

Decisions about clinically-
assisted nutrition and
hydration (CANH) –
information for healthcare
providers, funders and
managers



Royal College
of Physicians



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Decisions about whether to start, continue, or stop clinically-assisted nutrition and hydration (CANH) in patients who are not close to death are among some of the most legally, ethically, and professionally complex decisions doctors will make. To support doctors in making these decisions, the BMA has produced guidance jointly with the Royal College of Physicians (RCP) about decisions to start, re-start, continue or withdraw CANH. This has been endorsed by the General Medical Council (GMC).

Guidance can only improve practice if it is known about and there is a commitment to making it work, including an understanding of the legal responsibilities of all involved. This document is aimed at Trusts, Health Boards, Clinical Commissioning Groups (CCGs), independent healthcare providers, and anyone else involved in commissioning or providing healthcare services to patients receiving, or who may benefit from, CANH. It provides some key information about decisions about CANH and suggests some practical steps that can be taken to help healthcare professionals to follow this guidance – thus ensuring high-quality care for patients, and open and transparent decision-making that preserves public confidence.

Key principles in decision-making

The following is a brief summary of the law, regulation, and best practice as it currently stands in making decisions about CANH. More detailed information can be found in Part One of the full BMA/RCP guidance.

- CANH is a form of medical treatment, which, like all other forms of medical treatment, should only be provided when it is in a patient’s best interests.
- Health professionals are not required to offer treatments that they consider to be clinically inappropriate.^{1,2}
- Decision-makers should 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.
- All decisions must be made in accordance with the Mental Capacity Act 2005, which includes consulting with those close to the patient to reach a decision that is in the patient’s best interests.
- The Supreme Court has confirmed that there is no requirement for decisions about the withdrawal of CANH to be approved by the court, as long as there is agreement as to what is in the best interests of the patient, the provisions of the Mental Capacity Act have been followed and the relevant professional guidance has been observed.³
- 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.⁴
- the withdrawal of CANH does not mean the withdrawal of all other care or symptom relief, which will continue to be provided through end-of-life care.

1 R (on the application of Burke) v General Medical Council [2005] 2 FLR 1223. <https://www.bailii.org/ew/cases/EWCA/Civ/2005/1003.html>

2 General Medical Council (2010) Treatment and care towards the end of life: good practice in decision-making, GMC: London. Paras 14-16.

3 An NHS Trust v Y [2018] UKSC 46. <https://www.bailii.org/uk/cases/UKSC/2018/46.html>

4 General Medical Council (2010) Treatment and care towards the end of life: good practice in decision-making, GMC: London. Para 121.

CANH should not be provided or continued simply because to do so is easier than undertaking a best interests assessment and making a decision on that basis. To do so would be contrary to the Mental Capacity Act 2005.

The crucial point for doctors is that all decisions about CANH must follow careful consideration of the individual circumstances of the patient, and focus on reaching the decision that is right for that individual. The importance of having a formal process and detailed documentation of best interests decision-making must be a strong and consistent message to all those who are involved in decision-making in relation to CANH.

The role of Trusts, Health Boards and CCGs

Education and training

Whilst most establishments and/or organisations provide training on the Mental Capacity Act (MCA), it is clear that many patients continue to receive CANH “by default”, sometimes for many years or even decades, with no assessment of whether this treatment continues to be in their best interests.

A specific focus of continuing training should be on the need for regular best interests assessments and ensuring that these assessments are focused on the individual patient and his or her wishes and feelings, beliefs and values in order to reflect good practice and the case law discussed in the BMA/RCP guidance. The importance of this training should be emphasised, both in terms of providing high-quality patient care and for ensuring that health professionals are able to rely on the protection from liability provided by section 5 of the MCA and are not at risk of regulatory sanctions.

Given the nature of decisions about CANH, it is inevitable that assessments and decisions will fall to senior clinicians. It will therefore be especially important for medical students and doctors in training to receive exposure to the clinical care of patients receiving CANH, so that they can develop the skills and expertise they will need to make decisions in the future.

Practical and emotional support

The BMA/RCP guidance does not underestimate the scale of the task of making decisions about CANH, or the complexities and challenges that come with it. A crucial role for healthcare bodies and managers will be to provide the resources necessary to enable health professionals to follow the guidance. Steps must be taken to ensure that clinicians have sufficient time to carry out proper best interests assessments, mechanisms need to be in place for arranging second clinical opinions without delay and processes must be put in place for internal review and audit. The necessary support and resources also includes ensuring that there is personal and professional support for decision-makers who need support to build up their expertise and confidence.

There is also a role for healthcare bodies and managers in providing emotional support for doctors. Research carried out by the BMA⁵ has demonstrated that, despite their professional training, caring for patients who are dying can have a significant emotional impact on members of the healthcare team that often goes unrecognised. Decisions about giving, continuing or stopping CANH are difficult and can be very stressful for all concerned. Trusts, Health Boards and CCGs should ensure that both formal and informal support mechanisms are available to all staff involved in making and implementing, or who are affected by, these decisions – both during the decision-making process and after decisions have been made. It is important that this extends beyond the senior staff involved with making the decision itself; other team members who have spent a considerable amount of time with the patient may find these decisions very difficult and may also need support.

5 British Medical Association (2016) End-of-life care and physician-assisted dying. Vol 2 – Public dialogue research and Vol 3 – Reflections and recommendations. Available at: www.bma.org.uk/endoflifecare.

Many families who have been involved in the process of decision-making about CANH for their loved ones have highlighted their need for information and support. Healthcare providers should consider the type of information and assistance patients and their families might need – e.g., information about best interests decision-making, or counselling or other support services – and explore the best ways of making this information available, or signposting.

What steps can be taken to support widespread implementation of the guidance?

Each individual hospital, Trust, Health Board and CCG should assess the steps they need to take within their establishment to support implementation of this guidance. An implementation plan should be developed. In some cases, there may be benefit in joining with other establishments and/or organisations to develop a local or regional approach. There are a variety of ways in which these responsibilities can be fulfilled, including the following.

- Identifying those individuals, teams and departments, that are most likely to need to make decisions about CANH and ensuring that they know where and how to access guidance when they need it.
- Setting up specific training courses on decisions about CANH, or adding components around decision-making in CANH to existing training.
- Modifying existing training on the Mental Capacity Act to increase the focus on patient-centred best interests decision-making as set out in the guidance.
- Where named consultants change frequently due to staff rotation, setting up a system for ensuring that there is a designated decision-maker for each patient, to ensure that decisions are not delayed due to staff changes.
- Ensuring that there is one identified individual in each CCG/Health Board who takes responsibility for providing advice and support to those making decisions about CANH in the community.
- Setting up a database of individuals willing and qualified to carry out second opinions within the CCG/Health Board area, and providing funding for this, to enable GPs providing care to patients at home or in nursing or care homes, to fulfil their obligations. Some CCGs/Health Boards may wish to group together to do this on a regional basis. Some Trusts may also find it helpful to maintain their own, or a regional, database of clinicians qualified and willing to provide second opinions. Where there are a limited number of people with the relevant expertise, such as clinicians who meet the criteria for providing second opinions for patients in a prolonged disorder of consciousness (PDOC), a national database may need to be considered.
- 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 can comply with the guidance (e.g. for ensuring training is provided, putting arrangements in place for obtaining second opinions, ensuring that regular best interests assessments are taking place, review and audit of relevant decisions etc).
- Identifying a senior clinician with experience of best interests decision-making in relation to CANH who is familiar with the BMA/RCP guidance to provide advice and support to others in the local area as required.

- Setting up a local or regional multi-disciplinary special interest group to support the implementation and use of the guidance, to:
 - liaise with clinical management to address any challenges health professionals are experiencing (such as delays in arranging second opinions or specialist advice);
 - liaise with those responsible for implementing the “Learning from Deaths” agenda⁶ (in England) or the “Universal Mortality Review” (in Wales)⁷ to ensure that decisions to withdraw CANH are subject to internal audit and review and are consistently monitored;
 - provide advice, support and guidance on decision-making in individual cases where requested (including to GPs providing care to patients in community settings); and
 - reflect on challenging cases and use them as a basis for shared learning.
- Identifying an individual who is familiar with the guidance and the process that needs to be followed to:
 - help families to find their way through the process;
 - arrange the involvement of medical mediation or an independent advocate where appropriate; and
 - advise families how to go forward if they disagree with the best interests decision reached – whether that is to give, continue or to stop CANH.
- Publicising other sources of support, advice and guidance that might be available such as review by a local clinical ethics committee where one exists.
- Identifying one or more members of the in-house legal team or other legal advisers, who develop special expertise and familiarity with the guidance and the relevant legal process. They should be able to respond quickly and authoritatively to questions from the clinical team about the process to be followed and to ensure that where court approval is required, the application is initiated and progressed without unnecessary delay.
- Setting up mechanisms for internal review of cases where CANH was withdrawn from patients covered by this guidance. In England this would form part of the “Learning from Deaths” agenda, and in Wales, the “Universal Mortality Review”. The aim of such review is to ensure that the appropriate process was followed, including best interests assessments and second clinical opinions.
- Ensuring that all staff contribute information to any national database and formal clinical outcome review programme that may be established.
- Setting up and publicising the range of formal and informal support mechanisms that are available locally and nationally for those who are involved with making and implementing these decisions, acknowledging that these decisions can be difficult and stressful for all concerned and encouraging staff to utilise these services at an early stage.
- Putting in place a process whereby doctors with a conscientious objection can notify senior colleagues and managers, and for alternative arrangements to be made.

6 National Quality Board (2017) National Guidance on Learning from Deaths. A framework for NHS Trusts and NHS Foundation Trusts on identifying, report, investigating and learning from deaths in care. Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf>.

7 1000 Lives/NHS Wales. Supporting NHS Wales to Develop Mortality Reviews. Available at: <http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/PHW%20Mortality%20Reviews%285%29.pdf>

The role of providers of independent healthcare

Providers of independent healthcare should develop an implementation plan to ensure that all relevant staff are familiar with this guidance, have received appropriate training and that processes are in place to enable them to comply with the requirements as set out in the law, regulation and in the BMA/RCP guidance. A member of the management/governance team should be given specific responsibilities in relation to the guidance, including the following.

- Identifying all staff who will be making, or involved with, decisions about CANH and ensuring they are aware of the guidance and have received appropriate training in best interests decision-making, both generally and in relation to CANH specifically.
- Ensuring there is clarity, for both staff and families, about who is the designated decision-maker for each patient.
- Ensuring that staff have sufficient time and support to carry out the appropriate clinical and best interests assessments.
- Putting procedures in place to ensure that all decisions to provide, or continue, CANH are reviewed on a regular basis.
- Reaching agreement with CCGs or Health Boards about the procedures to be followed in relation to decision-making for patients who are in receipt of continuing healthcare funding.
- Making arrangements for suitably trained and experienced second-opinion clinicians to be available without delay once a decision has been made that CANH is not in a patient's best interests.
- Identifying an individual with expert knowledge of the guidance who is able to provide personal and professional advice and support to decision-makers and other staff involved with decisions about CANH.
- Ensuring that families are supported through the decision-making process, are appropriately consulted about all best interests decisions and are aware of the wider support and services that are available to them.
- Putting in place formal arrangements for internal audit and review of decisions about CANH.

In some cases independent providers may wish to establish formal links with other local providers of healthcare (in the independent sector or NHS) as part of a local or regional approach (such as the establishment of local or regional multi-disciplinary special interest groups suggested above).

To assist with the implementation and use of the BMA/RCP guidance, we have developed a range of resources aimed at supporting doctors which can be used in education and training. To find out more, visit the website at www.bma.org.uk/CANH

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