Prolonged Disorders of Consciousness and best interests decision-making about life-sustaining treatment

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Clinically-assisted nutrition and hydration
Supporting Decision-Making: Ensuring best practice
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Best interests decision making for CANH

**CANH** = all forms of tube feeding (including NG, PEG, RIG). Does not include oral feeding by cup, spoon or any other method for delivering food, liquid, supplements into P’s mouth). CANH is a medical treatment (*Bland*)

Best interests decision-making is required to **start, restart, stop or continue CANH** in adult patients EXCEPT when:

- **CANH** is a not clinically appropriate treatment that should be made available to the patient (e.g. gastrointestinal obstruction/bleeding/severe malabsorption)
- Patient has mental capacity to make decision for themselves
- There is a valid and applicable advance decision to refuse this treatment

Mental Capacity Act 2005
British Medical Association + Royal College of Physicians – endorsed by General Medical Council, December 2018

• Almost 100 pages of detailed guidance about the decision-making process for starting, re-starting, continuing, or stopping (withdrawing) CANH ....
• ... for adult patients who lack capacity to make their own decision....
• ... and are not imminently dying.
• ... and for whom CANH is clinically appropriate
• 3 categories: (1) neurodegenerative conditions;
  (2) multiple comorbidities or frailties;
  (3) Previously healthy patients in VS or MCS following sudden-onset brain injury
British Medical Association
Click here
Training materials

Here you can find learning and training materials to help put the principles of the guidance into practice.

You can watch the following presentations, or use them as part of any training sessions within your area.

- Dr John Chisholm, Chair of the BMA’s Medical Ethics Committee, introduces the guidance and explains more about how it was developed.
- Alex Huck Keene, a barrister specialising in mental capacity law, sets out the legal and regulatory principles which underpin the guidance.
- Dr Shuli Levy, a consultant geriatrician and general physician, discusses how the guidance will be used in clinical practice.
The role of family and friends in decisions about CANH

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Click here:
CDoC offers Online Resources and bespoke training
- e-learning for Health Professionals

• Free online learning resources
• cdoc.org.uk
• Click here
Who makes decisions about CANH?
(when person lacks capacity + has no ADRT)

Health and Welfare Attorney, registered by the OPG, and with appropriate powers

OR

the person with overall responsibility for the patient’s care as part of their clinical responsibility to ensure that treatment provided is in the patient’s best interests.

• In hospital – the named consultant..
• In a hospice/palliative care/rehab unit – the named consultant or senior doctor with overall clinical responsibility for the patient’s care.
• In the community (in a nursing or care home or living at home), GP

OR

The COP if there is disagreement on P’s best interests or the decision is finely balanced.
“It should be clearly established at all times who has responsibility for deciding whether CANH should be provided or continued and this information should be shared with those close to the patient. Seeking clarity about who the decision-maker is at an early stage ensures that CANH is provided, or withdrawn, as appropriate for the individual patient and is not continued, ‘by default’, because nobody sees it as their responsibility to carry out a best interests assessment.” (BMA/RCP Guidance)
Making a ‘best interests’ decision

The decision-maker must consider, so far as is reasonably ascertainable -

(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]
• The correct question to ask is whether it is appropriate to provide or continue to provide treatment, rather than whether it is appropriate to withdrawal CANH, on the basis that CANH should only be provided where it is in the patient’s best interests. (BMA/RCP Guidance)

• “Decisions to provide CANH should be reviewed every 6 months (or every 12 months where the patient has been in a stable condition over a long period of time) and more often if the clinical situation has changed significantly” (BMA/RCP Guidance)
• An increasing emphasis on patient-centred decision. The courts have emphasized the very strong presumption in favour of the preservation of life but that this can be rebutted by the principle of self-determination, if there is clear evidence that the individual would not want CANH provided in the circumstances that have arise

• An unequivocal position in law that a patient’s best interests incorporate not just their medical interests, but their welfare in the widest sense – medical, social and psychological.
• Courts have confirmed that decisions to withdraw CANH are compliant with human rights law if they are made appropriately.

• Managing conscientious objection to treatment withdrawal appropriately
Importance of palliative care

• Involving palliative care experts in best interests meeting
• Explaining palliative care to family
• Ensuring palliative care plan is agreed with independent expert
• Support for family and for staff
• Planning ahead and communication about coroner (and inquest if necessary)
Very rare to find formal records of BI decision-making process about CANH

- Almost all actions are simply done, without explanation.
  - Often for years.
  - Sometimes say ‘done in best interests’ or ‘duty of care’

“Treatment by default”

Ignorance of the law: e.g. (from medical records of a BI meeting held in response to family concerns about ongoing CANH): “the decision cannot be something that brings about the death of the patient therefore CANH is in her best interests”
To illustrate the large number of ways we fail

N = 34 Infographic from Derick Wade
Decision-making in Practice – the Family View

Three Case Studies
Case 1: My own family experience: **Polly Kitzinger**

- Catastrophically brain injured in a car accident in 2009.
- Family members all believed she have refused treatment if she could, given prognosis.
- Medical treatment delivered for years in vegetative + minimally conscious state.
- Survives with profound multiple physical + neurological disabilities + with quality of life she would not have considered worthwhile.
Polly Kitzinger
Involvement Development Office

SERVICE USER INVOLVEMENT
THE Local Picture

SERVICE USER INVOLVEMENT IS ABOUT

Citizen Voice & Human Rights
not Therapy
Polly’s voice?

We tried to represent what Polly would have wanted

But

- Our reports not heard? not believed? or not given much ‘weight’ against sanctity of life in the balance of best interests decision-making?

- Clinicians thought decision ‘belonged’ to them - correctly informing us that ‘next of kin’ had no decision making powers in England/Wales...but not outlining how we should be consulted.

- Clinicians felt clinically they could still do things for/to her....or believed ‘the law’ meant they had to wait (to confirm whether or not she would enter the category of ‘permanent vegetative state’)

Life sustaining treatment continued in the spite of our attempts to stop it
Decision-making in Practice – the family View: Case 2

See Kitzinger + Kitzinger in International Mental Health & Capacity Law (2017)
PVS for 23 years

• In August 2017 an English judge sanctioned withdrawal of CANH from a patient who’d been in a vegetative state for 23 years (I acted as Litigation Friend)
• 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
• Continued to be treated long after clinicians + family had abandoned hope for recovery ("we didn’t know there was any other option"; "no one has ever said, ‘look there’s another path, he doesn’t have to stay like this")

• 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 – the family view
Case no 3
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 (+ receiving invasive treatment for a previously undiagnosed cancer!)
• 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 ONE YEAR from date of collapse

• Family requested meeting one year from date of collapse – told not necessary. Persisted.

• Took several months to arrange meeting

• Meeting cancelled due to staff illness- family asked for our help

• Finally held BI meeting 21 months after patient collapse – agreed continuing treatment was not in her best interests
Polly’s letters
5 mins digital storytelling
Making healthcare decisions in a person’s best interests when they lack capacity: clinical guidance based on a review of evidence

Derick T Wade and Celia Kitzinger

Abstract
Objective: To clarify the concept of best interests, setting out how they should be ascertained and used to make healthcare decisions for patients who lack the mental capacity to make decisions.

Context: The legal framework is the Mental Capacity Act (MCA) 2005, which applies to England and Wales. Theory: Unless there is a valid and applicable Advance Decision, an appointed decision-maker needs to decide for those without capacity. This may be someone appointed by the patient through a Lasting Power of Attorney, or a Deputy appointed by the court. Otherwise, the decision-maker is usually the responsible clinician. Different approaches exist to surrogate decision-making crossationally. In England and Wales, decision-making is governed by the MCA 2005, which uses a person-centred, flexible best interests (substituted interests) approach.

Observations: The MCA is often not followed in healthcare settings, despite widespread mandatory training. The possible reasons include its focus on single decisions, when multiple decisions are made daily; the potential time involved and lack of clarity about who is the responsible decision-maker.

Solution: One solution is to decide a strategic policy to cover more significant (usual health-related) decisions and to separate these from day-to-day relational decisions covering care and activities. Once persistent lack of capacity is confirmed, an early meeting should be arranged with family and friends, to start a process of sharing information about the patient’s medical condition and their values, wishes, feelings and beliefs with a view to making timely treatment decisions in the patient’s best interests.

Keywords
Mental capacity, decision-making, best interests

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Value of advance care planning

• Advance decisions to refuse treatment (e.g. “If I am ever diagnosed as being in a prolonged disorder of consciousness, I refuse all life-sustaining treatment (including but not limited to CANH— even if this means my life is shortened as a result. (Signed + witnessed = valid ADRT)

• Advance statement: (e.g. “Once I lose capacity and can no longer engage meaningfully with my family, and am unlikely to regain that ability, I would prefer CANH to be discontinued”.)

• 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 can give them instructions)

• More information from Compassion in Dying: compassionindying.org.uk
Thank you

• How to contact us for:

• Training for staff
• E-learning opportunities
• Support with best interests decision-making
• Support for families
• KitzingerC@Cardiff.ac.uk