

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

Guidance for decision making in England and Wales

Consultation response form

The British Medical Association (BMA), Royal College of Physicians (RCP) and the General Medical Council (GMC) have been working together to develop professional guidance for health professionals on decisions about clinically-assisted nutrition and hydration (CANH). We are now keen to share this draft guidance with, and to hear from, those who are involved with making, implementing, or who are affected by, these decisions.

When considering the draft guidance, respondents should bear in mind the following points:

- The draft guidance reflects the law in England and Wales as it currently stands. We are aware that a judgment is expected shortly from the Supreme Court and the guidance will be amended to take account of this prior to publication.
- We start from a position of support for the current law that:
 - CANH is a form of medical treatment;
 - treatment should only be provided when it is in the patient's best interests;
 - decision makers should start from the presumption that it is in a patient's best interests to receive life-sustaining treatment but that presumption may be overturned in individual cases;
 - all decisions must be made in accordance with the Mental Capacity Act 2005.

You do not have to answer all of the questions if you prefer to focus on specific issues.

To let us have your views, please complete this form, save it as a word document with your name or organisation as the file name, and return it to CANHconsultation@bma.org.uk by 31 July 2018.

Name:

Organisation (if applicable): Christian Medical Fellowship (CMF)

Please briefly describe your (or your organisation's) professional role/interest in these decisions:

CMF is an association with over 4,500 medically qualified members throughout the UK. CMF has a particular interest in the care of dying persons. A significant proportion of our members are involved in palliative medicine and hospice care, and we recently produced a booklet, entitled Facing Serious Illness,¹ in collaboration with colleagues in the Lawyers' Christian Fellowship (LCF).

¹ <http://www.cmf.org.uk/resources/bookstore/?context=book&id=258>

PART ONE – SCOPE AND CONTENT OF THE GUIDANCE

Scope of the guidance

This guidance covers decisions to start, re-start, continue or stop CANH in adult patients in England and Wales who lack the capacity to make the decision for themselves. It covers patients who could go on living for some time if CANH is provided, where CANH is the primary life-sustaining treatment being provided.

Recognising that there will be some overlap, we have divided this broad spectrum of clinical situations into three broad categories:

- decisions about CANH in the context of degenerative conditions;
- decisions about CANH in patients who have suffered a sudden-onset, or rapidly progressing, brain injury and have multiple co-morbidities or frailty which is likely to impact on life expectancy; and
- decisions about CANH in previously healthy patients who are in a vegetative state (VS) or minimally conscious state (MCS) following a sudden-onset brain injury.

More information about these categories can be found in section 1.4.

Q1: Are the categories of cases covered by the guidance clear? Are there patients for whom a decision about CANH is needed, but who would not fit into any of these categories?
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The guidance helpfully categorises different clinical settings. However, in practice such tidy distinctions are not always possible. Accurate diagnosis of Prolonged Disorders of Consciousness (PDOC) is challenging, requiring special expertise, multidisciplinary assessment and time to minimise the risk of misdiagnosis. There is potential for serious error in establishing both the diagnosis and prognostic trajectory of PDOC, and some evidence that decisions are being taken too quickly or by those with insufficient expertise. The good intention to help users navigate a lengthy document more easily inadvertently increases the likelihood of overly simplistic application

The distinction between VS and MCS is critical to prognosis but is not easily drawn. Close observation over extended time-periods by trained observers is necessary. There is also a radical difference in outcomes in both conditions between acquired brain injury (ABI) due to trauma and that due to hypoxia. Assessment in specialised centres with a multidisciplinary approach will minimise but not remove risk.

People with PDOC can and occasionally do make extraordinary recoveries. Sometimes a diagnosis turns out to have been wrong. One study showed that about half of the cases of Persistent Vegetative State are incorrectly diagnosed.²

52% of traumatic brain injury (TBI) patients in VS at one month regain awareness at 12 months.³
In patients who are in MCS at one month post injury 48% of those with TBI will have emerged

² Andrews K, Murphy L, Munday R & Littlewood C. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *BMJ* 1996;313:13-16.

³ The Multi-Society Task Force on PVS. *Medical Aspects of the Persistent Vegetative State* N Engl J Med 1994; 330:1572-1579. DOI: 10.1056/NEJM199406023302206

from MCS at 12 months.⁴ The RCP PDOC Guidelines recognise that recovery from MCS can occur over very long time periods and so do not recommend MCS is regarded as ‘permanent’ until 3-5 years after onset.

Regrettably there is still only very limited data on outcomes in PDOC. The effect of neuroprotective therapies such as brain cooling, intracranial pressure monitoring and neurosurgical intervention and other positive interventions such as early nutritional replacement and improved nursing care is largely unknown. In the words of the RCP PDOC Guidelines (pp25):

‘At the current time, there is a dearth of information on long-term outcomes for patients with PDOC in the UK’.

The lack of any absolute necessity for external scrutiny from a specialist outside the treating Trust removes a necessary level of safeguarding, in our opinion, and we would suggest it be made an absolute requirement in the guidance.

We agree with Professor Sturman that *‘it is also essential that there be a process of external review and audit of all CANH withdrawal decisions in which all team members and families can have absolute confidence. Such a process should be confidential and non-judgemental. Without such a safeguard local variations in practice driven by individuals’ personal beliefs and institutional cultural factors are very likely to arise particularly in view of the major challenges in diagnosis and prognosis in PDOC cases. This could either put individual patients at risk of unwarranted termination of life or conversely deny patients and families the dignity of ending life in a timely way.’*⁵

Accessibility

Given the broad scope of the guidance, it is necessarily quite long. We have, however, tried to make it as accessible as possible by providing:

- a detailed contents list;
- an executive summary as an aide-memoire;
- a combination of text and key points summary boxes throughout the text;
- a flow chart (figure 2) giving an overview of the decision-making process cross-referencing to more detailed information;
- general guidance for all cases in part 1;
- specific guidance for each of the three categories in part 2, so that readers can focus on the guidance that is most relevant to their patient group; and
- broader information and guidance in the appendices, rather than as part of the main guidance.

⁴ Bruno M-A et al in Schnakers C and Laureys S,(eds). *Coma and disorders of Consciousness*. Springer, London 2012. pp11-23

⁵ Report of Professor Stephen Sturman For the Supreme Court In the Matter of The appeal Re: NHS Trust v Mr Y and Mrs Y. January 2018. Para 3.9

Q2: Do you find the guidance easy to navigate and use? What more can we do, or what could we do differently, to make the guidance more accessible?

The flow chart is helpful but there is a significant risk that inexperienced clinicians, pressed for time, will be tempted by it to reduce what is a nuanced and complex process of assessment to a tick box exercise.

Best interests

Best interests assessments are fundamental to decision making for patients who lack capacity to make a decision about CANH and so form a significant part of the guidance. Information is provided in three separate sections:

- Section 2.5 – which focuses on clarifying who is, and who is not, the decision maker;
- Section 2.7 – which provides an overview of the principles and guidance for best interests assessments in relation to CANH; and
- Appendix 2 – which provides detailed practical guidance for carrying out best interests assessments, including good practice examples and useful tips.

Q3. Is the information and guidance on best interests assessments clear and helpful? How could it be improved? Do you have other good practice examples we could include?

The lack of truly independent scrutiny

The requirement to apply to the Court for permission to withdraw CANH was time-consuming and expensive, and represented a significant disincentive. However, the Court did provide the necessary independent scrutiny, overturning several decisions to remove CANH, and we are concerned that the proposed guidance has insufficient safeguards built into it to compensate for the removal of this scrutiny.

There is very good evidence that marked differences in treatment withdrawal decisions can be seen between physicians in different institutions and in different countries, as detailed in Professor Sturman's report.⁶ He goes on to state: *'These data suggest that local culture and physician attitudes and beliefs have a significant bearing on treatment withdrawal decisions even when there is no absolute conscientious objection to withdrawal of LST. The delegation of CANH withdrawal decisions to local teams whilst in many ways desirable is fraught with the difficulties of coping with the impact of local cultural and individual factors. These local cultural and individual factors could work to either limit access to CANH withdrawal or encourage arbitrary and excessive use of the process. It is particularly the case in health care institutions where teams work intensely and inter-dependently together that the process of CANH withdrawal may be strongly and potentially adversely influenced by the effect of inter-personal relationships. Fear of exclusion, alienation, loss of privilege and denial of opportunity will all figure strongly in the minds of individuals involved in these decisions where there are expressions of strong opinion in either direction. Referral to the court will still be undesirable and so local resolution may not in fact happen appropriately'*.

⁶ *Op Cit.* Paras 3.7.1-3.7.4.

Some process for the external review and audit of all CANH withdrawal decisions we believe is an essential addition to the proposed guidance, if both local teams and families of those with PDOC are to have full confidence in the process.⁷ Further, ongoing audit and peer review of these cases against a national benchmark is essential to ensure uniformity of practice and compliance with existing guidelines. Registration of these cases would also inform ongoing practice over time.

The risk of misunderstanding the incapacitated person's wishes

We are concerned the proposed guidance is at significant risk of misunderstanding what the wishes of a person would have been.

The practice of 'proxy' decision-making is unsafe. In one study,⁸ patient-designated and next-of-kin surrogates incorrectly predicted patients' end-of-life treatment preferences in one third of cases.

Even in situations where advance directives have been made, there is evidence that people change their minds over time. A study of 150 competent persons, with advance directives, concluded that 61% thought there could be times when their best interests would be served if clinicians ignored their directive.⁹

There is also the danger that a conflict of interest may lead to 'best interests' being misrepresented for secondary motives. The need to release or conserve finances may sway the judgment of even the most devoted family towards shortening the remaining days of a loved one.

We are also concerned that the best interests of the individual patient be overshadowed by the best interests of other patients and the health service as a whole. The pressures on hospital or nursing-home beds and finances are ever present. In his witness statement to the Supreme Court, Dr John Chisholm of the British Medical Association made clear the costs of ongoing care for those patients with prolonged disorders of consciousness.¹⁰ In his opinion, to continue to meet these costs 'is to the detriment of patients at a time when the NHS is under considerable strain'.¹¹

People's attitudes and wishes frequently change with the onset of serious illness. It appears that life often seems more precious when it is precarious, and most patients when confronted with a choice between death and seriously disabled life, choose life. A study of 21 people who were paralysed from the neck down and needed ventilators to help them breathe, found that only one person wished that she had been allowed to die. Two were undecided, but the remaining 18 were pleased to be alive.¹² It is reasonable to believe that while healthy, they would have said they would rather die than live in this highly-dependent state.

⁷ *Op Cit*, 3.8

⁸ Shalowitz D, Garrett-Mayer E, Wendler D. The Accuracy of Surrogate Decision Makers: A Systematic Review. *Arch Intern Med*. 2006;166(5):493-497.

⁹ Sehgal A et al. How strictly do dialysis patients want their advance directives followed? *JAMA* 1992;267:59-63.

¹⁰ It is estimated that the annual cost of caring for a PVS patient is just under £92,000. Formby A, Cookson R, Halliday S Cost Analysis of the Legal Declaratory Relief Requirement for Withdrawing Clinically Assisted Nutrition and Hydration from Patients in PVS in England and Wales CHE Research Paper 108 February 2015.

¹¹ Statement made on behalf of the BMA in the case of *Y v an NHS Trust* [2018] UKSC 46, para 60.

¹² Gardner BP, Theocleous F, Watt JW & Krishnan KR. Ventilation or dignified death for patients with high tetraplegia. *BMJ* 1985;291:1620-22.

The so called 'disability paradox' describes the phenomenon that many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence.¹³ We are concerned that healthy family members and clinicians project onto the incapacitated patient their own assumptions about how they might feel in the patient's shoes. As a result they may unwittingly conspire to terminate the life of someone who would have chosen not to die prematurely.

The proper review, if necessary in the court, of all 'best interests' decisions is essential to avoid serious, albeit unintended, error.

Second opinions

The GMC's guidance on end of life care, requires a second clinical opinion to be sought where it is proposed not to start, or to stop, CANH and the patient is not within hours or days of death. The guidance sets out the skills, expertise and level of independence required from the second opinion clinician. The advice is different for the three categories (see figure 1) based on the consequences of the decision in terms of both the patient's prognosis and the impact of making the 'wrong decision' for that person (in terms of either CANH being withdrawn too soon, or being continued for too long). The guidance also specifies the role of second opinion clinicians and what is expected of them. Information about second opinions is provided in:

- figure 1
- part 1 – section 2.8; and
- part 2 – sections 3.3, 4.3 and 5.3.

Q4. Is the guidance on second opinions clear, appropriate and feasible? If not, how should it be changed?

We are concerned that it is not a requirement that second opinions be sought 'out of house'. That 'in-house' second opinions are provided by senior clinicians not part of the treating team does not ensure that they are truly independent opinions.

In health care institutions, different teams often work interdependently and this is generally a good thing. But such working inevitably cultivates inter-personal relationships that inhibit one clinician's willingness to challenge or disagree with another. Truly independent decision-making will therefore require the input of out-of-house specialists, in all three category settings, and this should be made clear in the guidance.

¹³ Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med*. 1999 Apr;48(8):977-88.

Additional guidance

Q 5. Are there other issues/areas on which guidance would be helpful that are not currently covered?

We are very concerned about the guidance regarding recording and reporting the death. The guidance explicitly states that 'the original brain injury or medical condition should be given as the primary cause of death'. It is disingenuous to attribute death to an underlying cause where clinically this would not have been expected to lead to the patient's demise within the actual time frame. Where the decision to discontinue CANH is followed by the death of the patient, then this should be reflected in the official cause of death on the death certificate. These patients are dying of dehydration, not of the underlying cause.

To state otherwise is not only factually incorrect, it suggests a desire to hide the fact. Whilst we commend the emphasis on detailed record-keeping, review and audit generally in the guidance, we strongly contend that reporting and recording of death should be similarly accurate and truthful. Quite apart from the moral imperative, it is also in the interests of medical research to be able to track the number of deaths resulting from withdrawal or withholding of CANH.

If the actual cause of death is not documented it will be impossible to maintain oversight or carry out audit or research. It may also open the BMA and its members up to legal challenge. Section 5 of the [Perjury Act 1911](#) reads as follows:

5 False statutory declarations and other false statements without oath

If any person knowingly and wilfully makes (otherwise than on oath) a statement false in a material particular, and the statement is made—

(a) in a statutory declaration; or

(b) in a... certificate, declaration... or other document which he is authorised or required to make, attest, or verify, by any public general Act of Parliament for the time being in force... he shall be guilty of a misdemeanour and shall be liable on conviction thereof on indictment to imprisonment... for any term not exceeding two years, or to a fine or to both such imprisonment and fine.

PART TWO - IMPLEMENTATION AND SUPPORT

The aim of this guidance is to provide a robust decision-making process which will promote a high quality of care for patients, protect health professionals from criticism and maintain confidence in the system. It will only achieve this, however, if people know about it, follow it and if there is a commitment, at all levels, to making it work. This responsibility falls not only to health professionals, but also to those who commission, provide, manage and direct healthcare. Appendix 5 of the guidance, sets out the steps that organisations such as Trusts, Health Boards, and CCGs can take to support the implementation of this guidance in their establishments.

Q6. Do you foresee any practical challenges that could prevent the guidance being followed? What can be done to remove these obstacles?

Q7. Are the suggestions made for implementation, training and support (in Appendix 5) reasonable, practical and helpful? If not, why not?

Many health care workers view nutrition and hydration as part of basic care, not as 'medical treatment'. They will object on the ground of their conviction to participating in the withdrawal of CANH. Their consciences should be respected, and their freedom of conscience in this regard should be recognised in the guidance and included in implementation training.

Q8. Are there other things Trusts/Health Boards/CCGs (or others) could/should be doing to enable health professionals to follow the guidance?

PART THREE- ANY OTHER COMMENTS/SUGGESTIONS

Please feel free to include here any other comments or suggestions about the guidance.

Additional comments

We have some general concerns:

Euthanasia 'by stealth'

The guidance is predicated on the view that CANH is a form of medical treatment¹⁴ and that as such it can be withdrawn or withheld if judged to be in the patient's best interests. CMF takes a different view – that the provision of nutrition and hydration is a basic human right and a foundational element of care. To withdraw or withhold food and fluids from a person who is not about to die, with the intention of bringing about their death, is a form of euthanasia as the clear intention is to end the life of the patient. Furthermore, the cause of death is dehydration and not the underlying disease or injury. Repeated attempts in recent years to legalise euthanasia or physician-assisted suicide in this country have failed to gain support. This guidance appears to recommend involuntary euthanasia by stealth, a means to end the lives of those who lack capacity and whose quality of life is deemed by others not to be worth living. As such, it is against both the spirit and also possibly the letter of the law.

There is no such thing as a life 'not worth living'

Our view, and that of our members, is shaped, first and foremost, by the belief that every human being is made 'in the image of God'¹⁵ and that as such every human being, no matter how old,

¹⁴ Airedale NHS Trust v Bland [1993] 1 All ER 821

¹⁵ Genesis 1:27

frail, ill, physically or intellectually disabled, has huge worth and significance. Nobody has the right to say of another that their life is 'not worth living'. Indeed, God calls us to treat the most vulnerable people with special respect.¹⁶ But it is not just Christians who take such a view; many of different faiths and none also hold that all human life has inherent value. Decisions about treatments should therefore focus on a consideration of the benefits and burdens of any medical intervention, rather than viewing some states of existence as being excessively burdensome in themselves. There is a world of difference between saying that a treatment is futile and that a life is futile.

The inevitability of incremental extension

We are concerned that what begins as involuntary euthanasia, by withholding or withdrawing CANH from those who lack competence, will extend incrementally to permit assisted suicide/voluntary euthanasia in practice. Following the Supreme Court ruling it will be legal to deny CANH to those who lack capacity, without application to the Court of Protection, where clinicians and family are in agreement about 'best interests'. But it will be argued, why wait two weeks for the person who lacks capacity to die from dehydration? Wouldn't it be in the best interests of the patient, more compassionate to the family and more economical for the NHS, to speed the process by the use of a lethal injection? It can only be a matter of time before that step is taken, on the same, 'best interests' basis and, having taken that small step, it will become impossible to resist the claims of those seeking voluntary euthanasia, certainly as long as patient, family and clinicians agree. There being no longer the need to apply to the Court for permission, what is to prevent doctors from assisting the suicide of those who wish to die? Under the cover of guidance from their professional bodies, doctors will be enabled to circumvent the law forbidding assisted suicide. It will be impossible to prosecute those doctors and ultimately a change in the law will be forced, in order to bring it into line with common practice. Having voted repeatedly against a change in the law to permit assisted suicide, parliament will have had its hand forced.

Once we accept in principle that it is in some patients' best interests to die, and that dehydration is a legitimate way of achieving this end, then we are on a very slippery slope indeed.

¹⁶ Exodus 22:22-23