examples:
• Don’t know what patient would have wanted (and no Advance Decision)
• Resistance to accepting diagnosis/prognosis (e.g. ‘his eyes are open, she is in there’; ‘he’s a fighter, he will defy the odds’)
• Not wanting ‘give up’ on the patient
• Family division of opinion – and waiting for consensus
• – or respect for one person’s primary role (‘We had to wait for dad to die before we could speak up – he was her next of kin’)
• They may grasp the prognosis and have a sense of what the patient would want – but not tell clinical team for their own reasons (e.g. own values or religious beliefs, or fear of ultimate loss)
Context of family/friends’ response

Information about diagnosis/prognosis: ‘only time will tell’ (not revisited); ‘wait until you get to rehab’, ‘he knows you are here’

Implicit message in unreflective ‘long term’ planning (e.g. financial settlements)

Understanding of their role: Not clearly asked what patient would have wanted (or only at beginning) and their own contribution not explained (‘consenting’, ‘deciding’), think ‘next of kin’ has priority

Distrust
E.g historical or current experience of treatment of patient (e.g. after clinical negligence or delays in access to timely, quality specialist treatment) or treatment of themselves (e.g. access to information, time to talk, being in ‘a battle’).
Explanations focused on the staff

- Don’t consider CANH as a best interest decision or conflating ‘clinical judgment’ & best interests
- Lack of ‘ownership’ of the process (e.g. who is decision-maker)
- Fear of difficult conversations’ or feeling ill-equipped for such conversations
- (historically) feeling ‘disempowered’ because of previous ‘need’ to go to court
- Ignorance of the law: e.g. “the decision cannot be something that brings about the death of the patient therefore CANH is in her best interests”
- and/or diagnostic led (rather than person-led) decision-making (e.g. myth ;have to wait for a year’ before making best interests decision)
Context for healthcare professionals

Includes:

• Patient trajectory, system issues (e.g. patients discharged with PEGS)
• Lack of access to expertise about prognosis (linked resources/funding)
• Lack of time to give to the best interest process
• Lack of continuity of care (those who make early decision not involved in later decisions)
• Institutional priorities, routines and loyalties (e.g. as rehab centres) (Reputational, Audit, Research, Financial)
What can healthcare professionals do?

• Ensure family/friends have been asked about patient’s wishes, feelings, beliefs and values
• Forward plan for ceilings of treatment (including regular review of CANH)

Use existing BMA/RCP guidance on CANH and soon to be published RCP guidance
• Guidelines address context
• Crystal clear about decision process and responsibility
• Offer support tools for families and staff
What can prospective patients do? (all of us)

Value of advance care planning

• **Advance decisions** to refuse treatment. (Signed + witnessed = valid; depends on how written+ situation to be ’applicable’)

• **Advance statement** (record to inform a best interests decision directly unmediated by family and friends)

• **Lasting Power of Attorney for Health and Welfare** (with the right to make decisions about life-sustaining treatments) – appointing someone to make decisions for you (and do talk to them!)

Will be information about this in the RCP guidelines

Also more information from: CompassionInDying.org.uk
Resources

1. The updated RCP guidelines – lots of key resources on all aspects of diagnosis, prognosis and best interests

2. The British Medical Association + Royal College of Physicians – endorsed by General Medical Council, December 2018 - detailed guidance about the decision-making process for starting, re-starting, continuing, or stopping (withdrawing) CANH ....
Online CDoC support resource for families (healthtalk.org.uk) - Family Experiences here

British Medical Association Award for ‘Patient Information on Ethical Issues’

- Filmed clips from families + medical professionals
- Wide range of perspectives + experiences
- Used in medical schools + patients referred to it by clinicians
CDoC offers training + e-learning for Healthcare Professionals (cdoc.org.uk)
Thank you

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To illustrate the large number of ways system can fail

N = 34 Infographic from Derick Wade