New, wide-ranging guidance on CANH decisions: what do you need to know?

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All clinicians, NHS Trusts, CCGs and independent healthcare providers need to be aware of important new guidance from the BMA on how to make decisions about clinically-assisted nutrition and hydration for those unable to decide for themselves - "*Clinically assisted nutrition and hydration (CANH) and adults who lack the capacity to consent - Guidance for decision-making in England and Wales*".

What do you need to know about the new guidance?

- **Far broader in scope than the interim version of the guidance, going beyond PVS/MCS cases;**
- **Includes practical guidance to support clinically and legally robust decision-making about CANH;**
- **Covers how to resolve disagreements and when to go to court;**
- **Lists steps which NHS Trusts, CCGs and independent sector providers need to be taking now to support implementation of this new guidance - the CQC will be watching…**

We look at the guidance in more detail and what needs to happen to ensure compliance.

What does the new guidance cover?

The interim version of this guidance - issued at the end of last year in the wake of a flurry of court cases about CANH - was limited to withdrawal of CANH from patients with prolonged disorders of consciousness (PDOC) - e.g. persistent vegetative state or minimally conscious state - following sudden-onset brain injury.

The new, final version of the guidance encompasses a much wider group of patients.

Decisions to start, re-start, continue or stop CANH for adults lacking capacity are all covered, with the focus on patients who could go on living for some time if CANH was provided (i.e. not those expected to die within hours or days) where CANH is the main life-sustaining treatment being provided.

This includes patients with:

- a neurodegenerative condition resulting in the patient ultimately being unable to take in sufficient nutrition orally (e.g. Huntingdon's Disease, Parkinson's);
- sudden onset or rapidly progressing brain injury where the person has multiple comorbidities/frailty likely to shorten life expectancy (e.g. catastrophic strokes, central nervous system infections, subdural haemorrhage);
- previously healthy PDOC patients - in a vegetative or minimally conscious state - due to sudden onset brain injury (e.g. trauma, hypoxia).

Whilst much of the guidance is applicable across all these patients, there is also some category-specific guidance in relation to each of the above (e.g. the guidance specific to previously healthy PDOC patients emphasises the need for expert assessment in a designated PDOC assessment unit).

How do you make legally/clinically robust decisions?

Running as a central thread throughout this guidance is the concept of making decisions about CANH in a proportionate way - i.e. the greater the uncertainty about the correct decision, the greater the degree of scrutiny needed. Key factors influencing this will be the person's prognosis (e.g. the potential for future recovery or deterioration and expected survival time) and the impact of making the 'wrong' decision about CANH (e.g. the impact of withdrawing it too soon or carrying it

on for too long).

Another key concept underpinning the guidance is the importance of keeping in mind at all times that the decision is about

what is in the best interests of the individual patient - not what is best for those close to them or what most people in their situation would want. The goal of those making decisions about CANH should therefore be to accumulate enough information to form a clear view of what the patient would have wanted if they still had capacity to make a decision.

The guidance takes us through all the fundamentals of best interests decision-making as required by the Mental Capacity Act (MCA), with an added layer of pragmatic help with meeting those requirements 'on the ground', including a separate appendix with *'Practical guidance for best interests decision-making'*.

As examples, the guidance gives practical pointers on the following:

- Who should be consulted and how extensive consultation should be depending on the particular scenario, including strategies to help ensure that a range of views are heard;
- Examples of the types of information about the patient's personality, lifestyle, views, beliefs which it is useful for those close to the patient to provide to the decision-maker;
- A list of questions which can be used to frame clinical assessment, such as:
    - What is the quality of his/her life at present from his/her perspective?
    - Is there any enjoyment in his/her life? If so, how can this be maximised?
    - Does he/she experience pain and/or distress and if so is this appropriately managed?
    - Is there any real prospect of recovery of any functions or improvement to a quality of life that he/she would value?
- How to go about obtaining second opinions in different clinical scenarios, and details of issues second opinion doctors should be asked to consider;
- Practicalities of running best interests meetings most effectively and applying the 'balance sheet' approach to decision-making.

Plus, the guidance includes a new checklist of evidence for best interests decision-making in relation to CANH, which should be held in the medical notes accompanied by supporting information such as records of best interests meetings.

What about resolving disagreements and going to court?

The guidance reflects the legal position as decided this summer by the Supreme Court in the 'Y' case - i.e. there is no requirement for decisions about withdrawing CANH to be approved by the court, provided there is agreement about what is in the person's best interests and provided that the provisions of the MCA and relevant professional guidance have been followed.

If, however, there is any disagreement about what is in the patient's best interests, the guidance makes a number of suggestions for informal resolution, as follows:

- Involve an independent advocate
- Obtain a further clinical opinion
- Hold a case conference

If these approaches are not working, consideration should be given to using a medical mediation service.

If these options fail to resolve matters, the guidance suggests that legal advice should be sought to decide whether a court application is necessary.

The guidance emphasises that, where there is disagreement or uncertainty about whether a course of action is in the patient's best interests, the Court of Protection is the ultimate decision-maker and can - and should - be asked to decide. It also makes clear that, where an application to court is needed, proceedings should be brought by the relevant NHS body.

How will compliance be monitored?

A key element of compliance with the new guidance is the need to ensure that decisions about CANH are subject to proper

internal review/audit - e.g. as part of the national Learning from Deaths Framework. This makes it important that information about CANH decisions is recorded in a format that allows it to be easily extracted for review/audit.

The CQC will have a central role to play here in terms of external scrutiny and will be looking carefully to ensure that appropriate processes are in place - and have been followed - in relation to CANH decision-making. If a provider is unable to show that CANH decisions have been properly made and documented, this is likely to impact on CQC ratings and could result in enforcement action.

As an additional layer of external scrutiny, we are expecting Medical Examiners to be rolled out nationally from April 2019 and they will also have a role in checking that decisions not to provide/to continue CANH have been properly made in accordance with the guidance.

What do you need to do now?

Providers and commissioners now need to follow the recommendations in the guidance about what they need to do to support implementation of this.

Specifically, the guidance stipulates that each individual Trust, CCG and independent healthcare provider should develop an implementation plan to ensure there is widespread awareness of the guidance and that health professionals are given the support they need to follow it.

The guidance includes many examples of steps which might need to be reflected in such plans, such as:

- Identifying the individuals, teams and departments that are most likely to have to make decisions about CANH and ensuring they are notified of the new guidance;
- Identifying one or more members of the management and/or governance team who are responsible for ensuring that the practical processes are in place to ensure health professionals are able to comply with the guidance (e.g. training, second opinion arrangements, review and audit of relevant decisions);
- Setting up specific training courses on CANH decision-making and ensuring that staff know where and how to access guidance when they need it;
- For CCGs, ensuring there is an identified individual responsible for providing advice/support to those making decisions about CANH in the community;
- Putting in place mechanisms to arrange second opinions without delay, including CCGs setting up a database of individuals willing/qualified to give second opinions to enable GPs providing care at home/in care homes to fulfil their obligations;
- Setting up and publicising a range of formal and informal support mechanisms that are available locally and nationally for those involved in making these decisions and acknowledging how difficult/stressful they can be for all concerned.

The guidance further suggests that there may be benefit in joining with other organisations to develop a local or regional approach to this.

How can we help?

Our national team of MCA and Court of Protection specialists provide responsive, practical advice on all aspects of the law in this area, including:

- Training on all aspects of the new CANH guidance, including best interests decision-making and resolving disagreements;
- Advice on the management of patients receiving CANH to ensure robust decision-making about continuance or withdrawal which will withstand scrutiny by the court or CQC;
- Advice on whether an application needs to be made to the Court of Protection in serious medical treatment cases, including decisions relating to CANH withdrawal;
- Court of Protection welfare applications relating to care and/or accommodation;
- Section 21A challenges to DoLS authorisations.

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