

Decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset profound brain injury

Interim guidance for health professionals in England and Wales

As is the case for other medical treatments, where clinicians need to take the decision about whether to provide and/or continue CANH for an adult who lacks capacity, the decision must be based on an assessment of the patient's best interests.¹ Decision makers should start from the presumption that it will be in a patient's best interests to prolong life, but there is no obligation to prolong life irrespective of the quality of that life or of the patient's own views. For some patients, there will come a point where continuing to provide CANH ceases to be in their best interests because it is not able to provide a quality of life the patient would find acceptable. In such a case the presumption in favour of prolonging life will have been rebutted.

The BMA,² Royal College of Physicians³ (RCP) and the General Medical Council⁴ (GMC) have all issued guidance (at different times) about making decisions in relation to life-prolonging treatment. This guidance continues to apply. However, supplementary guidance is provided in this document in response to recent legal developments in England and Wales.

In respect of the withdrawal of CANH from patients in permanent vegetative state (PVS) or minimally conscious state (MCS), following sudden-onset profound brain injury, previous guidance from the BMA, RCP and GMC has indicated that an application to the Court of Protection should be made in all such cases. The BMA is working with the RCP and GMC to update this existing guidance, to reflect recent developments in the law in relation to the role of the court. The new guidance will recommend safeguards to ensure that a robust and thorough assessment process continues to be followed prior to the withdrawal of CANH. Our aim is to publish this guidance in May 2018.

The purpose of this current document is to summarise the recent developments in the law, and provide interim guidance for doctors and other clinical professionals pending publication of the new guidance. This document summarises the views of the BMA, RCP and GMC about good clinical and professional practice in this context.

- 1 This does not cover situations where the patient has a legally valid and applicable advance decision refusing treatment (ADRT) or has appointed a lasting power of attorney for health and welfare decisions covering withdrawal of life-sustaining treatments (see BMA guidance for more information).
- 2 British Medical Association (2007) *Withholding and withdrawing life-prolonging medical treatment*.
- 3 Royal College of Physicians (2013) *Prolonged disorders of consciousness. National clinical guidelines. Report of a working party 2013*. Available at: <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>
- 4 General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. Available at: http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

Legal developments

The advice to seek court approval prior to withdrawing CANH from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) was based on a combination of the case law, the Court of Protection's Practice Direction 9E and the Mental Capacity Act (MCA) Code of Practice. There have been some significant recent legal developments which have changed the guidance for clinicians:

- The Court of Protection's Practice Direction 9E, which listed these cases as ones that 'should' be brought before the court, was withdrawn on 1 December. There is no indication that it is proposed that it should be replaced.
- Recent legal judgments⁵ have held that there is no requirement on treating clinicians to seek the court's prior approval to withdrawing CANH for a patient in PVS or MCS where existing professional clinical guidance has been followed and where the treating team and those close to the patient are all in agreement that it is not in the patient's best interests to continue such treatment.⁶
- Although the Mental Capacity Act Code of Practice⁷ states, at paras 6.18 and 8.18, that court approval should be sought prior to the withdrawal of CANH from patients in PVS (but did not mention MCS), the High Court has decided that the Code of Practice does not impose a legal obligation on treating clinicians to seek the court's approval. The High Court considered that these paragraphs were based on the caselaw as it stood at the time the Code of Practice was prepared, and can properly be set to one side where existing professional clinical guidance has been followed and all relevant parties are in agreement that it is not in the patient's best interests to continue such treatment.

This Interim Guidance may need revision if a case concerning these issues is considered by the Supreme Court.⁸ Clinicians are thus advised to check the up-to-date position on the BMA website.

However, in light of the developments set out above, our understanding is that, provided existing professional clinical guidance has been followed and all relevant parties agree that it is not in the patient's best interests to continue such treatment, good clinical practice does not require that court approval is sought before CANH can lawfully be withdrawn from patients in PVS and MCS.

There has also been a change in emphasis regarding the importance of making a diagnosis of vegetative state (VS) or MCS. Until recently withdrawal of CANH was routinely supported by the Court in cases of permanent VS on the grounds of futility, but was rarely supported in MCS. However, recent case law⁹ has increasingly emphasised the importance of decision making which gives effect to the patient's wishes and feelings, beliefs and values. This involves seeking to understand what decision the patient would have made for themselves if the patient had retained capacity. This can include an assessment of how the patient would have viewed the decision, given the likelihood of recovery to a level that they themselves would perceive as an acceptable quality of life.

Nevertheless, it is still necessary to conduct a detailed assessment in accordance with the RCP Guidelines in order to establish the patient's level of awareness and any trajectory towards improvement. Prognosis is essential in establishing whether the patient is likely to recover to a quality of life that he or she would consider worthwhile.

5 *NHS Trust v Mr Y and Mrs Y* [2017] EWHC 2866 (QB) (available at <http://www.bailii.org/ew/cases/EWHC/QB/2017/2866.html>); *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169. (available at: <http://www.bailii.org/ew/cases/EWCA/Civ/2017/1169.html>); and *M v A Hospital* [2017] EWCOP 19 (available at: <http://www.bailii.org/ew/cases/EWCOP/2017/19.html>).

6 Information about best interests decision making can be found in: Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*, chapter 5 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

7 Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice* (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

8 In the appeal from *NHS Trust v Mr Y and Mrs Y*

9 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 (available at: <http://www.bailii.org/uk/cases/UKSC/2013/67.html>); *Briggs v Briggs* [2016] EWCOP 53 (available at: <http://www.bailii.org/ew/cases/EWCOP/2016/53.html>)

Interim guidance concerning withdrawal of CANH from patients in PVS/MCS resulting from sudden onset brain injury¹⁰

In the interim period, until new guidance is published in May 2018, there will continue to be a need to make these very serious decisions and it is essential they are made with great care and the greatest respect for the patient as a person; that they are documented carefully; and are closely scrutinised to provide both the protection and reassurance that are required.

The first question is to establish whether there is a need to make a “best interests” decision. Such a decision cannot be taken:

- a) If the patient has made a valid and applicable Advance Decision to Refuse Treatment covering CANH which applies in the patient’s clinical situation. In this case the patient has already decided to decline treatment and that decision should be respected;
- b) If the patient has appointed a health and welfare attorney under a Lasting Power of Attorney which has been registered with the Office of the Public Guardian, and where the power of attorney specifically gives the Attorney the power to consent to, or refuse, life-sustaining treatment. In that case the power to consent to, or refuse, CANH rests with the Attorney who becomes the decision maker on behalf of the patient. Doctors should respect decisions made by the Attorney (unless these are overruled by a court);
- c) Where there is disagreement about best interests or the decision is finely balanced; in this circumstance an application should be made for a court declaration to determine whether CANH continues to be in the patient’s best interests.

In all other cases we understand that the patient’s clinical team can lawfully withdraw or not provide CANH, where they determine (after proper consultation) that this is in the patient’s “best interests”. To ensure proper consultation in such cases, we recommend doctors take the following steps.

1. Ensure that the RCP guidance has been followed regarding assessment in order to establish the patient’s level of responsiveness and awareness, any trajectory of change and prognosis in terms of recovery of consciousness and/or return to a quality of life that the patient him or herself would value. Assessment must be carried out by professionals with appropriate training in this field. If the expertise is not available locally, the patient should be referred to a specialist prolonged disorders of consciousness (PDOC) evaluation service.
2. Consult and follow existing guidance from the MCA Code of Practice (as well as from the BMA, RCP and/or GMC) about how best interests should be assessed (remembering that protection under section 5 of the Mental Capacity Act only applies where the correct process has been followed).
3. Hold formal, documented, best interests meetings with those who care for the patient and are interested in his or her welfare. Such meetings are both to share clinical information with them about the patient’s diagnosis and prognosis and to elicit information about the patient’s values, wishes, feelings and beliefs in order to decide whether it would be in the patient’s best interests to continue to provide CANH. Accurate information should be provided about how death following CANH-withdrawal would be managed.
4. Ensure that attempts are made to identify all relevant people to be consulted about best interests decisions (not simply one person designated as ‘next of kin,’ a term which has no legal meaning in the context of best interests decision-making). Those consulted would usually include family members and could also include friends, colleagues etc who have known the patient well and may be aware of his or her views and values, as well as all members of the care team. The views of care staff at all levels can be relevant and helpful in assessing what the patient would judge to be in his or her best interests, particularly those who have spent any considerable period of time with the patient.

¹⁰ The guidance to be produced in due course is likely to be broader in scope but this interim guidance only covers decisions to withdraw CANH from this specific group of patients.

5. If the patient has no known family, and nobody else to represent their views, an Independent Mental Capacity Advocate (IMCA) should be consulted. An IMCA should also be consulted in the event that the clinicians consider that family members (for whatever reason) are not properly able to represent the patient's views.
6. Unless the individual had previously indicated that information is not to be shared with others, it is reasonable to assume they would want information shared with those who may be asked to contribute to the decision-making process. Those people consulted should therefore be given realistic information about what the future holds for the patient. This should focus on specific activities, both active and passive, and interests that might be important to this particular person, such as the extent to which they will be able to interact and/or communicate with others or gain pleasure from activities such as listening to music or watching television, rather than general statements about the likely extent of the patient's disability.
7. Find out as much as possible about the patient's values, wishes, feelings and beliefs both generally and as they relate to their current situation. This will include the type of person the patient was before becoming ill, what was important to him or her, the types of things the patient valued and enjoyed doing whilst able to do so and any religious, spiritual or ethical beliefs he or she held. Family members, friends, colleagues etc should also be asked for any examples of things the patient said, or did, that might indicate the view that he or she is likely to have of the current situation. All of this information will form part of the assessment of best interests and help to determine what view the patient is likely to have taken about continuing CANH.
8. All of the information and evidence provided about the patient's past and present wishes, and likely views, should be carefully assessed in relation to the most realistic prognostic evidence to consider whether continuing CANH would be in the patient's best interests. Ideally, a decision maker should accumulate enough information so that he or she knows sufficient about the patient to form a clear view as to what the patient would have wanted for him or herself if they had retained the capacity to make the decision.
9. Health professionals with a conscientious objection to the withdrawal of CANH should declare any strongly-held personal views or beliefs that are a source of conflict of interest. If the individual clinician could not sanction a best interests decision in one direction, he or she should hand over the care of the patient to a clinician who can.
10. Seek a second clinical opinion from a consultant with experience in prolonged disorders of consciousness who has not been involved in the patient's care. So far as is reasonably practical in the circumstances of the case, this opinion should be external to the NHS Trust/CCG/Health Board, and based on an examination of the patient as well as review of the medical records and the information that has been collected. Where the patient is not seen by the PDOC specialist, the reasons for this should be documented in the medical record.
11. Keep a very detailed record of all discussions, best interests meetings, advice sought and resources consulted and add this to the patient's medical record.
12. Keep a detailed clinical record, in a format that can be easily extracted from the rest of the medical record for local review and audit. This should include:
 - a) the nature, cause and severity of the brain injury;
 - b) the clinical assessments that have been undertaken;
 - c) the treatment that has been provided to date;
 - d) the results and interpretation of formal tests to assess the patient's level of awareness (in line with the RCP guidelines on prolonged disorders of consciousness);
 - e) the patient's presentation and abilities: movements, language, speech, responses etc, and the reproducibility of these findings;
 - f) evidence of the patient's ability to feel pain;
 - g) evidence of the patient's ability to experience pleasure or enjoyment;

- h) clinical assessment of best, worst and most likely prognosis including life-expectancy if CANH is continued;
 - i) summary of views and evidence collected from those who care for the patient and are interested in his or her welfare about the past wishes and values of the patient and the patient's likely views regarding the continuation of CANH in their current and likely future situation;
 - j) a detailed summary of all best interests meetings;
 - k) the second opinion report prepared by a PDOC specialist who has not been involved in the patient's care and who (insofar as is practicable in the circumstances of the case) is external to the NHS Trust/CCG/Health Board;
 - l) discussion relating to the patient's preference for end of life care, including preferred place of death, any known spiritual or religious beliefs or pre-stated wishes that should be taken into account
13. If all parties agree that it is in the patient's best interests to continue with CANH, this decision should be reviewed at regular intervals in line with RCP Guidelines.
14. If all parties agree that it is not in the patient's best interests to continue with CANH, it should be discontinued as soon as is reasonably practicable in the circumstances of the case. It is necessary to prepare a detailed plan for the process of withdrawal and end-of-life care to ensure that any pain or distress is managed appropriately and that the patient's dignity is maintained. The plan should detail where end-of-life care will be managed, who will be responsible, how symptoms will be managed and how family members and friends will be supported. Palliative care in the context of CANH withdrawal in PDOC is not necessarily the same as other end-of-life care. The palliative care plan should follow the guidance set out in the RCP guidance. If the local palliative care team does not have direct experience in this context, referral to (or seeking advice from) a centre with specialist experience in this area should be considered.
15. When drawing up a death certificate after withdrawal of CANH, the original brain injury should be given as the primary cause of death. Depending on the cause of the brain injury, referral to the coroner may or may not be required. It may be helpful to discuss with the coroner's officer either in advance or immediately after death to determine whether referral is required or to agree the wording on the death certificate.

Until and unless the matter is definitively settled by the Supreme Court, NHS Trusts/CCGs/Health Boards may well wish to seek legal advice as to whether an application is required in any particular case, bearing in mind the twin imperatives of (a) ensuring that patients lacking capacity are treated in accordance with their best interests and (b) that these organisations and their employees are only asked to make a decision concerning the withdrawal of CANH which is clearly lawful and appropriate in the circumstances of an individual case. Some clinicians may also wish to seek advice from their professional organisation and/or defence body.

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