

QUICK REFERENCE GUIDE

Clinically-assisted nutrition
and hydration (CANH) and
adults who lack the capacity
to consent

Guidance for decision-making
in England and Wales



Royal College
of Physicians



BMA

Endorsed by the General Medical Council

'We welcome this joint guidance which will support doctors in making ethically and legally sound decisions in the interests of patients. It provides practical advice to support decision-making in a complex, sensitive area of practice. As part of the BMA advisory group, we consider that the general principles and standards are consistent with our own guidance on Consent (2008) and Treatment and care towards the end of life (2010).

This guidance is a valuable tool for healthcare staff, rather than a rule book, and it is not intended to set a threshold for GMC fitness-to-practise action.'

General Medical Council, 2018.

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I am:

Wondering if this guidance is for me (page 4)

Looking for information about who is the decision-maker in these cases (page 5)

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About this document

This document is a quick reference guide for all doctors involved in making a decision about clinically-assisted nutrition and hydration (CANH) for patients who lack the capacity to consent in England and Wales.

It is primarily aimed at doctors, but will also be of use to all other professionals involved in the care and treatment of these patients including nurses, therapists, carers, managers and advocates.

It is an initial introduction to the subject for healthcare professionals new to the issue, before moving on to the full guidance; and for professionals with more experience of this type of decision making, an aide mémoire.

Managers and others involved in commissioning or providing services to patients receiving CANH may be particularly interested in viewing a separate document which provides guidance on their role in helping health professionals follow the guidance and ensure high quality care for patients.

This quick reference guide should not be read in isolation from the full guidance document, which you can download from www.bma.org.uk/CANH. In this quick reference guide we refer to the relevant sections of the full guidance, which you should read before proceeding with a decision.

Key principles

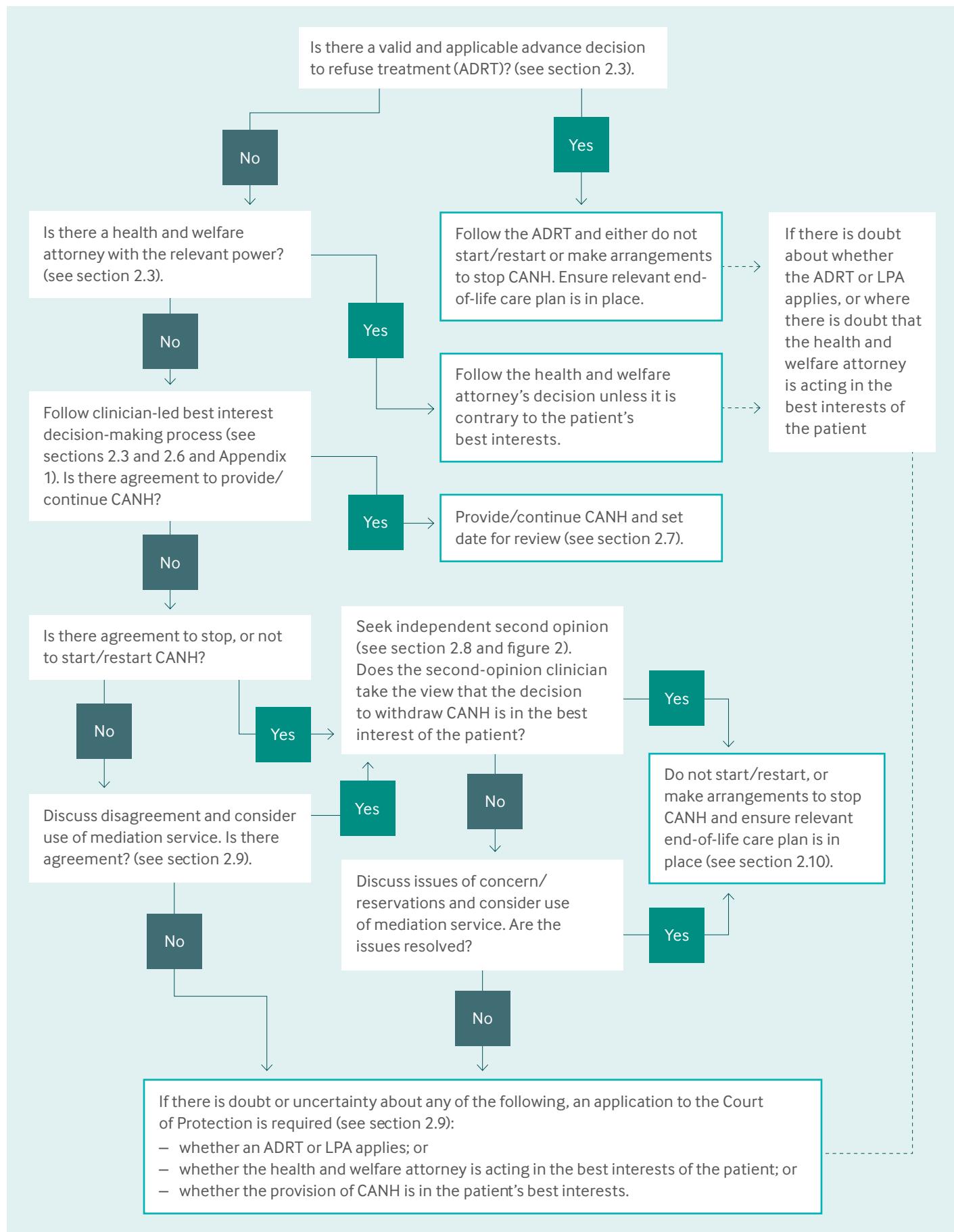
The following key principles are a statement of the current legal and regulatory position in England and Wales, and form the basis of the guidance:

- CANH is a form of medical treatment;
- CANH should only be provided when it is in the patient's best interests;
- decision-makers should start from a strong presumption that it is in a patient's best interests to receive life-sustaining treatment, but this can be rebutted if there is clear evidence that a patient would not want CANH to be provided in the circumstances that have arisen;
- all decisions must be made in accordance with the Mental Capacity Act 2005;
- all decisions must focus on the individual circumstances of the patient and on reaching the decision that is right for that person;
- there is no requirement for decisions about the withdrawal of CANH to be approved by the Court of Protection, as long as there is agreement upon what is in the best interests of the patient, the provisions of the Mental Capacity Act 2005 have been followed, and the relevant professional guidance has been observed; and
- as per GMC guidance, a second clinical opinion should be sought where it is proposed, in the patient's best interests, to stop, or not to start CANH and the patient is not within hours or days of death.

CANH (Clinically-assisted nutrition and hydration)

The decision-making process

www.bma.org.uk/CANH



What is the guidance about?

See Section 1 of the guidance – aim and scope

CANH refers to all forms of tube feeding (e.g. via nasogastric tube, percutaneous endoscopic gastrostomy (PEG) or parenteral nutrition). It does not cover oral feeding, by cup, spoon, or any other method for delivering food or nutritional supplements into the patient's mouth.

The guidance covers decisions to **start**, **restart** (e.g. after a tube has perished, become blocked or dislodged), **continue** or **withdraw** CANH from adult patients in England and Wales who lack the capacity to make decisions for themselves.

It provides general information on the decision-making process to be followed (in part one), but also provides specific information (in part two) about decisions about CANH in:

- patients with progressive neurodegenerative conditions;
- patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury;
- previously healthy patients who are in a vegetative state (VS) or minimally conscious state (MCS) following a sudden-onset brain injury.

You are encouraged to read both the general information on the decision-making process to be followed, as well as the specific information covering the category of patients you are treating.

The guidance does **not** cover the following decisions about CANH:

- patients for whom starting or continuing CANH is not clinically indicated;
- patients who are expected to die within hours or days;
- patients for whom a decision not to start, or to stop providing, CANH is part of a broader decision about life-sustaining treatment.

A proportionate approach to decision-making

In this guidance, the extent of the safeguards, documentation and external scrutiny recommended is proportionate to the consequences of the decision. The greater the severity of the consequences of the decision, the greater the degree of scrutiny that will be required.

Key factors that determine the appropriate level of scrutiny required will include:

1. the prognosis (in terms of the potential for future recovery or deterioration and the expected survival time) and the level of certainty with which this can be predicted; and
2. the impact of making the "wrong" decision for an individual patient, resulting either in CANH being withdrawn too soon – thus depriving the patient of an opportunity to live a life they would value – or of it being continued for too long – forcing the individual to continue a life that they would not have wanted.

PART ONE: GENERAL GUIDANCE FOR ALL DECISIONS ABOUT CLINICALLY-ASSISTED NUTRITION AND HYDRATION (CANH)

Decision-making for patients who lack capacity

See sections 2.1 – 2.5. of the guidance – the decision-making process

The Mental Capacity Act 2005 sets out the statutory framework for decision-making for patients who lack capacity.

Any act done, or decision made, for a patient who lacks capacity must be done or made in his or her best interests. This means that a decision-maker must consider all relevant circumstances, including any wishes, feelings, beliefs and values of the patient in making their decision.

Who is the decision-maker?

Best interests assessments are the responsibility of everyone involved in caring for the patient. It is important, however, to make sure that it is clearly established who has overall responsibility for making the decision about whether CANH should be provided or continued, and that this is communicated to those close to the patient and everyone else involved in his or her care.

The patient through an advance decision to refuse treatment (ADRT)

An ADRT must be valid and applicable to the patient's current clinical situation.

A health and welfare attorney

If the patient has made a lasting power of attorney (LPA) with the power to consent to or refuse life-sustaining treatment, and it has been registered with the Office of the Public Guardian, the health and welfare attorney is the decision-maker. They must act in the patient's best interests.

The best interests decision-maker

Where the patient does not have an ADRT or LPA, decisions must be made by the clinical team on the patient's behalf, based on his or her best interests. In practice, ultimate responsibility will normally fall to the individual with overall responsibility for the patient's care, e.g. the senior consultant or GP.

The Court of Protection

If there is doubt, uncertainty or disagreement about whether a course of action is in the best interests of the patient, the Court of Protection should be asked to decide.

Legally, family members cannot give consent to, or refuse treatment on the patient's behalf unless they have been formally appointed as a health and welfare attorney. Although not the decision-maker, they do have a crucial role in providing information about the patient as part of the best interests assessment.

Health professionals with a conscientious objection

Health professionals should ensure that their personal views do not influence the way in which clinical information is presented or affect their attitude towards those, including family members, who do not share their views.

A health professional who is unable, for reasons of personal beliefs, to make or implement a best interests decision to withdraw, or to continue, CANH should recognise this as a potential conflict of interest and hand over this aspect of the patient's care to a colleague.

Clinical assessments

Doctors should provide unbiased, honest and realistic information about the level of recovery that can be expected, and avoid raising expectations or giving false hope to those close to the patient.

Accurate prognosis can be difficult, and is full of uncertainty. That uncertainty should be explained to those close to the patient, and will also need to be considered as part of the best interests assessment.

The following questions, articulated in the legal case of *PL*, can be helpful in framing the assessments needed for decision-making.

- What is his/her current condition?
- What is the quality of his/her life at present (from his or her perspective)?
- What is his/her awareness of the world around him/her?
- Is there any (or any significant) enjoyment in his/her life? If so, how can this be maximised?
- Does he/she experience pain and/or distress and if so, is it appropriately managed?
- What is his/her prognosis, if CANH were to be continued?
- Is there any real prospect of recovery of any functions or improvement to a quality of life that he/she would value?
- What is the prognosis if CANH were to be discontinued?
- What end-of-life care will be provided following withdrawal?

Where there is reasonable doubt about the diagnosis or prognosis, or where the healthcare team has limited experience of the condition in question, advice should be sought from another experienced senior clinician before a decision about CANH is made.

Where previously healthy patients are in VS or MCS following a sudden-onset brain injury, there are some additional clinical considerations. For more information see section 5 of the guidance document.

Best interests assessments

See Appendix One of the guidance – Practical guidance for best interests decision-making

Decision-makers must start from the strong presumption that it is in a patient's best interests to receive life-sustaining treatment, but that presumption can be rebutted if there is clear evidence that a patient would not want CANH provided in the circumstances that have arisen.

The purpose of a best interests assessment is to consider matters from the patient's point of view. This means that the person must be at the centre of everyone's thoughts and actions – the focus must be on making the decision that is right for that individual. What is right for one person won't be right for another.

Who should be involved?

Even though they lack capacity, some patients may have some level of awareness. If they are able to contribute to the decision-making process in any way, they must be supported to do so.

The Mental Capacity Act states that the following people should be consulted in order to ascertain any views, wishes, values, or beliefs of the patient:

1. anyone named by the patient as someone to be consulted;
2. anyone "engaged in caring for the patient or interested in his or her welfare"; and
3. a court-appointed deputy (if there is one).

if the patient has no family or other person able to represent their views or, for whatever reason, it is not considered appropriate to consult those who are close to the patient, an Independent Mental Capacity Advocate (IMCA) must be instructed.

The second of the categories above is potentially very broad, and may include:

- Family members
- Friends
- Members of the healthcare team caring for the patient (i.e. doctors, nurses, therapists)
- Carers (paid or unpaid)
- Anyone else who might have relevant information about the patient (e.g. neighbours, colleagues)

It is sometimes difficult for those consulted to separate their own views and preferences from those of the patient, or they might have ulterior motives for the views they express. Seeking views from a number of different people and seeking examples or evidence to back up statements made is a good way of testing the information provided and ensuring that the decision is focused on what is in the best interests of the patient.

It is also essential that decisions are not influenced by the decision-maker's personal views about the quality of life of patients in this situation – either positive or negative.

The central point to keep in mind, throughout the decision-making process, is that the decision is about what is in the best interests of the **individual patient**, not what is best for those who are close to them, what most people in their situation would want or what is best for the family, the care team, or the providers or funders of care.

The impact of the decision on others is a relevant factor to consider, but only to the extent that the patient him or herself would have taken this into account.

What type of information?

Decision-makers should accumulate enough information to form a clear view as to what the patient would have wanted if he or she had retained the capacity to make a decision. This can include:

Clinical information

- the patient's condition, diagnosis and prognosis, and any uncertainty around this;
- the level of awareness of their current condition and environment;
- realistic information about what the future holds for the patient, including the long-term care options available;
- how far the patient's condition will affect activities and interests important to them (e.g. the ability to interact or communicate with loved ones; the ability to get pleasure from listening to music or watching television);
- what is likely to happen following the withdrawal of CANH;
- how withdrawal would be managed and what end-of-life care would be provided.

Personal information

- what was the patient like before becoming ill?
- what was their job, their hobbies, their likes and dislikes?
- what was important to them?
- did they do or say anything which indicates how they might feel about their current situation?
- did they write anything down? (e.g., diaries, letters, e-mails, social media posts)
- did they have any religious, spiritual or moral beliefs?
- would the patient have wanted CANH provided or continued? Why or why not?

It can be difficult for those being consulted to articulate all of this information in a short space of time. It can be helpful to ask those who are providing information to do so in writing. In some cases, ascertaining this type of information will not be problematic. In others, there will be no evidence about the individual's views because they had never considered being in their current situation. Evidence about aspects of the patient's personality, character, and beliefs that give a clear indication of what their views would have been should be considered, but decision-makers must evaluate the quality of the evidence being provided. Apparently passing comments (e.g. "shoot me if I ever get like that") should be evaluated to determine whether they are simply throwaway remarks or whether, in context, they convey more settled wishes. Decision-makers should not speculate about the individual's views *might* have been in the absence of reliable evidence.

How should the information be used?

The decision that needs to be made is whether the information about the patient is strong enough to rebut the strong presumption in favour of prolonging life. All information about the patient, both clinical and personal, has to be considered and assessed to decide what is in the best interests of the patient, taking into account the balance of current positive and negative experiences.

The amount and strength of evidence required to rebut the strong presumption in favour of prolonging life will depend on the individual circumstances of each case. In every case the benefits and harms of each approach must be weighed up in the light of what is known about the patient's likely wishes.

Best interests meetings

Although not a requirement of the Mental Capacity Act, it is good practice to convene a formal best interests meeting to share and exchange information and to discuss how the patient's best interests can be met. It is important to remember that best interests decision-making is part of a process rather than a single determinative event – and best interests meetings should be viewed as one step in that process.

It will normally be the responsibility of the decision-maker to set up a best interests meeting, but they can be requested by anyone. Careful planning – including thinking about who should be there and how much time will be necessary – can help maximise the effectiveness of a best interests meeting.

Minutes of the best interests meeting should be taken and shared with all parties to allow them the opportunity to confirm what was said. In addition, it may be helpful to make a digital recording of the meeting and to share a copy with all involved.

Recording best interests decisions

A detailed record of the best interests assessment process should be kept as part of the medical record, in a form that is easily accessible for review and audit. You can find a model proforma to assist with this at the end of this document.

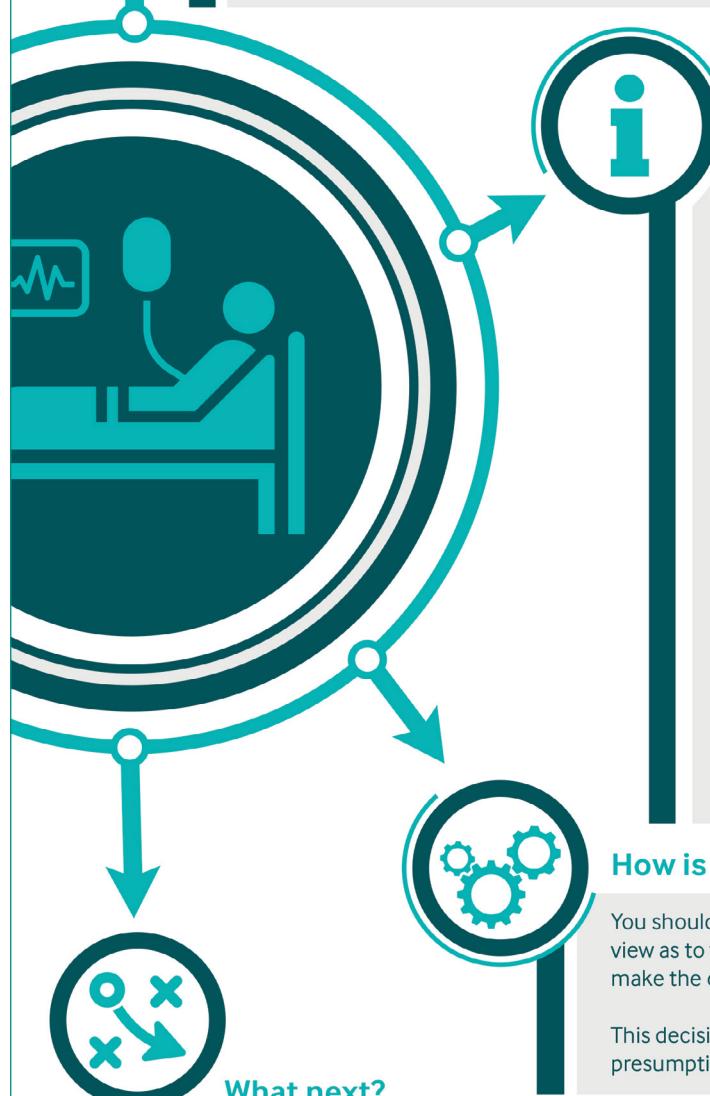
Making decisions about clinically-assisted nutrition and hydration (CANH) in England and Wales for patients who lack capacity – what is in the patient’s best interests?

Who should I involve?

The Mental Capacity Act 2005 states that “anyone engaged in caring for the patient or interested in his welfare” should be consulted. This could include:

- Family members and friends
- Members of the healthcare team caring for the patient (i.e., doctors, nurses, therapists)
- Carers (paid or unpaid)
- Anyone else who might have information about the patient (e.g. neighbours, colleagues)
- Court appointed deputies (if applicable)
- If there is no one who can represent the views of the patient, an independent mental capacity advocate (IMCA)

N.B. If there is a lasting power of attorney (LPA) with appropriate powers, that person will be the decision-maker.



What type of information should I consider?

Clinical

- What is the patient’s current condition?
- What is their prognosis? What is the level of uncertainty around this?
- How aware are they of their current condition and their environment?
- How will their condition affect how they participate in activities or interests that are important to them?
- What will happen if CANH is continued? What will their life be like?
- What will happen if CANH is withdrawn? What end-of-life care will be provided if it is?

Personal

- What was the patient like before becoming ill?
- What was their job? What were their hobbies?
- What did they like or dislike? What was important to them?
- Have they ever said or done anything which shows how they might feel about their current situation?
- Did they write anything down which shows how they might feel (e.g. in a diary, in letters or e-mails, on social media)?
- Did they have any religious, spiritual, or moral beliefs?
- Would the patient have wanted CANH provided or continued? Why or why not?

How is it used?

You should accumulate enough information so you can form a clear view as to what the patient would have wanted if he or she were able to make the decision.

This decision must always be made against the backdrop of a strong presumption that it will be in the patient’s best interests to prolong life.

What next?

Document the decision, and the process followed - including your thoughts and analysis, and the discussions you had, with whom. You should ensure a plan is in place to implement the decision. If the decision is to withdraw CANH, this will include an end-of-life care plan and seeking a second opinion. If the decision is to continue CANH, a date should be set for review.

For more detailed information and guidance:

www.bma.org.uk/CANH

Second opinions

See section 2.8 of the guidance – second opinions

In line with GMC guidance, doctors should seek a second clinical opinion where it is proposed to stop or not start CANH and the patient is not within hours or days of death.

Your CCG, Health Board, or hospital should be able to assist with identifying and appointing an appropriate individual to undertake a second opinion.

The second-opinion clinician should:

- have relevant clinical knowledge and experience;
- have experience of best interests decision-making;
- not be part of the current treating team (for previously healthy patients in VS or MCS following a sudden-onset brain injury, wherever possible this should be someone who has had no prior involvement in the patient's care); and
- be able to act independently.

Independent scrutiny of decisions not to provide, or to stop, CANH in adults who lack capacity

Following clinical, and documented best interests assessments, there is agreement between the clinical team and those engaged in caring for the patient or interested in his or her welfare, that CANH is not in the patient's best interests

Patients with neurodegenerative conditions

Second clinical opinion:*

- does not need to be from a separate department but this may be advisable where the patient could go on living for a number of years;
- identified by the CCG/ Health Board, if the patient is in the community.

Internal and external review and audit.

Refer to section 3

Patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury

Second clinical opinion:*

- external to the treating department, if the patient is in hospital; or
- identified by the CCG/ Health Board, if the patient is in the community.

Internal and external review and audit.

Refer to section 4

Previously healthy patients in VS or MCS following sudden-onset brain injury

Second clinical opinion:*

- must be from an expert PDOC physician, unless treating clinician is a PDOC physician;
- as far as possible, external to the organisation caring for the patient;
- wherever possible someone who has had no prior involvement with the patient's care;
- identified by the CCG/ Health Board, if the patient is in the community.

Internal and external review and audit.

National data collection and clinical outcome review.

Refer to section 5

*All persons providing a second clinical opinion should: have relevant clinical knowledge and experience; have experience of best interests decision-making; not be part of the current treating team; and be able to act independently. They do not necessarily have to be a doctor and could be, for example, a nurse or a consultant allied health professional with the relevant skills and experience.

Second-opinion clinicians should:

- examine the patient and review the medical records;
- write a report summarising the review they have undertaken; and
- outline their own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient.

Where there is disagreement or uncertainty

See section 2.9 – managing disagreement or uncertainty

Where there is uncertainty or disagreement about whether CANH is in the patient's best interests, steps should be taken to resolve it promptly. You may wish to think about some of the following steps:

- obtaining a further clinical opinion;
- holding a case conference; or
- using medical mediation services.

If agreement is not reached, or there is still uncertainty about the patient's best interests, legal advice should be sought and an application to the Court of Protection should be made, if necessary. This should be initiated and funded by the CCG/Trust/Health Board responsible for commissioning or providing the patient's care.

Where those close to the patient disagree with the view of best interests taken by the decision-maker, they should be provided with clear information about the process to follow to challenge the decision and directed to sources of help or support.

Record keeping and reviewing decisions

See section 2.11 – record-keeping

A detailed record should be kept of the decision-making process and the decision reached, in a format that can be easily extracted from the rest of the medical record. This should include the following information:

- the name and position of the decision-maker;
- the date on which the decision was made (and if CANH is continued, when the decision should be reviewed);
- how the decision about the patient's best interests was reached;
- what the reasons for reaching the decision were;
- who was consulted to help work out best interests; and
- what particular factors were taken into account.

To assist with this, a model proforma for recording supporting information for decisions to withdraw CANH from patients in VS or MCS has been developed as part of the process of developing this guidance. This can be accessed via the BMA website.

More detailed guidance about what information should be recorded in specific circumstances is provided in Part 2 of the main guidance.

Decisions that it is in the patient's best interests to provide CANH must be kept under review to ensure that this continues to be the case. Decisions should be reviewed:

- every 6 months; or
- 12 months where the patient has been in a stable condition over a long period of time; or
- more frequently if the clinical situation has changed significantly or if information comes to light that might affect the original decision.

It is the responsibility of the individual with overall responsibility for the patient's care to ensure that reviews take place.

Governance and audit

Decisions about CANH must be subject to regular review and audit as part of internal governance and external regulatory review procedures. This is to ensure that decisions have been made in line with the MCA and good practice guidance, and to provide reassurance about the way in which these decisions are being made.

This includes internal governance processes, such as the "Learning from Deaths" agenda in England, or the "Universal Mortality Review" (UMR) in Wales; external regulatory review by bodies such as the Care Quality Commission (CQC), Healthcare Inspectorate Wales (HIW), and Care Inspectorate Wales (CIW); and contributing to any national data collection and audit processes.

PART TWO: GUIDANCE FOR SPECIFIC SCENARIOS

Decisions about clinically-assisted nutrition and hydration (CANH) in patients with a progressive neurodegenerative condition

See section 3 of the guidance

This guidance covers those patients who have a recognised neurodegenerative condition that is likely, eventually, to result in the patient being unable to take sufficient nutrition orally. This includes conditions such as Parkinson's or Huntington's disease. It also covers patients with dementia, in the limited circumstances in which CANH is clinically indicated and where a decision is needed about whether to continue CANH that has already been started.

Due to the degenerative nature of their condition, these patients are on an expected downward trajectory and will inevitably die, usually as a result of their underlying condition(s), although perhaps not imminently. Some of these patients could, potentially, go on living for many years.

Clinical assessments

Decisions to start CANH in patients with neurodegenerative conditions should be made in line with the most up-to-date clinical guidelines.

In some clinical situations, such as in patients with dementia, CANH is not usually clinically indicated where inadequate intake of nutrition is related to the advancing disease itself. It may be indicated in some cases, however, where it is provided for a relatively short period for a potentially reversible comorbidity, such as acute infection. In these cases, decisions should be made in line with this guidance.

Clinicians should share the following information with those close to the patient:

- What is the standard clinical progression of the disease?
- What is the current condition of the patient and how does this affect their experiences?
- What is their estimated life expectancy?

Best interests assessments

In these patients, there is no prospect of recovery and they are on a recognised downwards trajectory, but at the time capacity is lost some patients could continue to live for a number of years. This means that the risks of making the "wrong" decision for that individual – whether that is to continue or to withdraw CANH – are very significant.

Where this is the case an extensive best interests assessment will be appropriate with formal best interests meetings conducted to discuss whether CANH continues to be in the patient's best interests and whether there may come a stage at which the patient would want CANH to be stopped.

Within this group, some patients will have a level of awareness and every effort should be made to communicate with these patients in order to glean any information they are able to contribute to the best interests assessment.

Second opinions

A second opinion should be sought from a senior independent clinician who is not part of the current treating team.

This person should have relevant expertise and be sufficiently independent from the treating team but does not need to be from a separate department.

In some cases, for example where the patient could potentially survive for a number of years, there may be benefit in increasing the level of scrutiny by seeking a second opinion from a clinician from another department or hospital.

Decisions about clinically-assisted nutrition and hydration (CANH) in patients who have multiple comorbidities or frailty which is likely to shorten life expectancy, and have suffered a brain injury

See section 4 of the guidance

This category covers patients with a sudden-onset or rapidly progressing brain injury where the patient has multiple comorbidities or frailty (either pre-existing or as a result of the incident that led to the brain injury) which is also likely to shorten life expectancy. This includes patients who have suffered a catastrophic stroke or traumatic or hypoxic brain injury. It may also include those with other conditions when, despite treatment or when treatment is not possible, there is extensive brain injury resulting in long-term neurological deficit e.g. CNS infections, subdural haemorrhage, or complications following neurosurgery.

Some may have no awareness at all, some may have limited awareness, while others may be fully conscious but may still have profound cognitive/communicative and/or physical impairment rendering them incapable of making or communicating decisions about CANH.

The diagnosis, prognosis and age range for patients in this group will also vary widely, with life expectancy ranging from weeks to several years. Patients within this group may be clinically stable, or currently on an upward trajectory but with limited potential for further recovery, or they may be on a downward trajectory as a result of their multiple morbidities or general frailty.

Clinical assessments

Due to their comorbidities or frailty, it is very unlikely to be appropriate to admit these patients to a specialist unit for investigations (as is recommended for those in the category below).

It will still be important, however, for the clinical team caring for the patient to carry out some assessment of the patient's level of awareness, and the following factors will be relevant to that assessment:

- the extent to which the patient is able to experience pain or pleasure;
- the extent to which the patient is aware of self and environment; and
- the extent to which the patient has the ability to interact with others.

These are all likely to have a bearing on the individual's perception of their quality of life.

Best interests assessments

The nature of the best interests assessments will vary considerably within this category but the guiding principles of prognosis and certainty, and the consequences of making the “wrong” decision, should be used to determine the appropriate investigations that should be performed:

- where patients have a life-expectancy of a few months or less: less extensive best interests investigations will be appropriate;
- where patients could survive for a significant period of time: a more extensive best interests assessment will be appropriate with formal best interests meetings conducted to discuss whether CANH is, or continues to be, in the patient’s best interests and whether there may come a stage at which the patient would want CANH to be stopped.
- The patient’s level of awareness will also be a relevant factor in determining the appropriate level of scrutiny. Within this category, some patients, although lacking capacity, will have a level of awareness and every effort should be made to communicate with them in order to glean any information they are able to contribute to the best interests assessment.

Second opinions

A second opinion should be sought from a senior clinician from a different department from the treating team but who could be from the same hospital.

Decisions about clinically-assisted nutrition and hydration (CANH) in previously healthy patients in VS or MCS following a sudden-onset brain injury

See section 5 of the guidance

This covers patients who were previously healthy (or have ongoing medical conditions that are effectively managed), and suffer a sudden-onset profound brain injury resulting, for example, from trauma, stroke or hypoxia. This is the patient group that is covered by the Royal College of Physicians’ (RCP) clinical guidelines for prolonged disorders of consciousness (PDOC).

According to these guidelines, patients in this group who remain in PDOC for four weeks after severe brain injury should go through a formal PDOC assessment. Some will emerge into consciousness although with varying degrees of cognitive/communicative and/or physical impairment.

Other patients will remain in a disorder of consciousness and may go on to be diagnosed as being in a vegetative state (VS) or minimally conscious state (MCS). Many of these patients are relatively young and fit and could potentially go on living for many years or possibly decades. These patients are usually clinically stable or may currently be on an upward trajectory but the prognosis in terms of the “best case scenario” for functional recovery is poor.

Clinical assessments

Where patients are in a prolonged disorder of consciousness (i.e. for longer than four weeks) following a sudden-onset brain injury, providing accurate prognostic information is a very important part of the decision-making process.

In these cases, the RCP's PDOC guidelines should be followed with regard to the assessments needed in order to obtain information about the patient's level of responsiveness and awareness; and, in those who may still change, to establish any trajectory of change and prognosis in terms of recovery of consciousness and/or return to a quality of life that the patient would value. Assessment must be carried out by professionals with appropriate training in this field.

The perceived importance of obtaining a precise and definitive diagnosis has reduced over time, as it is increasingly recognised, by clinicians and the courts, that drawing a firm distinction between VS and MCS is often artificial and unnecessary.

In practice, when assessing best interests, information about the patient's current condition and prognosis for functional recovery and the level of certainty with which these can be assessed is often more important than achieving a precise diagnosis.

Best interests assessments

Best interests assessments should take into consideration:

- the potential for recovery: the likely final level of consciousness and autonomy for activities and participation (which will be dependent on the trajectory for recovery, the severity and type of brain injury and the time since onset);
- the patient's perceived quality of life: the patient's own likely view of whether a quality of life at that level would be acceptable; and
- predicted life expectancy: the period of time for which the patient would live with the benefits or harms of continued CANH.

Given that, in this group, the patient could potentially live for many years if CANH was continued, an extensive and formal best interests process should be followed and attempts must be made to identify all relevant people to be consulted about best interests decisions.

It is not necessary to wait until a formal diagnosis has been made, or patients have reached their full potential for improvement, before beginning to discuss their likely views about continuing CANH. Beginning those discussions does not mean that a decision must be made imminently but will ensure that those close to the patient are aware of the options available and can begin to think about what the patient would want. The RCP guidelines recommend that best interests discussions should begin within four weeks of the original injury.

Sometimes it will be clear that the "best case scenario" in terms of recovery would not provide a quality of life that would be acceptable to the patient. Where there is evidence that this is the case, it would not be in the patient's best interests (and would therefore be contrary to the MCA) to continue treatment until that level of recovery has been achieved and all possible clinical assessments have been carried out.

Second opinions

A decision to stop CANH should be subject to formal review by a second opinion clinician.

- If the treating consultant is a specialist PDOC physician (as set out in electronic annex 2b of the RCP guidelines), the second clinician could, but does not need to be another expert PDOC specialist;
- If the treating consultant is not a PDOC physician the second opinion clinician must be.

So far as is reasonably practical in the circumstances of the case, the second opinion clinician should be external to the organisation caring for the patient and should have no prior involvement in the patient's care. In some cases this will not be possible, and where this is the case, the reasons for this should be clearly documented in the medical records.

The second-opinion clinician should provide a detailed report setting out the details of his or her review and his or her judgement as to whether the decision to withdraw CANH is in the best interests of the patient.

Record-keeping

A model proforma for collecting information about decisions to withdraw CANH has been developed as part of the process of developing this guidance. This can be accessed via the BMA website. This sets out the assessments that are needed in order to establish a high level of diagnostic and prognostic accuracy and provides a way of ensuring that the proper process has been followed.

Checklist of evidence for best interests decision-making in relation to clinically-assisted nutrition and hydration (CANH)

This checklist summarises the requirements for best interests decision-making in relation to CANH. Once completed, it should be held on the medical record, accompanied by:

- any written information provided by family/friends/others with an interest in the patient's welfare;*
- records of the best interests meetings;
- a description of the ascertained wishes and feelings that led to the conclusion reached; and
- if there is disagreement about the patient's best interests, the steps that are being taken to resolve the disagreement.

Copies of this form can be downloaded from www.bma.org.uk/CANH

*“Family/friends” is used in this document as shorthand to refer to all those who are engaged in caring for the patient or interested in his or her welfare, whether or not related to the patient.

Patient Details	Treating Team
Name:	Clinician in charge of patient's care:
DOB:	Specialty:
Ref/NHS no:	

Minimum requirement	Detail/comment (optional)	Completed and Signed/ Date of signing
1. PRE-STATEDED WISHES/PROXY DECISION-MAKING Is there a valid and applicable ADRT with respect to life sustaining treatment? Is there a health and welfare attorney authorised to make decisions regarding CANH?	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>	
2. BEST INTERESTS DECISION-MAKING MEETINGS Have best interests decision-making meetings been conducted with the relevant people including family/friends and any health and welfare attorney/deputy?	Yes <input type="checkbox"/> No <input type="checkbox"/> Dates of meetings:	
Were the family members/friends made aware of: – the patient's likely prognosis for recovery (or range of possible outcomes); and – the patient's estimated life expectancy if CANH is continued?	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>	
Have the best interests discussions taken into account the patient's likely wishes so far as these can be known?	Yes <input type="checkbox"/> No <input type="checkbox"/>	

3.	<p>FAMILY MEMBERS/FRIENDS INVOLVED</p> <p>The following family and friends have been involved in best interests decision-making:</p> <p>(a) Name..... Relationship</p> <p>(b) Name..... Relationship</p> <p>(c) Name..... Relationship</p> <p>(d) Name..... Relationship</p> <p>(e) Name..... Relationship</p> <p>(f) Name..... Relationship</p>		
<p>Have all the relevant family members and friends been involved? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Are there key family members/friends who have not been consulted? If yes, why were they not consulted? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, is anyone likely to hold a different view regarding the patient's best interests with respect to CANH? Yes <input type="checkbox"/> No <input type="checkbox"/></p>			
4.	<p>INVOLVEMENT OF CARE TEAM</p> <p>The following members of the care team have been involved in best interest decision-making:</p> <p>(a) Name..... Role</p> <p>(b) Name..... Role</p> <p>(c) Name..... Role</p> <p>(d) Name..... Role</p> <p>(e) Name..... Role</p> <p>(f) Name..... Role</p>		
5.	<p>AGREEMENT ON BEST INTERESTS</p> <p>Are the clinical team and family members/friends in agreement that it is in the patient's best interests to give, restart or continue CANH?</p> <p>If yes, date for review: OR</p> <p>Are the clinical team and family members/friends in agreement that it is not in the patient's best interests to give, restart or continue CANH?</p> <p>If there is no agreement, give information about what action is being taken.</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
	<p>Completed by: (Print name and signature)</p> <p>Position:</p>	<p>Date</p>	

Useful Links

- British Medical Association and Royal College of Physicians (2018) Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: guidance for decision-making in England and Wales – www.bma.org.uk/CANH
- Royal College of Physicians (2015) Prolonged disorders of consciousness: national clinical guidelines – <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>
- healthtalk.org – Family Experiences of Vegetative and Minimally Conscious States – <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics>
- Coma and Disorders of Consciousness Research Centre – www.cdoc.org.uk

