Clinically Assisted Nutrition and Hydration (CANH) for patients with a Disorder of Consciousness:
Decision-making challenges for professionals & implications for families

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Introducing the Coma & Disorders of Consciousness Research Centre @cdocuk

1. Research

- Interviews with 100+ family members with PDoC relatives + interviews with healthcare professionals
- Observation + tracking patient pathways (up to 10+ yrs in some cases)
- Case studies of specific decisions (through court/clinical best interests for ceilings of treatment) (includes series of reports on recent case law)

2. Training

Face-to-face training in care homes, rehabilitation centres & hospitals

Now online courses on all aspects of care, includes a course on "Law, Ethics & Best Interests" (click here: https://cdoctraining.org.uk)

Talk structure

1. Key context for decision-making about CANH (in England and Wales)
2. Our research findings & 2 illustrative case studies
3. Summary of key challenges
4. Reflection on changes since 2018 Supreme Court ruling re CANH
5. Examples of recent court cases
6. Moving Forward – what can we do?

1. Key context for decision-making about CANH (in England and Wales)

Context – CANH, key facts/guidance – a brief recap for shared understanding

- Clinically assisted nutrition and hydration (CANH) is a medical treatment (*Bland*, 1992)
- Withdrawing CANH is not, by law, murder (*Bland*, 1992) or ‘euthanasia’ (Cause of death = original injury)
- There is no legal difference between withholding CANH (i.e. deciding that starting it is not in a person’s best interests) and withdrawing CANH (i.e. deciding after it has been started that continuing it is not in a person’s best interests).

Deciding to provide CANH is a 'best interests' decision if (and only if)

- it's on offer as a treatment (clinicians can not be forced to provide)
- And there's no valid and applicable Advance Decision to Refuse it

<u>Responsibility</u> for ensuring treatment is in patient's best interests is with the clinician providing it - <u>not</u> responsibility of 'next-of-kin' or family (although Health and Welfare Attorneys may make be best-interests decision-makers for life-sustaining treatment – check!)

A ‘best interests’ decision-maker must consider what person themselves would choose if they had capacity

Mental Capacity Act 2005

(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 – “**anyone engaged in caring for the person or interested in his welfare**” [MCA 4(7(b)]

Best interests applies irrespective of diagnosis and at all times from moment of brain injury

W v M 2011 EWHC 2443 (Fam)

confirmed that best interests analysis applies to both Vegetative and Minimally Conscious state.

Paul Briggs [2016] EWCOP 53

withdrawal of CANH was approved even though Paul Briggs was in a minimally conscious state with the potential to improve.

Conscientious objection

- This may be but is not always based on religious belief
- Members of the treating team whose religious/ethical - perspectives means they do not and cannot actively comply with the law as it stands should declare “conscientious objection” and withdraw as decision-makers. Someone else who can comply with the law should take over responsibility for the patient’s care. (See section 2.4 on conscientious objection National Guidance on CANH).
- This is not a ‘get out’ clause for practitioners who simply prefer not to be involved in time-consuming and difficult decision-making processes.

2. Our research findings & 2 illustrative case studies

What we found in our research from 2009 onwards

- Some families told us their relatives' past wishes, feelings, beliefs, values have not informed 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.

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

This means:

- Cannot know whether or not treatment is in their best interests
- Some of these patients are likely to be being treated against their best interests (& indeed proper process often reveal this to be the case)
- Families left feeling guilt-ridden, responsible, feeling 'abandoned'

We're going to present 2 case studies and then pull out what the challenges appeared to be for clinicians and the implications for families

First, a moment of reflection for you

Can you confidently say that all PDoC patients you are involved with have had a robust best interests assessment in relation to CANH?

The case studies
Decision-making in Practice

Decision-making in Practice
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.
- 1995 Diagnosed PVS (diagnosis confirmed 1997, 1998 + 1999)
- 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 - Case no 2

- 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

As in previous case this process was very distressing for the family – they felt their relative had been treated contrary to her best interests.

3. Summary of key challenges

‘Reasons’/’challenges’ revealed by these case studies (and other cases we’ve supported)

- Some patients are ‘lost in the system’ (eg out in care homes/in the community’) without access to proper reassessment follow up
- Some clinicians don’t consider CANH as topic for best interests decision-making or conflate ‘clinical judgment’ & best interests
- Some have undeclared conscientious objection
- Has been a lack of ‘ownership’ of the process (e.g. who is decision-maker)
- Fear of ‘difficult conversations’ or feeling ill-equipped for such conversations
- Clinicians may evade addressing cases where there is no family consensus (so treat by default if even one relative thinks that is the right thing to do)

‘Reasons’/’challenges’ continued

- (historically) Clinicians have felt ‘disempowered’ because of previous requirement to go apply to court for authorization of withdrawal decisions (but not for continuing treatment)
- 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*”
- diagnosis-led (rather than person-led) decision-making (e.g. myth of ‘have to wait for a year’ before making best interests decision)

Context for healthcare providers

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 interests process
- Lack of continuity of care (those who make early decision not involved in later decisions)
- Institutional priorities, routines and loyalties (e.g. as a Trust, hospital or rehab centres) (Reputational, Audit, (perceived)Risk, Research, Financial)

4. Reflection on changes

Re Y 2018 Landmark case

- Re Y in Supreme Court 2018
- No duty at common law or under European Court of Human Rights for mandatory applications to court.
- Follow Mental Capacity Act 2005 and professional guidance and if all agree CANH is not in person's best interests, then withdraw CANH (with appropriate palliative care)
- Court is still available for disputed or finely balanced cases.

Reflecting on changes since 2018 Supreme court judgment

- Clinicians taken (back) responsibility for best interests decision-making about CANH; families empowered to ask for best interest reviews (e.g 33 years PVS case)
- Some clinicians report process may need attention & time and choice of 'least worst option' may be very sad – but no 'dilemma' per se once process followed , building up body of expertise
- Major organizational initiatives to invest in and improve services in some Trusts
- More best interests meetings
- …AND seem to be **more** court cases
- More court cases seems counter-intuitive and opposite of what had been feared by some who opposed change
- More patients getting access to justice?

Court hearings 2019-2022

- Which case get to court, and the evidence that is heard, and judgments made are a rich source of insight into how best interests decision making is working or now

What we are seeing is:

- Contested cases – where there's disagreement between clinicians and family, or between family members
- Often at an earlier stage (e.g. within first year of injury) as best interests has been properly addressed from immediately post brain-injury.

5. Examples of Recent Court cases

Promoting Open Justice in the Court of Protection

https://openjusticecourtofprotection.org

Re GU

Re GU (PDoC, man in late 60s, Ongoing CANH given & no court application made for years – in spite of dispute)

- 23rd June 2021 Clinically-assisted nutrition and hydration: Decisions that cannot be ignored or delayed by Jenny Kitzinger
- 24th June 2021 Urgency, delayed decision-making and ethics in the Court of Protection by Dominic Wilkinson
- 15th July 2021 Delay is inimical to P's welfare: Guidance on clinically-assisted nutrition and hydration for PDoC patients by Jenny Kitzinger
- 17th November 2021 "Burdensome and futile" treatment and dignity compromised: Poor practice at a leading UK hospital by Jenny Kitzinger

Court very critical of Royal Hospital for Neuro-disability for an 'ethos' which led to failure to implement the Mental Capacity Act 2005 + professional guidance.

Re ED

Re ED (PDoC, young man, Family dispute re assessments & Best Interests re CANH, father wants more tests)

- 14th October 2021 When another assessment is not needed: Best interests decision-making for a patient with a prolonged disorder of consciousness by Jenny Kitzinger

Re RS

Re RS (PDoC, middle-aged man, clinical/family dispute re CANH) (Polish family involvement + videos of patient placed on social media. Involvement of Dr with contested expertise)

- 7th April 2021 Faith, Science and the objectivity of expert evidence by Celia Kitzinger (with links to judgments)
- 31st March 2021 A perspective from the ICU on best interests at the end of life (with links to judgments) by Alex Warren
- 30th March 2021 Ambiguity and uncertainty in clinical reasoning by Derick Wade
- 30th March 2021 Use of videos in assessing consciousness: A clinical perspective by Lynne Turner-Stokes
- 29th March 2021 Seeing is Believing? Patient Videos in Life-Sustaining Treatment Disputes (with links to judgments) by Jenny Kitzinger

6. Moving Forward – what can we do?

What can healthcare professionals & organisations do?

1. Ensure family/friends have been asked about patient's wishes, feelings, beliefs and values & that they are informed about their own role (& know that they are not responsible for decision)
2. Advance care plan – including ceilings of treatment where appropriate
3. Regular review of whether CANH is in person's best interests
4. Engage across MDT and across professional groups and organisations
5. Use BMA/RCP (2018) guidance on CANH and RCP (2020) guidance
   - Guidelines address context
   - Crystal clear about decision process and responsibility
   - Offer support tools for families and staff

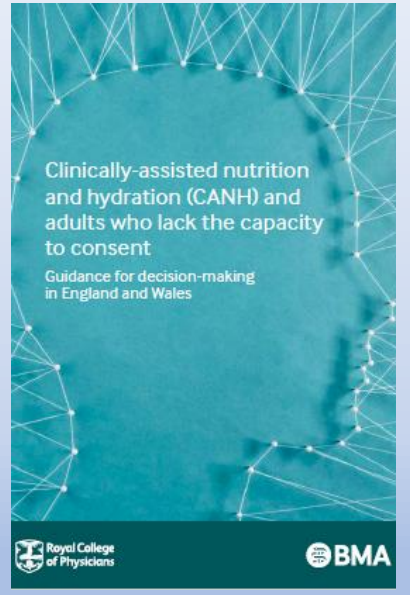
Resources

1. The RCP guidelines 2020 – 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 ….

To listen to podcast Click here:



CdocTraining.org.uk

- e-learning for Healthcare Professionals

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Thank you!

Comments? Questions? Discussion?

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