

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



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.

General
Medical
Council

Acknowledgements

The development of this guidance was overseen by a core group made up of representatives of the British Medical Association, Royal College of Physicians, and General Medical Council and a number of experts appointed to advise the group on the basis of their expertise. We are indebted to them for the considerable time and knowledge they gave in producing this guidance.

Dr John Chisholm CBE, Chair of BMA Medical Ethics Committee (Chair of the Core Group)

Sharon Burton, Head of Standards and Ethics, GMC

Ruth Campbell, Senior Policy Advisor (Medical Ethics and Human Rights), BMA

Dr Chris Danbury, Consultant in Anaesthetics and Intensive Care

Veronica English, Head of Medical Ethics and Human Rights, BMA

Professor Celia Kitzinger, Co-Director, Coma and Disorders of Consciousness Research Centre, Cardiff University

Dr Shuli Levy, Consultant Geriatrician and General Physician

Paul McGough, Senior Associate (Healthcare Regulatory Team), DAC Beachcroft

Alex Ruck Keene, Barrister, 39 Essex Chambers

Professor Lynne Turner-Stokes MBE, Consultant in Rehabilitation Medicine, Royal College of Physicians

Jessica Watkin, Policy Manager (Standards and Ethics), GMC

Thanks are also due to the following individuals and organisations who were part of the wider professional consultative group, who were consulted during the development of the guidance, and who commented on earlier drafts. Whilst their contributions were invaluable in helping to inform our views, it should not be assumed that the guidance reflects the views of all those who contributed.

Dr Judith Allanson, Consultant in Neurorehabilitation

Yogi Amin, Irwin Mitchell

Dr Idris Baker, Association of Palliative Medicine

Ian Barker, Medical Defence Union

Jim Beck, Office of the Official Solicitor

Dr Dominic Bell, Consultant in Intensive Care/Anaesthesia

Victoria Butler-Cole, 39 Essex Chambers

Naomi Campbell, Royal College of Nursing

Jakki Cowley, Empowerment Matters

Dr Stephanie de Giorgio, BMA General Practitioners Committee
Department of Health and Social Care

Bridget Dolan QC, Serjeants' Inn Chambers

Dr Aaron D'Sa, Specialty Registrar in Anaesthetics and Intensive Care

David Edwards, Office of the Official Solicitor

Dr Karen Elliott, Co-Managing Director of Gill-Thwaites & Elliott Consultants

Professor the Baroness Ilora Finlay, Mental Capacity Forum

Dr Helen Fidler, BMA Consultants Committee

Professor Rob George, Professor of Palliative Care

Professor Robin Gill, Emeritus Professor of Applied Theology

Professor Raanan Gillon, Emeritus Professor of Medical Ethics

Helen Gill-Thwaites MBE, Co-Managing Director of Gill-Thwaites & Elliott Consultants

Katie Gollop QC, Serjeants' Inn Chambers

Dr John Gorst, Consultant in Intensive Care

Joan Goulbourn, Senior Advisor Mental Capacity Policy, Ministry of Justice

Dr Marion Gray, Consultant Psychiatrist

Dr Zoë Greaves, Deputy Chair of BMA Medical Ethics Committee

Dr Andrew Hanrahan, Consultant in Neurorehabilitation

Dharinee Hansjee, Royal College of Speech and Language Therapists

Susan Hardie, Office of the Official Solicitor

Professor Richard Huxtable, Professor of Medical Ethics and Law,
Centre for Ethics in Medicine, University of Bristol

Suzi Kerrell-Vaughan, Independent Neurological Providers Association

Dr Jatt Khaira, British Association of Stroke Physicians
Professor Jenny Kitzinger, Co-Director, Coma and Disorders of Consciousness Research Centre, Cardiff University
Gavin Knox, NHS Wales
Michelle Kudhail, Independent Neurological Providers Association
Dr Julie Latchem-Hastings, Research Associate, Coma and Disorders of Consciousness Research Centre, Cardiff University
David Lock QC, Landmark Chambers
Paula Mansell, Care Quality Commission
Professor David Menon, Head of Division of Anaesthesia, University of Cambridge
Sophy Miles, Doughty Street Chambers
Michael Mylonas QC, Serjeants' Inn Chambers
Naeem Nazem, Medical and Dental Defence Union of Scotland
Dr David Nicholl, Association of British Neurologists
Dr Zoe Oliphant, Clinical Fellow, Care Quality Commission
Camilla Parker, Partner, Just Equality
Dr Marina Platts, Consultant in Neurorehabilitation
Rebecca Raeburn, Royal College of Occupational Therapists
Sophia Roper, Serjeants' Inn Chambers
Katie Scott, 39 Essex Chambers
Caroline Shehu-Pearce, Barts' Health, Palliative Care CNHS/Royal College of Nursing
Dr David Smithard, Consultant in Elderly Medicine
Dr Alison Stroud, Royal College of Speech and Language Therapists
Professor Derick Wade, Professor and Consultant in Neurological Rehabilitation
Dr Krystyna Walton, Consultant in Neurorehabilitation
Dr Bee Wee, Consultant in Palliative Medicine
Mr Robert Wheeler, Consultant Surgeon, Director of Clinical Law, University Hospitals Southampton

We would also like to thank the many individuals and organisations who provided advice and who commented on an earlier draft of the guidance. Again, it should not be assumed that the guidance reflects the views of all those who contributed.

Alzheimer's Society

Kiran Bhogal, Partner & Head of Healthcare, Hill Dickinson LLP

British Dietetic Association

British Geriatric Society

British Society of Rehabilitation Medicine

Catholic Medical Association (UK)

Sir William Charles

Professor Hannah Cock, Professor of Epilepsy and Medical Education, St George's, University of London

Professor John Coggon, Professor of Law

Dr Peter Critchley, Consultant in Neurology and Rehabilitation Medicine

Compassion in Dying

Jane Dale, Healthcare Inspectorate Wales

Dementia UK

Faculty of Intensive Care Medicine

Health Education England

Hospice UK

Huntington's Disease Association

Dr Judith Ibson, Reader in Primary Care, St George's, University of London

Intensive Care Society

Professor Chris Jones, Deputy Chief Medical Officer for Wales

Dr Stephen Lewis, Consultant Gastroenterologist

Dr Jonathan Martin, Consultant in Palliative Medicine

Jill Mason, Mills & Reeve LLP

Medical Ethics Alliance

Medical Protection Society

Nursing and Midwifery Council

UK Parkinson's Excellence Network**Dr Catherine Millington-Sanders**, Royal College of General Practitioners**Dr Lucy Series**, Wellcome Research Fellow and Lecturer in Law**Dr Claire Stark Toller**, Consultant in Palliative Medicine**Amanda Swain**, Vice Chair and Policy Officer, UK Acquired Brain Injury Forum**Dr Andrew Wilcock**, Clinical Reader in Palliative Medicine and Medical Oncology

All those who attended the consultative session on the guidance at the Independent Neurorehabilitation Providers Association conference, July 2018

All members of BMA committees and BMA Council who commented on the draft guidance

All BMA members who contributed their views at focus groups in London and Cardiff, July 2018.

Two other organisations participated in the consultation but have asked not to be listed here.

We are particularly grateful to the individual family members with experience of decision-making around CANH who shared their experiences with us.

This guidance is published under the auspices of the BMA Medical Ethics Committee which considered drafts at various stages of its development. The MEC's membership for the year 2017-2018 was:

Dr John Chisholm CBE (Chair), General practice, London**Dr Hannah Barham-Brown**, junior doctor, London**Dr Charlie Bell**, junior doctor, London**Dr Iain Brassington**, Bioethics, Manchester**Dr Mary Church**, General practice, Glasgow**Professor Bobbie Farsides**, Clinical and biomedical ethics, Brighton**Professor the Baroness Ilora Finlay**, Palliative medicine, Cardiff**Professor Robin Gill**, Theology, Canterbury**Professor Raanan Gillon**, General practice (retired) and medical ethics, London**Dr Zoë Greaves (Deputy Chair)**, GP trainee, South Tees**Professor Emily Jackson OBE**, Medical law and ethics, London**Dr Surendra Kumar**, General practice, Widnes**David Lock QC**, Barrister, London**Dr Helena McKeown**, General practice, Salisbury**Dr Mary Neal**, Medical law and ethics, Glasgow**Professor Wendy Savage**, Obstetrics and gynaecology (retired), London**Professor Mona Siddiqui OBE**, Theology, Edinburgh**Dr M E Jan Wise**, Psychiatry, London*Ex officio members***Dr Andrew Dearden**, treasurer**Dr Anthea Mowat**, chair of the representative body**Dr Chaand Nagpaul CBE**, chair of council**Sir John Temple**, president

Contents

Executive summary	6
Figure 1: The decision-making process	12
1. The aim and scope of this guidance	13
1.1. Why is there separate guidance for CANH?	13
1.2. Scope	14
1.3. Which decisions are covered?	15
Decisions about CANH in the context of neurodegenerative conditions.....	15
Decisions about CANH in patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury	15
Decisions about CANH in previously healthy patients who are in VS or MCS following a sudden-onset brain injury	16
1.4. Which decisions are not covered?	16
Patients in whom CANH is not clinically indicated	16
Patients who are expected to die within hours or days.....	16
Patients for whom a decision to stop or not to start CANH is part of a broader decision about life-sustaining treatment.....	17
1.5. Withdrawing or withholding?	17
1.6. Physician-assisted suicide and euthanasia	17
1.7. Format of the guidance	18
Part one: general guidance for all decisions about clinically-assisted nutrition and hydration (CANH)	
2. Decisions about CANH: the decision-making process	19
2.1. The legal context	19
2.2. A proportionate approach to decision-making.....	21
Figure 2: Independent scrutiny of decisions not to provide, or to stop, CANH in adults who lack capacity	21
2.3. Who is the decision-maker, and who must be consulted?	22
Advance decisions to refuse treatment (ADRT)	22
Health and welfare lasting power of attorney (LPA).....	22
Clinician-led decision-making.....	23
Who is responsible for making decisions?.....	23
Who should be involved in decision-making?.....	24
The Court of Protection.....	25
2.4. Health professionals with a conscientious objection.....	25
2.5. Clinical assessments	27
Factors to consider	27
Uncertainty in care and treatment.....	28
Initiating a trial of CANH	28
2.6. Best interests assessments.....	30
What are best interests assessments?	31
Gathering information about the patient.....	31
Ascertaining wishes, beliefs, values and feelings	32
Weighing and using the information about the patient.....	33
Documenting and sharing information about best interests assessments	34
Pregnant women	34
Figure 3: Best interests decision-making	35

2.7. Keeping decisions to provide CANH under review.....	36
Who is responsible for ensuring that reviews take place?.....	36
2.8. Second opinions.....	37
The second-opinion clinician.....	37
The role of the second-opinion clinician	38
2.9. Managing disagreement and uncertainty	39
Applications to the Court of Protection	40
2.10. The withdrawal of CANH.....	42
2.11. Record-keeping.....	42
Recording and reporting the death.....	42
2.12. Governance and audit.....	44
Internal governance	44
External regulatory review	44
National data collection	44
Medical Examiners	45
Part two: guidance for specific scenarios	
3. Decisions about clinically-assisted nutrition and hydration (CANH) in the context of neurodegenerative conditions.....	
46	
3.1. Clinical assessments	46
3.2. Best interests assessments.....	47
3.3. Second opinions.....	47
3.4. Record-keeping	47
4. Decisions about clinically-assisted nutrition and hydration (CANH) in patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury	
48	
4.1. Clinical assessments	48
4.2. Best interests assessments.....	49
4.3. Second opinions.....	49
4.4. Record-keeping	49
5. Decisions about clinically-assisted nutrition and hydration (CANH) in previously healthy patients in vegetative state (VS) or minimally conscious state (MCS) following a sudden-onset brain injury	
50	
5.1. Clinical assessments	50
Diagnosis and prognosis.....	50
The need for specialist evaluation	51
5.2. Best interests assessments.....	51
Timing of best interests discussions	52
5.3. Second opinions.....	53
5.4. The withdrawal of CANH	53
5.5. Record-keeping	54
5.6. National review and audit.....	55
Appendix 1 – Practical guidance for best interests decision-making	56
Appendix 2 – Checklist of evidence for best interests decision-making in relation to clinically-assisted nutrition and hydration (CANH)	69
Appendix 3 – recommendations for implementation, training and support	71
Appendix 4 – Decisions about clinically-assisted nutrition and hydration (CANH) – the legal background	75

Executive summary

This summary is intended as an aide-mémoire and is not designed to be read in isolation from the full guidance.

The aim and scope of the guidance

1. 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.
2. This guidance is based on the current legal and regulatory position which is that:
 - clinically-assisted nutrition and hydration (CANH) is a form of medical treatment;
 - treatment should only be provided when it is in the patient's best interests;
 - 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;
 - all decisions must be made in accordance with the Mental Capacity Act 2005;
 - there is no requirement for decisions to withdraw CANH to be approved by the court, 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;¹ and
 - the General Medical Council's guidance states that a second clinical opinion should be sought where it is proposed, in the patient's best interests, to stop or not start CANH and the patient is not within hours or days of death.²
3. 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 focuses on patients who could go on living for some time if CANH is provided, where CANH is the primary life-sustaining treatment. It covers:
 - decisions about CANH in the context of neurodegenerative conditions;
 - decisions about CANH in patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury; and
 - decisions about CANH in previously healthy patients who are in a vegetative state (VS)³ or minimally conscious state (MCS) following a sudden-onset brain injury.
4. All decisions about CANH should follow careful consideration of the individual circumstances of the patient and focus on reaching the decision that is right for that person.
5. This guidance does not cover the following decisions:
 - patients for whom CANH is not clinically indicated;
 - patients who are expected to die within hours or days;
 - patients for whom a decision to stop or not start CANH is part of a broader decision about life-sustaining treatment, e.g. mechanical ventilation.

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

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

3 We recognise that some people may find the term 'vegetative state' (VS) to be offensive or upsetting. Where we refer to VS in this document we do so with no intention of causing offence, but in recognition of the fact that it is still the most widely used clinical term in the UK for this condition. If and when a more acceptable, internationally agreed term emerges, this will be adopted in future iterations of this guidance.

Who is the decision-maker and what is their role?

6. 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.
7. It should be clearly established at all times who has responsibility for deciding whether CANH should be provided or continued and this information should be made available to everyone involved in the patient's care and those close to the patient.
8. The person ultimately responsible for making decisions about CANH is:
 - the patient, if there is a valid and applicable advance decision to refuse treatment (ADRT) which refuses CANH;
 - the health and welfare attorney if one exists with the appropriate powers; or
 - the person with overall responsibility for the patient's care, as part of their clinical responsibility to ensure that treatment provided is in the patient's best interests. This will usually be a consultant or general practitioner.
9. Where the patient does not have a valid and applicable ADRT, the role of the decision-maker is to consult with those close to the patient in order to make the decision that is in the best interests of the individual, taking account of their individual circumstances and past and present wishes, feelings, beliefs and values.
10. Decisions to provide CANH should be reviewed every 6 months (or every 12 months where the patient has been in a stable condition over a long period of time) and more often if the clinical situation has changed significantly. It is the responsibility of the decision-maker to ensure that decisions are reviewed but providers and funders of healthcare also have a responsibility to ensure that treatment provided is in accordance with the Mental Capacity Act (MCA).

Clinical assessments

11. Doctors should provide unbiased, honest and realistic information about the level of recovery that can be expected. Where the prognosis is very poor, they should avoid raising unrealistic expectations or giving false hope to those close to the patient.
12. The level of uncertainty in the prognosis should be explained to those close to the patient and this should form an integral part of the best interests assessment.
13. The following questions, articulated in the legal case of PL,⁴ can be helpful to frame the clinical assessments needed for decision-making about CANH in patients who are not imminently dying:
 - 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 would be provided?

4 *PL v Sutton Clinical Commissioning Group & Anor* [2017] EWCOP 22. 29. <http://www.bailii.org/ew/cases/EWCOP/2017/22.html>

14. 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.
15. Where previously healthy patients are in a prolonged disorder of consciousness (lasting more than four weeks) following a sudden-onset brain injury:
 - for patients in the post-acute phase following brain injury, detailed assessment should be conducted over a period of time (usually 3-4 months) in a designated prolonged disorders of consciousness (PDOC) assessment unit, in accordance with the Royal College of Physicians' (RCP's) clinical guidelines;⁵
 - for patients who have been in VS/MCS for some years and are established in long-term community care, specialist assessment is still required, but may be conducted using structured assessment tools supported by a physician experienced in PDOC on an outreach basis.
16. There may be some cases in which there is clear evidence that the findings of detailed assessment will not affect the outcome of the best interests decision because, for example, even the most optimistic prediction of recovery would not constitute a quality of life the patient would find acceptable. Where this is the case, a decision can be made before these assessments have been completed.

Best interests assessments

17. Our approach in this guidance is that the extensiveness of the best interests assessments, the safeguards, documentation and external scrutiny should be proportionate to the consequences of the decision in each case.
18. The consequences of the decision relate both to the prognosis (in terms of the level of anticipated recovery or deterioration and the expected survival time, and the certainty with which these can be predicted) and the impact on the individual of making the 'wrong decision'. A 'wrong decision' could result 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 too long – forcing the individual to continue a life they would not have wanted.
19. In making best interests assessments decision-makers must take account of the individual's past and present views, wishes, feelings, values and beliefs where these are known or can be reasonably ascertained. Detailed practical guidance for carrying out best interests assessments is provided in [Appendix 1](#).

Who should be consulted?

20. Where, although lacking capacity, patients are able to contribute to some extent to the decision-making process, they must be encouraged and supported to do so. Speech and language therapists can play a role here.
21. When assessing the patient's best interests, the following people should be consulted:⁶
 - anyone named by the patient as someone to be consulted on such matters;
 - those 'engaged in caring for the patient or interested in his or her welfare'; and
 - a court-appointed deputy (if there is one).

5 Royal College of Physicians (2013) *Prolonged disorders of consciousness: national clinical guidelines. Report of a working party 2013*. RCP: London.

6 Mental Capacity Act 2005, s.5(7)(a).

22. Where there is nobody that fits into the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.
23. Attempts must be made to identify all relevant and appropriate people to be consulted under the second of the groups listed at point 21. This would usually include family members and could also include friends and colleagues who may have relevant information to share about the patient's views and wishes. Members of the care team and those responsible for commissioning or funding the patient's care should also be involved in these discussions. The aim should be to accumulate sufficient information to form a clear view as to what the patient would have wanted if they had retained the capacity to make the decision.

Sharing and assessing information

24. Unless the individual had previously indicated that information is not to be shared with others, it is reasonable to assume they would want relevant information shared with those who may be asked to contribute to the decision-making process.
25. Information that can be collected about the patient's past and present wishes and feelings, beliefs or values 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.
26. The impact of the decision on others, including family members, is a relevant factor to consider, but only to the extent that the patient him or herself would have taken this into account.
27. Decision-makers must not be motivated by a desire to bring about the death of the patient. In describing the patient's likely reaction to their current situation, however, those close to the patient frequently use expressions such as 'he would rather be dead'; this does not equate to a desire to bring about the patient's death and should not be interpreted as such.
28. Decisions must not be influenced by the decision-maker's personal views about the quality of life of patients in this situation, either positive or negative – including, for example, any pre-existing negative views about living with a particular condition or disability. The information provided should be objectively assessed to decide what would be best for this individual patient, taking into account the balance of positive and negative current experiences.
29. The quality of the evidence that is provided about the individual's views and values needs to be assessed and decision-makers should not speculate about what the individual's views *might* have been in the absence of reliable evidence.
30. 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.
31. 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. A model proforma is included at [Appendix 2](#) of this guidance to assist with this.

Health professionals with a conscientious objection

32. 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.⁷
33. 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.
34. Provider organisations that carry religious or other convictions that would prevent them from making and implementing particular decisions about CANH should declare that fact. They have a responsibility to ensure that regular best interests assessments are carried out and should make arrangements for these to be carried out in, or by staff from, another establishment where necessary.

Second opinions

35. The GMC guidance states that all reasonable steps should be taken to get a second clinical opinion where it is proposed to stop, or not to start, CANH and the patient is not within hours or days of death.
36. 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.
37. The level of independence of the second-opinion clinician will depend on the circumstances and the consequences of the decision – see [figure 2](#).
38. The Clinical Commissioning Group (CCG)/Health Board should maintain a database of individuals willing and qualified to carry out second opinions for patients being cared for in the community, and should provide funding for them.
39. Second-opinion clinicians should examine the patient, consider and evaluate the medical records and review information about the patient's best interests. They should write a report summarising the review they have undertaken and outlining their own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient.

Managing uncertainty and disagreement

40. Where there is uncertainty or disagreement about whether CANH is in the patient's best interests, various informal conflict resolution options should be explored – for example, the involvement of an independent advocate, obtaining a further clinical opinion, holding a case conference, or the use of medical mediation services.
41. Where those close to the patient disagree with the decision made, they should be provided with clear information about the process to follow to challenge the decision and directed to sources of help or support.

⁷ General Medical Council (2013) *Personal beliefs and medical practice*. GMC: London.

42. Where there is disagreement about the patient's best interests, or the decision is finely balanced (i.e. there is ongoing uncertainty), and this is unresolved by seeking a further opinion or mediation, the Court of Protection should be asked to resolve the matter.

Applications to the Court of Protection

43. Court of Protection proceedings should be initiated and funded by the relevant CCG/ Health Board/NHS Trust⁸ responsible for commissioning or providing the patient's care.
44. The family should be kept informed at all stages and every effort should be made to avoid any unnecessary delays, but they should not be responsible for initiating or funding the proceedings.
45. Applications should clearly set out the treatment that is currently being provided and any decisions that have already been made about ceilings of treatment or intervention.
46. If an immediate decision is needed about whether or not to re-start CANH, if the feeding tube becomes blocked or dislodged, whilst a case is under consideration by the court, an urgent application should be made to the court, out of hours if necessary.

Record-keeping, review and audit

47. 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.
48. For patients in VS or MCS following a sudden-onset brain injury, use of the model proforma developed as part of this guidance is recommended. This can be accessed at www.bma.org.uk/CANH.
49. Decisions about CANH should be subject to internal review and audit, including through established procedures for reviewing deaths. They should also form part of the external review undertaken by the Care Quality Commission and Healthcare Inspectorate Wales.
50. Where relevant national data collection and audit exist, health professionals should contribute to them.

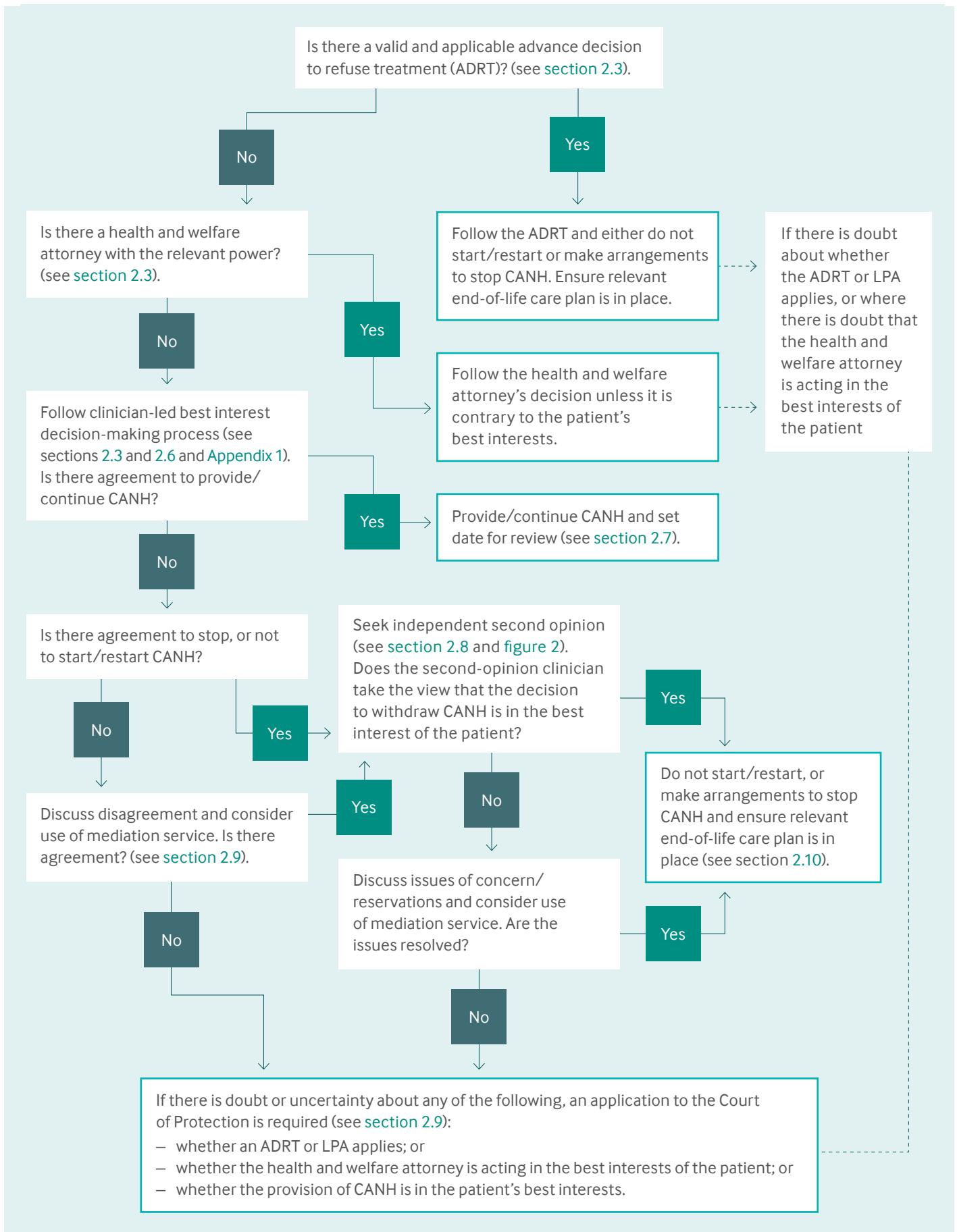
8 Please note that where we refer to NHS Trusts throughout this document, this encompasses both NHS Trusts and NHS Foundation Trusts.

CANH (Clinically-assisted nutrition and hydration)



www.bma.org.uk/CANH

Figure 1: The decision-making process



1. The aim and scope of this guidance

Decisions about whether to start, continue or stop clinically-assisted nutrition and hydration (CANH) are made on a daily basis across England and Wales. Decision-makers must start from the strong presumption that it will be in a patient's best interests to prolong life, but for some patients providing, or continuing to provide, CANH is not in their best interests because it is not able to provide a quality of life they would find acceptable. Legally and ethically, where treatment is not, or ceases to be, in the patient's best interests, it should not be provided. For this reason, all decisions about CANH – to provide, continue or stop – should follow careful consideration of the individual circumstances of the patient. This guidance sets out how these decisions should be made, in a wide range of clinical situations.

All decisions about CANH must recognise, consider, and balance patients' rights to life and rights to autonomy and self-determination. The right to self-determination can outweigh the right to life if it is known with sufficient certainty that continuing treatment would not provide a quality of life the patient would find acceptable. Also underpinning the framework we have provided in this guidance are the rights of patients to be treated with dignity and respect.

This guidance does not provide a simple set of instructions or define rules which must be followed without reflection, but is a tool to inform and aid decision-making. It does not provide easy answers, but offers an approach through which an appropriate decision may be reached.

1.1. Why is there separate guidance for CANH?

Since 1992 it has been established in law that CANH is a form of medical treatment, rather than a facet of basic care.⁹ In spite of this, it is clear that some people attach to CANH a symbolic, emotional or ethical significance that sets it apart from other forms of life-sustaining treatment. It is in response to this that decisions about CANH have historically been treated differently, in some respects, to decisions about other forms of life-sustaining treatment. In order to demonstrate that the patient's interests have been thoroughly considered in relation to CANH, and to provide reassurance to those close to patients and the wider public, some additional levels of scrutiny have traditionally been applied to these decisions.

One example of this is the belief, until 2017, that all decisions to withdraw CANH from a small group of patients – those in permanent vegetative state (VS) or minimally conscious state (MCS) – needed to be authorised by the Court of Protection. In July 2018, the Supreme Court confirmed that there is no requirement to seek approval from the Court of Protection where there is agreement as to what is in the best interests of the patient, and where the Mental Capacity Act 2005 and good practice guidance have been followed.¹⁰ This brings these cases into line with decisions about CANH in other groups of patients (see [section 1.3](#)) and with decisions about other forms of life-sustaining treatment.

Another example is the General Medical Council's guidance on end-of-life care,¹¹ which states that a second clinical opinion should be sought where a decision is made to stop or not start CANH in certain circumstances – an additional step that is not required routinely in respect of other forms of life-sustaining treatment.

We do not believe CANH to be fundamentally different from other forms of life-sustaining treatment, but, because of this history, the changing legal position and the additional scrutiny of these decisions required by the GMC, we have made the decision to produce separate guidance on CANH.

9 *Airedale NHS Trust v Bland* [1993] AC 789. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>.

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

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

1.2 Scope

This document provides guidance for health professionals on decisions about CANH in adult patients in England and Wales who lack capacity to make the decision for themselves. It covers decisions to:

- start;
- re-start (after, for example, a tube has perished, become blocked or dislodged);
- continue; or
- stop providing (i.e. withdraw) CANH.

CANH includes the use of all forms of tube feeding (e.g. via nasogastric tube, percutaneous endoscopic gastrostomy (PEG) or parenteral nutrition) but does not cover oral feeding, by cup, spoon or other method for delivering food or nutritional supplements into the patient's mouth. Throughout this guidance we refer to clinically-assisted nutrition *and* hydration. Although patients' nutrition and hydration needs should be assessed separately, in many of the circumstances covered in this guidance, decisions will usually be made to give, continue or stop nutrition and hydration together. Decisions should be made in line with the most up-to-date relevant clinical guidelines.

This guidance extends beyond patients in VS or MCS following a sudden-onset brain injury, the group that was previously the subject of applications to the Court of Protection. It also covers the much larger group of patients who have multiple comorbidities, frailty or neurodegenerative conditions in whom decisions about CANH are needed. In this guidance the terms vegetative state (VS), minimally conscious state (MCS), and prolonged disorders of consciousness (PDOC) are used only in the context of previously healthy patients with a sudden-onset brain injury.

The guidance is limited to circumstances where CANH is the primary form of life-sustaining treatment being provided. Where the withdrawal of CANH is incidental to the withdrawal of other life-sustaining treatments, such as ventilatory or cardiac support, or dialysis, many of the same principles will apply but other professional guidance should be consulted.¹²

This guidance applies whether the need for CANH is a recent development or the patient has been receiving CANH for many years. It covers treatment provided in a hospital setting and in the community (whether in the patient's home or elsewhere) and applies equally to treatment in the NHS and the private and charitable sectors. While the primary focus of this guidance is on situations in which there is time for detailed investigations and assessments, the same principles apply in emergency settings, although the practicalities will differ as treatment decisions will need to be made urgently.

The guidance is restricted to decisions about CANH in adults who lack capacity but the principles and much of the guidance also apply to some other decisions. For example:

- decisions about CANH in younger patients – the law governing decision-making differs for children and young people between 16 and 18, and so additional guidance should be consulted where the patient is under the age of 18;¹³ and
- decisions about other forms of life-sustaining treatment (such as ventilation or renal dialysis) – with the exception of the requirement for second opinions, the decision-making process, including the need for best interests assessments, is the same for all forms of life-sustaining treatment. Clinicians should consult additional guidance when making these decisions.

12 See, for example, Harvey D, Butler J, Groves J *et al.* Management of perceived devastating brain injury after hospital admission: a consensus statement from stakeholder professional organisations. *British Journal of Anaesthesia* (2018) 120(1): 138-45.

13 See, for example, British Medical Association (2007) *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making*. 3rd ed. Blackwell Publishing: London. 96-108; Larcher V, Craig F, Bhogal K, *et al.*, on behalf of the Royal College of Paediatrics and Child Health. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives of Disease in Childhood* (2014) 100 suppl 2. Available at: <http://dx.doi.org/10.1136/archdischild-2014-306666>

A significant part of the guidance focuses on what factors should be taken into consideration and the correct process to be followed in cases where a decision is made not to provide, or to withdraw, CANH. This is not because we believe this will be the correct decision in the majority of cases, or because we have particular views about the outcome of such assessments. It is simply because the serious and irreversible nature of a decision to withhold or withdraw CANH requires additional safeguards.

The BMA,¹⁴ the Royal College of Physicians (RCP)¹⁵ and the General Medical Council (GMC)¹⁶ have all issued guidance, at different times, about life-sustaining treatment, which incorporates guidance on CANH. This document provides a legal update and expands on that guidance, but does not replace it.

1.3 Which decisions are covered?

This guidance covers decisions in patients who are not imminently dying and could go on living for some time (potentially many years) if CANH is provided, in circumstances where CANH is the primary life-sustaining treatment.

We have divided this spectrum of cases into broad categories based on medical condition and comorbidities, in order to provide some clarity about the level of scrutiny that will be appropriate and proportionate in different situations. It needs to be recognised, however, that these different clinical situations often overlap considerably and every case needs to be considered on its individual facts; the categories should be viewed as various points on a spectrum rather than being clearly distinguishable categories.

Decisions about CANH in the context of neurodegenerative conditions

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 (see [section 3.1](#)) 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.

Decisions about CANH in patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury

Another group is those 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 group will include 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. central nervous system (CNS) infections, subdural haemorrhage, or complications following neurosurgery.

Many of these patients may be discharged from hospital to a specialist unit, nursing home or to be cared for at home, without any formal assessments of awareness being undertaken. 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.

14 British Medical Association (2007) *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making*. 3rd ed. Blackwell Publishing: London.

15 Royal College of Physicians (2013) *Prolonged disorders of consciousness: national clinical guidelines. Report of a working party 2013*. RCP: London.

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

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.

Decisions about CANH in previously healthy patients who are in VS or MCS following a sudden-onset brain injury

This group of patients includes those 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' clinical guidelines for PDOC.¹⁷ 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 VS or 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.

1.4 Which decisions are not covered?

Patients in whom CANH is not clinically indicated

In some patients CANH is not clinically indicated because it is unable to achieve its clinical aim. The courts¹⁸ and the GMC¹⁹ have made clear that health professionals are not required to offer treatments that they consider to be clinically inappropriate. This may because:

- it is not possible to provide it (e.g. it is not physically possible to insert a feeding tube or the patient repeatedly pulls it out); or
- the clinical risks associated with CANH are too great (e.g. patients for whom tube placement (usually PEG or radiologically inserted gastrostomy (RIG)) is considered a high mortality risk, or in whom there is a high risk of aspiration); or
- CANH would provide no clinical benefit (in terms of extending the patient's life or providing symptom relief) and would carry potential risks (e.g. in patients with end-stage dementia for whom the inability to take sufficient nutrition/hydration indicates they are approaching death and where CANH is not expected to prolong their life).²⁰

In these circumstances, the clinical reasons why CANH is not an option should be sensitively explained to those close to the patient.

Patients who are expected to die within hours or days

Many patients who are approaching death do not feel thirst or hunger and do not need nutrition and hydration; it would be inappropriate – and unnecessarily invasive – to routinely start CANH in every patient who loses the ability to swallow. Irrespective of the cause of the patient's illness, where they are expected to die imminently it will usually not be appropriate to start or continue CANH. The patient's condition should be kept under review and reassessed if the situation changes. Doctors should follow good practice guidance on managing end-of-life care.

17 Royal College of Physicians (2013) *Prolonged disorders of consciousness: national clinical guidelines. Report of a working party 2013*. RCP: London.

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

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

20 National Institute for Health and Care Excellence (2018) *Dementia: assessment, management and support for people living with dementia and their carers* (NICE guideline NG97) NICE: London. Recommendation 1.10.8; Royal College of Physicians (2010) *Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life*. RCP: London.

Patients for whom a decision to stop or not to start CANH is part of a broader decision about life-sustaining treatment

In many cases where there has been a devastating brain injury, a decision is made in critically ill patients that providing life-sustaining treatments (such as cardiovascular or ventilatory support and CANH) is not appropriate, because the injuries sustained are not compatible with survival or because they are 'incompatible with good functional recovery' such that 'patient-centred outcomes are recognised to be unacceptable, regardless of the extent of neurological improvement'.²¹

Similarly, some patients in acute care may be receiving CANH in addition to other forms of life-sustaining treatment. In some of these cases, a decision not to provide, or to stop, all forms of life-sustaining treatment, with transition to end-of-life care, will be appropriate and in accordance with good clinical practice. In these cases, the decision not to provide, or continue, CANH is incidental to the decision to stop other life-sustaining treatments. The same general principles about best interests decision-making still apply in these cases and a second clinical opinion will sometimes be required as a matter of good practice. Where they are available, relevant clinical guidelines should be followed.

1.5 Withdrawing or withholding?

The courts have made clear that there is no legal or moral difference between withholding and withdrawing CANH.²² That is not to say, however, that everyone shares this view about their moral equivalence, or that psychologically the two are equivalent, either for family members or for members of the treating team. Some people feel there is a significant difference in the message conveyed by a decision not to start, or re-start, as opposed to withdrawing treatment. There can be an impression attached to a decision to withdraw treatment which can be interpreted as abandonment or 'giving up on the patient'.²³

This is understandable, but there is a risk that the psychological difficulty of withdrawing treatment could lead to some patients failing to receive treatment that could benefit them. Treatment should never be withheld where there is a possibility that it will benefit the patient, simply because withholding is considered to be easier than any subsequent withdrawal of treatment. Equally, it is not appropriate to deliberately wait until a tube becomes blocked or dislodged, requiring a decision about whether to re-start CANH, before making a best interests assessment.

1.6 Physician-assisted suicide and euthanasia

Some people and jurisdictions refer to withdrawing or withholding life-sustaining treatment as 'passive euthanasia'. This is not the position in the UK, where euthanasia has been given a very specific meaning: the taking of active steps with the intention of terminating the patient's life. The courts in England and Wales proceed on the basis that there is a fundamental distinction between decisions not to provide, or not to continue, life-sustaining treatment and euthanasia.²⁴

Euthanasia or assisted suicide involves taking active steps with the intention of terminating the patient's life. The intention behind a decision to withdraw treatment, however, is to stop providing medical treatments or interventions that are not able to benefit the patient, allowing them to die from their pre-existing condition.

All forms of assisted dying are unlawful in the United Kingdom.

21 Harvey D, Butler J, Groves J *et al.* Management of perceived devastating brain injury after hospital admission: a consensus statement from stakeholder professionals organisations. *British Journal of Anaesthesia* (2018) 120(1): 138-45.

22 Airedale NHS Trust v Bland [1993] AC 789, 875. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>.

23 British Medical Association (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making*. Third Edition. Blackwell Publishing: London. 19.

24 Airedale NHS Trust v Bland [1993] AC 789, 866. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>.

1.7 Format of the guidance

There are many similarities between the different categories of patient covered by this guidance and the decision-making process is broadly similar for all of them. There are, however, some factors that distinguish between them and which have some bearing on the decision-making process. This guidance is therefore divided into two parts:

- general guidance which applies in all cases (part 1); and
- specific guidance for the different categories (part 2).

Those using this guidance are therefore advised to read the whole of part 1 and the relevant section(s) of part 2 depending on the particular circumstances of their patients. Information in the appendices, particularly the practical guidance on best interest assessments, will help with decision-making in all cases.

The main guidance is supplemented by a series of appendices which include:

- [Appendix 1](#) – Practical guidance for best interests decision-making;
- [Appendix 2](#) – A sample form for recording information and discussion about best interests;
- [Appendix 3](#) – Recommendations on implementation, training and support; and
- [Appendix 4](#) – The legal background to decisions about CANH.

A range of other resources has been developed alongside this guidance including:

- a quick reference guide to be used in conjunction with the guidance;
- a guide for Trusts, Health Boards or CCGs to support decision-making;
- various training materials; and
- information for family members about their role in the decision-making process.

All of these resources are available for download from the BMA website at:

www.bma.org.uk/CANH.

Box 1: Scope – key points:

1. 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.
2. It focuses on patients who could go on living for some time if CANH is provided, where CANH is the primary life-sustaining treatment.
3. This document provides general guidance that is applicable in all cases and specific guidance on:
 - decisions about CANH in the context of neurodegenerative conditions;
 - decisions about CANH in patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury; and
 - decisions about CANH in previously healthy patients who are in VS or MCS following a sudden-onset brain injury.
4. This guidance does not cover decisions for the following groups:
 - patients for whom CANH is not clinically indicated;
 - patients who are expected to die within hours or days; and
 - patients for whom a decision to stop or not to start CANH is part of a broader decision about life-sustaining treatment, e.g. mechanical ventilation.
5. This guidance provides a legal update and expands on existing guidance about life-sustaining treatment from the BMA, RCP and GMC.
6. The courts have made clear that there is no legal or moral distinction between withholding and withdrawing CANH. Treatment should never be withheld where there is a possibility that it will benefit the patient, simply because withholding is considered to be easier than any subsequent withdrawal of treatment.
7. Withdrawing and withholding CANH are legally and morally distinct from euthanasia. All forms of euthanasia and assisted suicide remain illegal in the UK.

Part one: general guidance for all decisions about clinically-assisted nutrition and hydration (CANH)

2. Decisions about CANH – the decision-making process

This section expands on the information in [figure 1](#), providing an overview of the decision-making process that should be followed when considering decisions about CANH, in line with the Mental Capacity Act 2005 (MCA).

The MCA provides protection for patients by ensuring that decisions are focused on the individual and on providing the care and treatment that is right for that individual in the widest sense rather than considering just medical interests. Section 5 of the MCA also protects health professionals, by providing protection from liability in relation to the decisions they make, but only where the correct decision-making process has been followed. It is important to recognise that it is not just the decision reached which determines liability, but also the process through which that decision was made. In a case involving a decision about cardiopulmonary resuscitation (CPR), the judge held that although there was no dispute that the doctor:

‘took the decision he did on clinical grounds that he believed was in Carl’s best interests, the issue is whether he took it in accordance with the procedure set out in s.4. ... As reflected in the references to human dignity inherent in the ECHR [European Convention on Human Rights], in guidance and elsewhere, ‘best interests’ means something broader than clinical judgment. A ‘best interests’ decision normally requires consultation.’²⁵

Mr Justice Blake, *Winspear*

2.1. The legal context

The legal developments in this area are set out in detail in [Appendix 4](#), but some of the key points are summarised in the box below to set the backdrop against which this guidance was written.

25 *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB). 42. <http://www.bailii.org/ew/cases/EWHC/QB/2015/3250.html>

Key legal developments

1. In the past it was widely understood that prior court approval was required before withdrawing CANH from patients in permanent vegetative state (VS) or minimally conscious state (MCS). In July 2018, the Supreme Court confirmed that there is no requirement to seek approval from the Court of Protection in any cases where there is agreement as to what is in the best interests of the patient, and where both the Mental Capacity Act 2005 and good practice guidance have been followed.

'I do not consider that it has been established that the common law or the ECHR, in combination or separately, give rise to the mandatory requirement, for which the Official Solicitor contends, to involve the court to decide upon the best interests of every patient with a prolonged disorder of consciousness before CANH can be withdrawn. If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court.'²⁶

Lady Black, *An NHS Trust v Y*

2. A number of significant points have also emerged from the case law on how decisions are to be made, which need to be reflected in decision-making:
 - reinforcement of the message that the correct question to ask is whether it is appropriate to provide or continue to provide treatment, rather than whether it is appropriate to withdraw CANH, on the basis that CANH should only be provided where it is in the patient's best interests;
 - an increasing emphasis on patient-centred decisions. The courts have emphasised 'the very strong presumption in favour of the preservation of life',²⁷ but that this can be rebutted by the principle of self-determination, if there is clear evidence that the individual would not want CANH provided in the circumstances that have arisen;
 - less emphasis placed on making a clear distinction between permanent VS and MCS and more on the patient's prognosis for functional recovery in determining the patient's best interests; and
 - an unequivocal statement that a patient's best interests incorporate not just their medical interests, but their welfare in the widest sense – medical, social, and psychological.
3. The Human Rights Act 1998 means that doctors must be aware of how human rights will impact on their decision-making. The courts have confirmed that decisions to withdraw CANH are compliant with human rights law if they are made appropriately.^{28,29}

²⁶ *An NHS Trust and other v Y* [2018] UKSC 46. 126. <https://www.bailii.org/uk/cases/UKSC/2018/46.html>

²⁷ *Briggs v Briggs* [2016] EWCOP 53. 6(9). <https://www.bailii.org/ew/cases/EWCOP/2016/53.html>.

²⁸ *NHS Trust A v M and NHS Trust B v H* [2001] Fam 348. <https://www.bailii.org/ew/cases/EWHC/Fam/2000/B2.html>.

²⁹ *Lambert v France* (2015) ECHR 185. <https://www.medstra-online.de/pdf/Lambert.pdf>.

2.2. A proportionate approach to decision-making

In this guidance, the extent of the safeguards, documentation and external scrutiny recommended in relation to the three groups identified in [section 1.3](#) is proportionate to the consequences of the decision (see [figure 2](#)). 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:

- a. 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
- b. 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.

Figure 2: 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	Patients with multiple comorbidities or frailty which is likely to shorten life expectancy, who have suffered a brain injury	Previously healthy patients in VS or MCS following sudden-onset brain injury
<p>Second clinical opinion:*</p> <ul style="list-style-type: none"> – 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. <p>Internal and external review and audit.</p>	<p>Second clinical opinion:*</p> <ul style="list-style-type: none"> – 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. <p>Internal and external review and audit.</p>	<p>Second clinical opinion:*</p> <ul style="list-style-type: none"> – 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. <p>Internal and external review and audit.</p> <p>National data collection and clinical outcome review.</p>
Refer to section 3	Refer to section 4	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.

2.3. Who is the decision-maker, and who must be consulted?

Advance decisions to refuse treatment (ADRT)

If the patient has made a valid and applicable advance decision to refuse treatment (ADRT) covering CANH which applies in the patient's clinical situation, the patient has already decided to decline treatment and that decision must be respected. An ADRT will be valid and applicable if:

- it was made by someone aged 18 or older who had capacity to make the decision at the time it was written;
- it clearly applies to the treatment to be refused in the circumstances that have arisen;
- it has been made in writing, signed and witnessed;
- it includes a statement that it is to apply even where life is at risk;
- it has not been withdrawn;
- the individual has not, after the ADRT was made, appointed a health and welfare attorney to make the specific decision; and
- the person making the decision has not done anything clearly inconsistent with the decision remaining a fixed decision.

Where patients lack capacity and have an ADRT, there should be a presumption that they had capacity when the ADRT was made, unless there are grounds to believe otherwise.

As with contemporaneous decisions, when adult patients with capacity make an ADRT, they do not need to make what others perceive to be a wise decision. The fact that the healthcare team and/or the family do not agree with the decision made does not mean that the patient lacked capacity or that the decision can be overruled or set to one side. Equally, the fact that the patient who now lacks capacity appears content, or even happy, with their quality of life does not mean that their ADRT is invalid. Where there is genuine doubt about the capacity of the patient at the time, or the validity or applicability of an ADRT (as set out above), legal advice should be sought, and an application to the Court of Protection may be needed.

An ADRT that does not meet the criteria to be legally binding must be considered as part of the best interests assessment (see [section 2.6](#) and [Appendix 1](#)).

Health and welfare lasting power of attorney (LPA)

If the patient has made a lasting power of attorney (LPA) appointing a health and welfare attorney with the power to consent to, or refuse, life-sustaining treatment, and the LPA has been registered with the Office of the Public Guardian (OPG), the health and welfare attorney is the lawful decision-maker.³⁰ In that case the power to consent to, or refuse, CANH rests with the health and welfare attorney, and health professionals should respect their decisions. As with patients who have capacity however, health and welfare attorneys do not have the power to insist on treatments that the healthcare team deems not to be clinically indicated.

Health and welfare attorneys must follow the principles of the MCA when making decisions and must act in the patient's best interests.³¹ This will involve them carrying out a best interests assessment and consulting with carers, family members and others interested in the patient's welfare. If the clinical team has proper grounds to doubt that the health and welfare attorney is acting in the patient's best interests, the team members should discuss the matter further with the health and welfare attorney and seek to resolve the issue. If disagreement or doubt persists about whether the attorney is acting in the best interests of the patient, the Court of Protection should be asked to decide.

30 s.11(8)(a) of the Mental Capacity Act states that an LPA does not 'authorise the giving or refusing of consent to the carrying out or continuation of life-sustaining treatment, unless the instrument contains express provisions to that effect'.

31 Mental Capacity Act 2005 Code of Practice, paras 7.18-7.20.

Health professionals should ask to see the original LPA document (embossed with 'validated – OPG' at the bottom of each page) or a certified copy and should check that it gives authority to make decisions about life-prolonging treatment before relying on it to make decisions about CANH.

If an ADRT is made refusing CANH, after a health and welfare attorney is appointed, the ADRT takes precedence.

Clinician-led decision-making

Where decisions about CANH are needed and the patient has neither an ADRT nor an LPA, they must be made by the clinical team on the patient's behalf, based on his or her best interests (see [section 2.6](#) and [Appendix 1](#)).

Discussions about best interests should begin at an early stage and, in some cases, may continue over a significant period; this process is likely to involve both informal discussions and sharing of information, and formally recorded meetings. The aim is for the clinical team and those close to the patient to share clinical information and information about the patient, so that the decision-maker has sufficient knowledge about the patient to make a judgement about whether CANH would be in the patient's best interests. Although this guidance refers specifically to decisions about CANH, in reality these decisions will be made as one part of an overall plan for care and treatment, as part of an ongoing dialogue. This may also involve decisions about ceilings of treatment or intervention, such as whether antibiotics should be provided if the patient develops an infection, as part of an ongoing dialogue.

Who is responsible for making decisions?

For significant decisions, such as those to provide or withdraw CANH, decisions should ideally be made and agreed by the whole of the treating team and those close to the patient. Nevertheless, it should be established clearly, at all times, who has formal decision-making responsibility and this information should be shared with those close to the patient. Seeking clarity about who the decision-maker is at an early stage ensures that CANH is provided, or withdrawn, as appropriate for the individual patient and is not continued, 'by default', because nobody sees it as their responsibility to carry out a best interests assessment.

The MCA does not identify a particular individual as having legal responsibility for decision-making, focusing instead on collaborative decision-making. Nevertheless, in practice, this will fall to the individual with overall clinical responsibility for the patient's care, as part of their duty of care to ensure that the care being delivered to the patient is in their best interests. This will usually be:

- *In hospital* – the named consultant. Where consultants rotate on a regular basis, it is the responsibility of the Trust or hospital management to have a protocol that identifies at any given time the individual with overall responsibility for the patient, and to ensure that decisions are not delayed because of regular staff changes.
- *In a hospice/palliative care unit* – the named consultant or senior doctor with overall clinical responsibility for the patient's care.
- *In the community (in a nursing or care home or living at home)* – the patient's general practice, which will be responsible for determining which of their GPs has the most direct involvement in the patient's care. In some cases, there will be no named GP and GP practices will provide care on a rotational basis. The GP who prescribes it is ultimately responsible for ensuring that CANH is in the best interests of the patient. Where the patient is under the care of a secondary care team, however, the decision should be made with support from the relevant secondary care clinician.

If the patient is in a nursing or care home with NHS continuing care funding, the general practitioner should be supported by a named individual (usually the case manager) identified by the Clinical Commissioning Group (CCG) or Health Board to take on this responsibility. In these circumstances, the CCG/Health Board must satisfy itself that the package of care the patient receives is appropriate.

Who should be involved in decision-making?

The Mental Capacity Act states that, as far as practicable and appropriate, those 'engaged in caring for the patient or interested in his or her welfare' should be consulted as part of best interests decision-making. This will include those who are close to the patient (such as family, friends, neighbours or colleagues) as well as those who have a professional interest in the patient's welfare (such as members of the healthcare team and providers and funders of healthcare). For more information about who should be consulted as part of best interests decision-making, see [Appendix 1](#).

Sometimes confusion has arisen about the role of certain individuals who must be consulted about best interests but are not decision-makers. For the avoidance of doubt, the following are **not** decision-makers but must be involved in the discussions about best interests that precede decision-making.

- Anyone named by the patient as someone to be consulted on such matters
Where the patient has named one or more people to be consulted but has not formally appointed them as health and welfare attorneys, their views about the patient's best interests should be sought but will not be determinative.
- Family and friends, etc. (including 'next of kin')
For practical reasons, patients are frequently asked to name their 'next of kin' when being admitted to hospital or registering with a general practice. This has led to some confusion, with many family members believing that – as 'next of kin' – they have some legal status in terms of decision-making on behalf of the patient. This is not the case. Legally, those close to the patient cannot give consent to, or refuse, treatment on the patient's behalf unless they have been formally appointed as a health and welfare attorney (see above).

Although not the decision-maker, those close to the patient have a crucial role in providing information about the patient as part of the best interests assessment. It will be helpful to discuss with them early on what their role is in the decision-making process, and how they will be involved and can contribute. It may also be helpful to signpost them to other sources of information about their role, so they are supported in participating in the decision-making process.

Some family members or friends do not want to be involved in the discussion or to feel, in any way, responsible for the decision and so would prefer others to decide for the patient. This is entirely acceptable and understandable; this information should be included on the medical record and they should be considered as people it is 'not practicable or appropriate to consult'. This does not prevent agreement being reached; where we refer to 'agreement' in this guidance, it means agreement between the clinical team and those who have been consulted as part of the best interests assessment.

- The multi-disciplinary team
The approach to decision-making should be multi-disciplinary and seek to hear from all members of the care team (doctors, nurses, carers, therapists, etc.) on their views about the wishes and feelings or beliefs and values of the patient. This concept also includes those who are not decision-makers but who have a professional interest in commissioning or providing the patient's care.

It may also be helpful to involve the local palliative care team or a palliative care consultant in discussions early on, as this will aid decision-making and help to inform discussions about any withdrawal process and the end-of-life care to be provided.

- Court-appointed deputies
If the patient has not appointed a health and welfare attorney, the Court of Protection may appoint a 'deputy' to make ongoing healthcare decisions on behalf of the patient. Court-appointed deputies should be consulted and invited to contribute to best interests assessments, but do not have the power to refuse CANH.

- Independent Mental Capacity Advocates (IMCAs)
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. IMCAs should be consulted about decisions and should be invited to contribute to best interests assessments, but do not have the power to consent to, or refuse, CANH.

The Court of Protection

Where there is disagreement about whether a course of action is in the best interests of the patient, or the decision is ‘finely balanced’³² (i.e., there is ongoing uncertainty), the Court of Protection remains the ultimate decision-maker, and can and should be asked to decide.

Box 2: Who is the decision-maker and who should be consulted? – Key points

1. It should be established at all times who has responsibility for deciding whether CANH should be provided or continued and this information should be shared with those close to the patient.
2. The person ultimately responsible for making decisions about CANH is:
 - the patient, if there is a valid and applicable ADRT refusing CANH;
 - the health and welfare attorney if one exists with the appropriate powers; or
 - the person with overall clinical responsibility for the patient’s care, as part of their duty of care to ensure that the care being delivered to the patient is in their best interests.
3. The following people do not have decision-making responsibility, but should be consulted:
 - anyone named by the patient as someone to be consulted on such matters;
 - those ‘engaged in caring for the patient or interested in his or her welfare’; and
 - a court-appointed deputy (if there is one).
4. Where there is nobody who fits into the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.
5. Where there is disagreement about whether a course of action is in the best interests of the patient, or the decision is ‘finely balanced’ (i.e., there is ongoing uncertainty), the Court of Protection remains the ultimate decision-maker, and can and should be asked to decide.

2.4. Health professionals with a conscientious objection

A conscientious objection, in the context of this guidance, can apply to clinicians who are always in favour of providing, and continuing to provide, CANH as well as those who are always against providing CANH in certain categories of cases.

Under the MCA, health professionals may only provide treatment that is in the best interests of the individual patient. Whilst CANH is formally established, and widely recognised, as a form of medical treatment, some health professionals set CANH apart from other forms of treatment and are not personally willing to withdraw it from patients who could, otherwise, go on living for some time. There is no statutory right for health professionals to claim a conscientious objection to participating in the withdrawal of CANH. Nevertheless, it is in nobody’s interests for health professionals to be forced to participate in making or implementing such decisions (or to simply avoid making them) where there are others willing to take over that role.

The strongly held personal views of members of the healthcare team must not stand in the way of a decision being made that is in the best interests of the individual patient, whether that is to provide or to withdraw CANH. As with other circumstances, health professionals must provide information in an unbiased and honest way, admitting uncertainty where it arises. When providing this information, health professionals should take particular care to ensure that their personal views about the patient's quality of life – or about the nature of CANH – do not influence the way in which clinical information is presented to those close to the patient or affect their attitude towards those, including family members, who do not share those views.³³

Where health professionals have a conscientious objection to the withdrawal of CANH, they have a responsibility to recognise this as a potential conflict of interest when considering decisions about CANH; this should be declared prior to beginning discussions within the healthcare team or with those close to the patient. If individual clinicians could not sanction a best interests decision to withdraw CANH, they should hand over the care of the patient to a clinician who could. Where, however, a health professional does not disagree in principle with the withdrawal of CANH but believes, in a particular case, that it is not appropriate, this should lead to further discussion and, where appropriate, a further clinical opinion being sought.

A health professional who believes that CANH should never be provided in particular categories of patient, and could not agree to continuing to provide CANH under such circumstances, should also recognise that their views represent a potential conflict of interest and transfer the patient's care to a colleague.

Provider organisations, including care homes, that carry religious or other convictions that would prevent them from making and implementing particular decisions about CANH should be open about that fact when a best interests decision is needed. All such organisations have a duty, however, to comply with the law, including ensuring that best interests assessments are carried out on a regular basis. These assessments should specifically consider the question of whether CANH continues to be in the patient's best interests as part of the care plan review. Where necessary, organisations should make arrangements for these assessments to be carried out in, or by staff from, another establishment.

Some health professionals do not have a conscientious objection to withdrawal of CANH but are nonetheless anxious or uncomfortable about making such decisions. Continuing treatment 'by default', however, in order to avoid making these difficult decisions, is contrary to the interests of patients and health professionals' legal duties under the Mental Capacity Act. Following this good practice guidance, and seeking support and advice from colleagues, may help to provide reassurance.

Box 3: Health professionals with a conscientious objection – key points

1. 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.
2. 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.
3. Provider organisations that carry religious or other convictions that would prevent them from making and implementing particular decisions about CANH should declare that fact and make arrangements for best interests assessments about CANH to be carried out in, or by staff from, another establishment.

2.5. Clinical assessments

Decisions about CANH must be underpinned by high-quality clinical information. In all cases, factual clinical information should be presented to those close to the patient in a way that they can understand, in order for them to contribute effectively to the best interests assessment (see [section 2.6](#)). It is understandable that some health professionals may want those close to the patient to retain some hope but care needs to be taken to ensure that this desire to help them to deal with what has happened does not affect the accuracy of the information presented. The clinical information provided must be unbiased, honest and realistic and should not raise unrealistic expectations or give false hope to those close to the patient about the level of recovery that can be expected.

Where relevant locally or nationally agreed clinical guidelines exist, they should be referred to and health professionals should justify any significant divergence from established practice. Where guidelines are not available and 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 senior clinician with experience of the condition before a decision about CANH is made.

Factors to consider

Mr Justice Cobb summed up the clinical information he needed to consider when assessing whether CANH should be continued for a patient, PL, who had severe cognitive impairment following a catastrophic stroke.³⁴ This acts as a useful summary of the questions to consider when assessing individuals:

- 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 would the palliative care package include?

When considering the 'palliative care package' the following questions should be considered:

- Where and how will end-of-life care be provided?
- What principles will inform care?
- Where will the patient be cared for?
- Which doctors will lead on providing end-of-life care?
- Has a palliative care doctor been involved in discussions and decision-making?

The amount of time over which all this information is collected, and decisions are made, will depend on the individual circumstances: both the clinical situation and evidence about the views of the individual. Unnecessary delay should be avoided to prevent treatment being provided or continued inappropriately. Equally, however, decisions should not be made too hastily, before there is sufficient information available about the patient's potential for recovery or improvement to allow a proper best interests assessment to take place.

34 *PL v Sutton Clinical Commissioning Group & Anor* [2017] EWCOP 22. 9. <http://www.bailii.org/ew/cases/EWCOP/2017/22.html>

Uncertainty in care and treatment

Despite being evidence-based, there are some aspects of medical management that will always remain uncertain. Where this is the case, those close to the patient should be made aware of the uncertainty inherent in making predictions about levels of recovery, and provided with realistic information in plain language about the patient's current condition and likely potential for improvement. Part of the discussion between the healthcare team and those close to the patient should include frank but sensitive discussion about the fact that medicine is not a precise science, and that it is often impossible to predict with certainty how any particular person will respond. They should be informed that, rather than basing a diagnosis and prognosis on absolute certainty, doctors often need to estimate the worst, best and most likely scenario for the patient, in terms of returning to consciousness, ability to interact at any level, undertake self-directed actions or regain the ability to make decisions.

Predicting the length of time the patient may live, if treatment is provided, is also difficult. Nevertheless, this can be a crucial factor in the best interests assessments. For some patients continuing to survive for a matter of months in their condition may be acceptable but surviving for years would be intolerable. Others would perceive the prospect of many years of life as a more positive outcome than only having the possibility of a few months. These issues are for the decision-maker, treating team and those close to the patient to weigh up – based on the information provided – to assess where each individual patient's best interests lie.

Similarly, the level of uncertainty in diagnosis and prognosis is a relevant factor to consider in relation to what the patient's attitude to risk and uncertainty was. The decision-maker must assess what level of uncertainty or risk the patient themselves would be likely to accept in making a decision either to continue, or to cease, CANH.

Initiating a trial of CANH

The fact that CANH is started does not mean that it should be continued indefinitely and CANH should not be withheld simply because it is considered easier than withdrawing it once it has been established. Where there is doubt about whether to start CANH, it should be started on a 'time-limited trial' basis, with a pre-arranged and scheduled review of the decision. This will be appropriate where, for example:

- more time is needed for the patient's condition to be assessed and for the likely extent of recovery to become clearer; or
- a decision about whether to start CANH is needed before best interest assessments can be completed.

Box 4: Clinical assessments – key points

1. Where relevant locally or nationally agreed clinical guidelines exist, they should be referred to and health professionals should justify any significant divergence from established practice.
2. 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 senior clinician with experience of the condition before a decision about CANH is made.
3. 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.
4. The following questions can be helpful to frame the clinical assessment needed for decision-making about CANH in patients who are not imminently dying:
 - 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 would be provided?
5. Doctors should be open with those close to the patient about the uncertainty inherent in all medical practice and the difficulty of predicting change with absolute accuracy. This can usefully include the 'best', 'worst' and 'most likely' case scenarios to illustrate the extent of uncertainty.
6. CANH should be started on a time-limited trial basis with a pre-arranged and scheduled review where:
 - more time is needed to assess the patient's condition and prognosis, or
 - a decision is needed before best interests assessments can be completed.

2.6. Best interests assessments

Detailed practical guidance for carrying out best interests assessments can be found at [Appendix 1](#) but some of the key points and general principles that should inform the process are outlined here.

Best interests assessments – general principles

1. The Supreme Court (in *Aintree v James*)³⁵ reiterated that treatment (including CANH) should only be provided where it is in the patient's best interests and that the correct question should be whether it is appropriate to provide or continue to provide treatment, rather than whether it is appropriate to withdraw it.
2. 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.
3. Best interests decisions require healthcare staff to consult with those who know the patient and can provide information about the patient's past or present wishes, feelings, beliefs and values in order to assess what the patient is likely to have wanted. It may also be helpful to involve patient advocates in these discussions.
4. Unless the individual had previously indicated that information is not to be shared with others, it is reasonable to assume they would want relevant information shared with those who may be asked to contribute to the decision-making process.
5. Where, although lacking capacity, patients are able to contribute to some extent to the decision-making process, they must be encouraged and supported to do so. Speech and language therapists can play a role here.
6. 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.
7. The clinical team and those who know the patient each have information that is crucial to the decision about whether providing or continuing CANH is in the patient's best interests; all of this information needs to be assessed as part of the decision-making process.
8. The impact of the decision on others, including family members, is a relevant factor to consider, but only to the extent that the patient him or herself would have taken this into account.
9. Decisions must not be influenced by the decision-maker's personal views about the quality of life of patients in this situation, either positive or negative – including, for example, any pre-existing negative views about living with a particular condition or disability. The information provided should be objectively assessed to decide what would be best for this individual patient, taking into account the balance of positive and negative current experiences.
10. Those contributing to the decision must not be motivated by a desire to bring about the death of the patient.³⁶ However, in describing the patient's likely reaction to their current situation, those close to the patient frequently use expressions such as 'he would rather be dead'. This does not equate to a desire to bring about the patient's death and should not be interpreted as such.
11. Decisions to provide CANH should be reviewed on a regular basis to ensure that its provision continues to be in the patient's best interests.
12. All decisions reached, and the reasons for them, should be carefully documented and available for review and audit.

35 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. <http://www.bailii.org/uk/cases/UKSC/2013/67.html>

36 Mental Capacity Act 2005 s.4(5).

What are best interests assessments?

Decisions for adults who lack the capacity to consent are governed by the Mental Capacity Act 2005 (MCA). The MCA specifies that any act done, or decision made, for a patient who lacks capacity, and who does not have a valid and applicable advance decision to refuse treatment (ADRT), must be done or made in his or her best interests.

The primary aim of best interests assessments is to find out about the patient's past and present values, wishes, feelings and beliefs, both generally and as they relate to their current situation, in order to make the decision that is right for the individual patient. All of the information collected about the patient 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.

Decision-makers should accumulate enough information to form a clear view as to what the patient would have wanted if they had retained the capacity to make a decision. (It can be helpful to think about this in terms of whether the patient would consent to the treatment if they regained full capacity for a very short period of time.) The decision needed is whether the information provided about the patient, combined with the clinical information about the patient's likely prognosis would provide sufficient evidence to rebut the strong presumption that it will be in the patient's best interests to prolong his or her life.

'In considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.'³⁷

Lady Hale, *Aintree v James*

Gathering information about the patient

The Mental Capacity Act states that in order to determine best interests, the person responsible for decision-making should consult with 'anyone engaged in caring for the patient or interested in his or her welfare'. This is a broad category, and covers family members and friends, as well as colleagues, neighbours, carers, or others close to the patient who may be aware of his or her views or values. It should also include other members of the multi-disciplinary team. If the patient has no one close to them who are able to represent his or her views, an independent mental capacity advocate (IMCA) should be appointed.

The increasing emphasis on patient-centred decision-making means that the clinical team and those who know the patient each have information that is crucial to the decision about whether providing or continuing CANH is in the patient's best interests. Best interests assessments should therefore be viewed as an exchange of information between the clinical team and those close to the patient rather than simply as an opportunity for the clinical team to inform those close to the patient about the patient's care.

37 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 39. <http://www.bailii.org/uk/cases/UKSC/2013/67.html>

'I cannot over-emphasise the importance of listening to the family who ultimately know the patient's personality best. That is not to say that their wishes and views should be determinative, but it is extremely important that they are heard and their observations given appropriate weight.'³⁸

Mr Justice Hayden, Miss S

How wide the consultation should be will depend on the individual circumstances and the consequences of the decision being made, and it is for the decision-maker to make that judgement. Speaking to a range of family members and friends, however, as well as others who may have an interest in the welfare of the patient, helps to protect against intentional or unintentional bias and gives the decision-maker a broader view of the patient's life, personality, feelings, beliefs and values. As a result, it increases the chance of obtaining sufficient information to be able to reach a decision about whether CANH would be in the patient's best interests.

Those close to the patient should be made aware, at an early stage, of the decision-making process and the part they will play within it. It should be made clear that, unless they have been given formal legal powers, as a health and welfare attorney with the scope to make decisions about life-sustaining treatment, the responsibility for decision-making does not rest with them. They should, however, be informed of how best interests decision making is carried out, and what information is required, so that they can begin to consider the information about the patient that would be helpful for the treating team to know when they are carrying out best interests assessments.

Ascertaining wishes, beliefs, values and feelings

The Mental Capacity Act, as interpreted by the courts, places significant emphasis on identifying the patient's prior wishes, feelings and beliefs as part of any best interests assessments. This includes finding out about what the patient was like as a person; any examples of things the patient said or did which indicate what view they would have of their current situation; any views or values that were particularly important to the patient; and any aspects of the patient's personality that might be relevant to the decision.

In some cases, this will not be problematic. In others, there will be times where there is no evidence about the individual's views about CANH, because they had never considered being in their current situation. This is particularly likely where patients were previously healthy before suffering a sudden-onset brain injury. Nevertheless, evidence is sometimes provided about aspects of the patient's personality, character or beliefs that give a clear indication of what their views would have been, had they been able to express them. The quality of the evidence that is provided about the individual's views and values needs to be assessed. Apparently casual passing comments (e.g. 'shoot me if I ever get like that') should also 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 what the individual's views *might* have been in the absence of reliable evidence.

38 *Cumbria Clinical Commissioning Group v Miss S & Ors*. [2016] EWCOP 32. 13. <http://www.bailii.org/ew/cases/EWCOP/2016/32.html>.

‘Thus I am in the position here of evaluating RY’s best interest with no evidence of sufficient quality to indicate to me what his wishes would be, were he in a position to communicate them. It would be both wrong to speculate and, in my judgement, flawed to assume that in the absence of clear and reliable evidence as to RY’s views, the emphasis on the ‘sanctity of life’ becomes in some way greater. This powerful and important consideration will always weigh heavily in the balance but it must not be permitted to quash all other considerations.’³⁹

Mr Justice Hayden, *Abertawe Bro Morgannwg University Local Health Board v RY & Anor*

The complexity and challenge of making these assessments should not be underestimated and Trusts, hospital management, CCGs and Health Boards should ensure that adequate time and support are available when required. Where a local or regional multi-disciplinary special interest group, or similar mechanism, has been set up (see [Appendix 3](#)) this can provide invaluable help to assess the quality of the evidence in a particular case, and can also provide emotional and practical support for the decision-maker. Where doubt remains about the patient’s best interests, or where there is an element of disagreement, CANH should be provided or continued and the Court of Protection should be asked to decide.

Weighing and using the information about the patient

We have spoken throughout this guidance of the need to take a proportionate approach to decision-making: the extent of the safeguards, documentation, and external scrutiny is proportionate to the consequences of the decision being made. In relation to best interests, this means that the extensiveness of the best interests decision-making process, and the amount of evidence required to justify decisions (for example, the breadth of people consulted on the patient’s wishes, views and feelings, or the number of formal best interests meetings convened), will depend, in part, on the clinical situation and the consequences of the decision. A range of views should be heard and, in deciding who to consult, the decision-maker must not be influenced by a desire to achieve agreement on a particular outcome.

The decision-maker must carefully consider the information provided about the patient, combined with the clinical information about the patient’s likely prognosis, to assess whether there is sufficient evidence to rebut the strong presumption that it will be in the patient’s best interests to prolong his or her life. Clinicians might find it helpful to adopt a ‘balance-sheet approach’ to this task, a tool which has been used by the courts in decision-making.⁴⁰ This involves weighing the benefits and harms of each outcome in light of what is known about the patient’s likely wishes, feelings, beliefs and values, taking into account the balance of positive and negative current experiences, and drawing up a balance sheet of the benefits and risks or disadvantages to the patient of each option.

This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the patient’s best interests. There may be some factors which are of such overriding importance to the patient that they will have a decisive influence on the outcome. These are often called ‘factors of magnetic importance’.

39 *Abertawe Bro Morgannwg University Local Health Board* [2017] EWCOP 2. 41. <http://www.bailii.org/ew/cases/EWCOP/2017/2.html>

40 *W v M & Ors* [2011] EWCOP 2443. 35. <http://www.bailii.org/ew/cases/EWCOP/2011/2443.html>

The balance-sheet approach to decision-making was first considered by the Law Lords in *Bland* where, at the same time, they also held that such an approach would be inappropriate in that case: as Tony Bland was in a permanent VS, continuing treatment had no therapeutic benefit and was therefore 'futile'.⁴¹

The BMA has always taken the view that a balance-sheet approach should be applied across all categories of patients,⁴² and considers that this follows from the approach of the Supreme Court in *Aintree v James*.⁴³ Even for patients who are in a permanent VS, there may be benefits to put in the benefits side of the balance sheet. If, for example, a patient believed strongly in the principle of sanctity of life and in there being intrinsic value in being alive, this should be given serious consideration in making a best interests decision on whether to provide treatment aimed at prolonging his or her life. In all cases the decision should be about what is in the best interests of that individual patient, and not a blanket approach to particular categories or groups of patients.

Documenting and sharing information about best interests assessments

A model proforma is attached as [Appendix 2](#) which provides a way of ensuring that a thorough best interests assessment has been undertaken and documenting the process. Once completed, the form and accompanying documents (including any written submissions made by those close to the patient and the agreed minutes, or digital recording, of all best interests meetings – see [Appendix 1](#) for more details) should be included as part of the medical record.

Where the patient transfers to another healthcare establishment, a record of the best interests assessments undertaken should form part of the information that transfers with the patient. When the patient goes home, or to a nursing or care home, a copy should be sent to the patient's GP. This will allow a record to be kept of when the last assessment took place (and so when the next review is due) and will allow future assessments to build on the information already collected.

Pregnant women

The same principles apply when decisions about CANH are made in relation to a woman who is pregnant, where her death would also result in the death of the fetus. The decision must represent the best interests of the woman.

It is a clearly established legal principle that the right to life (as protected by Article 2 of the European Convention on Human Rights) does not extend to the fetus,⁴⁴ and so any decision relating to a pregnant woman must be concerned only with her best interests and not those of the fetus. Nevertheless, factors such as the gestational age of the fetus and the woman's own views about the pregnancy will form a crucial part of the best interests assessment. If the woman is pregnant with a viable fetus, and it is proposed to withdraw CANH, legal advice should be sought.

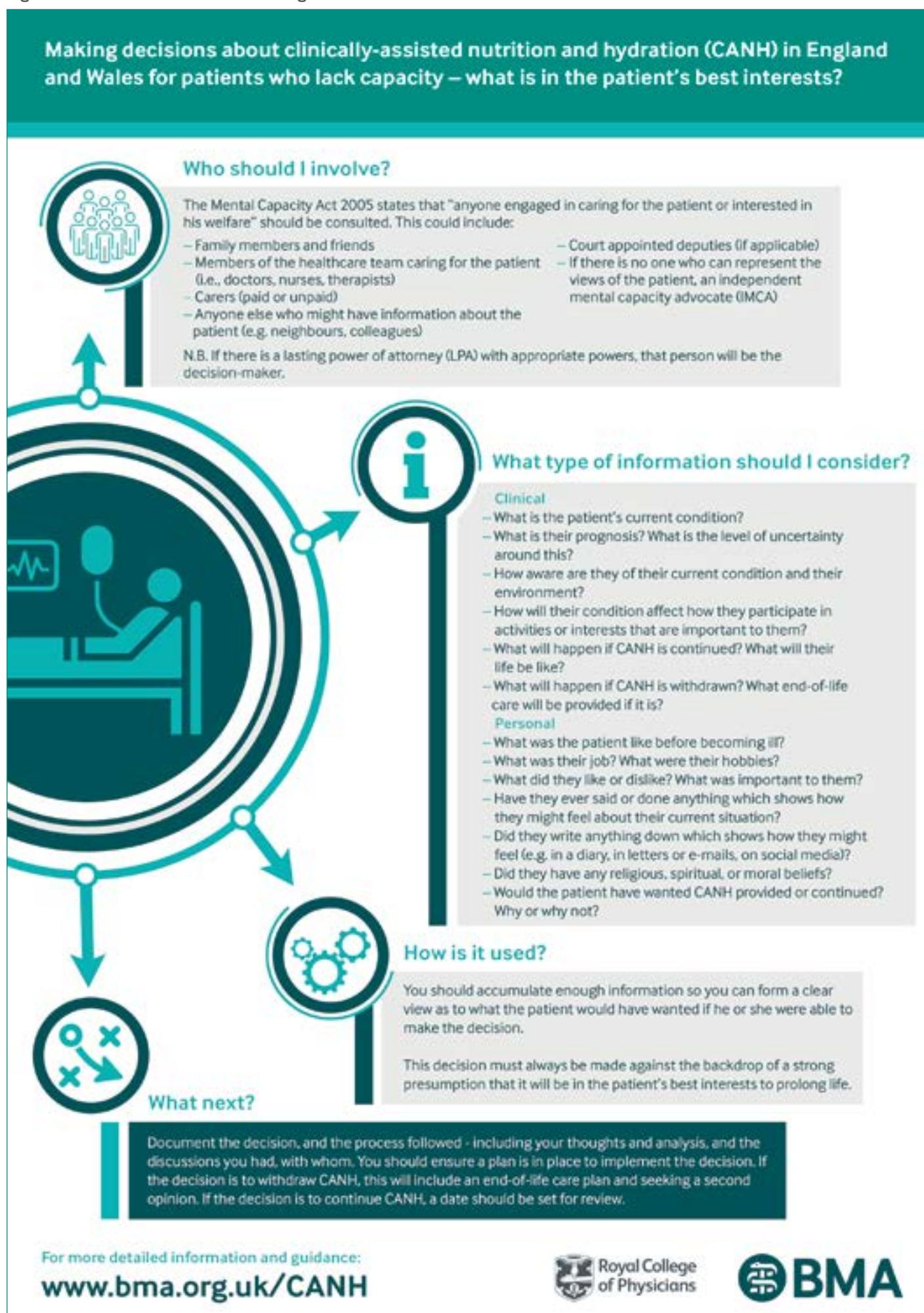
41 *Airedale NHS Trust v Bland* [1993] AC 789, 868. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>

42 British Medical Association (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making*. 3rd Ed. Blackwell Publishing: London. 62.

43 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. <https://www.bailii.org/uk/cases/UKSC/2013/67.html>

44 *Vo v France* [2004] ECHR 326.

Figure 3: Best interests decision-making



2.7. Keeping decisions to provide CANH under review

Decisions that it is in the patient's best interests to provide CANH must be reviewed on a regular basis to ensure that this continues to be the case. This decision should be reassessed as part of every treatment and care review undertaken and be discussed as a part of more general future care planning. Such reviews are essential to ensure that patients are receiving all necessary and appropriate treatment and care and that adjustments are made, as appropriate, to respond to any change in the patient's circumstances, such as an increase or decrease in levels of awareness or increasing certainty about prognosis.

Decisions should be reviewed every 6 months (or every 12 months where the patient has been in a stable condition over a long period of time). They should be reviewed more often if the clinical situation has changed significantly (e.g. if there are signs that the patient is not tolerating the intervention, or if a feeding tube needs replacing); or if information comes to light that might affect the original decision.

Who is responsible for ensuring that reviews take place?

Responsibility for the decision to continue CANH, and therefore for assessing that it continues to be in the patient's best interests, rests with the individual with overall responsibility for the patient's care (see [section 2.3](#)).

Organisations responsible for providing care for patients who are receiving CANH – including NHS Trusts, Health Boards, nursing homes (including independent providers of care) and GP practices – must ensure that practice within, or provided by, their establishment complies with the law. As such, providers of healthcare should put systems in place to ensure that regular best interests reviews are taking place and should raise the issue with the person with overall clinical responsibility for the patient's care if such assessments are not being initiated.

In addition, CCGs and Health Boards have a responsibility to ensure that the care they arrange is provided in accordance with the MCA. They should therefore require providers to ensure that the patient's best interests are assessed on a regular basis, and that those decisions are acted upon. CCGs and Health Boards should ensure that decisions about CANH form a standard part of the patient's annual review to ensure that the healthcare provided is appropriate.

Where patients are living in a nursing or care home, under the care of a general practitioner, information should be included in both the GP-held record and the records in the nursing/care home, to ensure that there is a prompt for the review to take place. A senior nurse with day-to-day responsibility for caring for the patient also has a duty to ensure that decisions to provide CANH are regularly reviewed and to contribute to the reviews.

Where patients are living at home, under the care of a general practitioner, the review timing should be shared with the family or other carers and included in the patient's general practice medical record.

Box 5: Keeping decisions to provide CANH under review – key points:

1. Decisions to provide CANH should be reviewed every 6 months, or more often if the situation changes. Reviews may be extended to every 12 months where the patient has been in a stable condition over a long period of time.
2. The individual who has overall responsibility for the patient's care has a clinical responsibility for ensuring that the care being delivered to the patient – including CANH – is in their best interests.
3. Organisations providing care for patients who are receiving CANH – including independent providers – must ensure their establishments comply with the law and so should put systems in place to ensure that regular best interests reviews are taking place.
4. CCGs/Health Boards should ensure that decisions about CANH form a standard part of the patient's annual review to ensure the healthcare provided is appropriate.

2.8. Second opinions

The use of independent second opinions ensures that the patient's interests have been thoroughly considered and helps provide reassurance to those close to the patient and the wider public that the decision has been made correctly.

GMC guidance is clear that doctors should seek a second clinical opinion where a decision is made not to start, or to withdraw, CANH in a patient who is 'not expected to die within hours or days'.⁴⁵ A second opinion is not required, however, where there is a valid and applicable ADRT, or a health and welfare attorney with the appropriate powers. If a second opinion is requested by an attorney, in order to provide clarity on particular issues around diagnosis and prognosis, however, this should be provided.

Where a decision has been made that continuing CANH is not in the patient's best interests, obtaining a second opinion, so that the decision can be acted upon, should be seen as a high priority.

The second-opinion clinician

GMC guidance states that doctors should 'take all reasonable steps to get a second opinion from a senior clinician (who might be from another discipline) who has experience of the patient's condition but who is not already directly involved in the patient's care'.⁴⁶ This does not need to be a doctor and could, for example, be a nurse or a consultant allied health professional with the relevant skills and experience.

The level and type of expertise required, and the independence of the clinician providing the second opinion will depend on the individual circumstances; our recommendations are set out in the specific sections in [part 2](#) and in [figure 2](#). The most important factors are that the senior 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 – see [section 5.3](#) for more information); and
- be able to act independently.

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

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

Where care is provided in the community, the CCG/Health Board should maintain a database of individuals willing and qualified to carry out second opinions within the locality, and should provide funding for them, to enable general practitioners providing care to patients at home or in nursing or care homes to fulfil their obligations.

Those close to the patient, or interested in the patient's welfare, should always be informed about the arrangements for this review to take place and should be offered the opportunity to be present during the examination and to discuss the case with the second-opinion clinician if they so wish.

The role of the second-opinion clinician

The second-opinion clinician should assess the case objectively, taking particular care to consider the issue from the patient's perspective. They should take whatever steps they consider necessary to make a judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient. This will not require a further full best interests assessment to be carried out, but they must review the information about the assessment that has taken place. If they consider it necessary, they can seek a meeting with those close to the patient. In all cases the second-opinion clinician should:

- carry out their own examination of the patient (in exceptional circumstances, this examination may take place by a remote method – such as Skype – that allows the clinician to view the patient; in these cases, the reasons why it was not possible to conduct a physical examination of the patient should be recorded in the medical record);
- consider and evaluate the medical records to check that the appropriate investigations and tests have been conducted and to assess the interpretation of the results;
- review all information about the best interests assessments undertaken paying particular attention, as appropriate, to the following questions:
 - Have all relevant interested parties been involved: family, friends, healthcare team members, court-appointed deputy or IMCA?
 - Have all the names and relationships of those consulted been clearly documented?
 - Was the prognosis given in functional (behavioural) terms, with upper and lower bounds?
 - Have the patient's prior wishes, feelings, beliefs and values, the current balance of positive and negative experiences, and their likely opinion regarding the CANH decision in question been documented?
 - Are there examples of statements by the patient?
 - Are there examples of similar situations known to the patient where they gave an opinion?
 - Are there examples of the patient's responses to previous accidents or illnesses?
 - Was the decision agreed by all?
 - Is there sufficient evidence available about the patient's views to make a decision about CANH?
 - Have the reasons for the decision been clearly documented?

On the basis of their examination, evaluation and review, the second-opinion clinician should write a report summarising the details of the review undertaken and outlining their own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient.

Where the second-opinion clinician disagrees with the original decision, or has reservations or concerns about some aspects of it, this should be discussed with the original decision-maker to provide any additional information or to resolve the issue.

Box 6: Second opinions – key points

1. The GMC requires a second clinical opinion to 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.
2. We recommend that 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 see [section 5.3](#)); and
 - be able to act independently.
3. Second-opinion clinicians should carry out their own examination of the patient and consider and evaluate the medical record and review the best interests process and documentation.
4. Those close to the patient, or interested in the patient's welfare, should be informed about the arrangements for this review to take place and be offered the opportunity to be present during the examination and to discuss the case with the second-opinion clinician if they so wish.
5. The second-opinion clinician should write a report summarising the details of the review undertaken and outlining their own judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient.
6. If the clinician providing the second opinion disagrees with the original decision or has reservations or concerns about some aspects of it, this should be discussed with the original decision-maker to explore how the matter should be resolved.

2.9. Managing disagreement and uncertainty

Everyone who has provided information should be informed of the decision reached, and the reason for it, at the earliest opportunity. Ideally, all parties will agree with the decision, but where there is uncertainty or disagreement about the patient's best interests, steps should be taken to address the issue without delay.

Disagreement can arise in many ways: within the treating team, within families, between the treating team and those close to the patient, or between a general practitioner and CCG for example. Or there could be disagreement between the original decision-maker and the second opinion clinician. Depending on the nature of the disagreement, further discussion, the involvement of an independent advocate, obtaining a further clinical opinion or holding a case conference can help to resolve the issue.⁴⁷ Where those close to the patient have reservations about, or disagree with, the decision made, they should be informed of the options open to them to challenge the decision. Given their relative lack of knowledge about the way in which decisions are made and disagreements resolved, they should be provided with clear information about the process to follow and be directed to an appropriate body or support group for help and advice.

There is increasing recognition of the role of medical mediation services in helping to resolve disputes about treatment decisions. Where the above strategies have not been successful, the use of medical mediation services should be considered.

If these options fail to resolve the issue, legal advice should be sought to decide whether an application to the Court of Protection is needed.

47 General Medical Council (2008) *Consent: patients and doctors making decisions together*. GMC: London. 77.

Box 7: Managing disagreement and uncertainty – key points:

1. Where there is disagreement or uncertainty about whether CANH is in the patient's best interests, steps should be taken without delay to address the issues.
2. 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.
3. Where there is uncertainty or disagreement about whether CANH is in the patient's best interests, various informal conflict resolution options should be explored – for example, the involvement of an independent advocate, obtaining a further clinical opinion, holding a case conference, or the use of medical mediation services.
4. If agreement is not reached, or if there is uncertainty about the patient's best interests, legal advice should be sought and an application to the Court of Protection made, if necessary.

Applications to the Court of Protection

Where there is disagreement about the patient's best interests, or the decision is finely balanced (i.e. there is ongoing uncertainty), and this is unresolved by seeking a further opinion or mediation, the Court of Protection should be asked to resolve the matter.

'...I would emphasise that although application to court is not necessary in every case, there will undoubtedly be cases in which an application will be required (or desirable) because of the particular circumstances that appertain, and there should be no reticence about involving the court in such cases.'⁴⁸

Lady Black, *NHS Trust v Y*

Uncertainty about best interests is more likely to arise in some cases than others. For example, if the patient has never been able to express feelings, wishes or values, or if the patient has nobody to speak for them and to recount previous views or values, it may be very difficult to assess whether treatment would be in the patient's best interests. In these cases, court involvement is more likely to be necessary.

Where an application to court is needed, proceedings should be initiated and funded by the relevant NHS body responsible for commissioning or providing the patient's treatment. In Wales this will be the Health Board. In England it will be either the CCG or the NHS Trust, depending on where the patient is being treated. This is particularly important given the high cost of legal proceedings and the lack of legal aid available for families to take such cases. Where an application is initiated, the family should be kept informed at all stages and every effort should be made to avoid any unnecessary delays. The courts have, in the past, been highly critical of the parties concerned where there has been delay in bringing cases to court.⁴⁹ Ensuring that all of the necessary assessments have been carried out and are properly documented helps to reduce delays in the court process.

48 *An NHS Trust v Y* [2018] UKSC 48. 126. <https://www.bailii.org/uk/cases/UKSC/2018/46.html>

49 See, for example, *Cumbria NHS Clinical Commissioning Group v Miss S & Ors* [2016] EWCOP 32. 13. <http://www.bailii.org/ew/cases/EWCOP/2016/32.html>

Applications should clearly set out the treatment that is currently being provided and any decisions that have already been made about ceilings of treatment or intervention. This should distinguish between:

- treatments that would be clinically futile – in terms of not being able to achieve their physiological aim;
- those that cannot be provided for clinical reasons (e.g. where it is not possible to reinsert a feeding tube);
- those that are covered by hospital or CCG-wide policies (e.g. a decision not to use antibiotics in particular situations due to the risk of antibiotic resistance); and
- those cases where the treatment may be clinically effective but agreement has been reached between all relevant parties that it would not be in the patient’s best interests.

Where the court is considering the disputed question of whether providing CANH would, or would not, be in the patient’s best interests, health professionals should not pre-empt that judgment by making their own decision to replace, or not replace, a tube that becomes blocked whilst the case is ongoing. Where an immediate decision is needed about whether or not to re-start CANH if the feeding tube becomes blocked or dislodged, and no prior agreement has been reached, an urgent application should be made to the court, out of hours if necessary. If there is no time to seek the view of the court, the presumption should be that the steps required to secure the person’s life should be taken until the court has had the chance to consider the question.

Where there is a material change in the situation (e.g. the clinical team and family reach agreement or clinical uncertainty is resolved), while there is a Court of Protection decision pending, the application can be withdrawn and the decision could then proceed on the basis of the patient’s best interests.

Box 8: Applications to the Court of Protection – key points:

1. Where there is disagreement about the patient’s best interests, or the decision is finely balanced (i.e. there is ongoing uncertainty), an application to the Court of Protection should be made.
2. Uncertainty about best interests is more likely to arise if the patient has never been able to express feelings, wishes or values, or if the patient has nobody to speak for them and to recount previous views or values.
3. Proceedings should be initiated and funded by the relevant CCG/Health Board/NHS Trust responsible for commissioning or providing the patient’s treatment.
4. Where an application is initiated, the family should be kept informed at all stages and unnecessary delays should be avoided.
5. Applications should clearly set out the treatment that is currently being provided and any decisions that have already been made about ceilings of treatment or intervention.
6. A decision to replace, or not to replace, a blocked tube should not be made whilst the issue is under active consideration by the court. Where such a decision is needed, and time permits, an urgent application should be made to the Court of Protection, out of hours if necessary.

2.10. The withdrawal of CANH

If all relevant parties – including the second-opinion clinician – agree that it is not in the patient’s best interests to continue with CANH, this professional guidance has been followed and the details recorded, it should be discontinued as soon as is reasonably practicable in the circumstances of the case.

The withdrawal of CANH does not mean the withdrawal of all other care or symptom-relief, which will continue to be provided throughout the end of life process. A detailed plan for the process of withdrawal and end-of-life care should be prepared, seeking additional help or support from senior colleagues or specialist palliative care teams where necessary. This should ensure that any pain or distress is managed appropriately and that the patient’s dignity is maintained and should include basic steps designed to keep the patient comfortable, such as moistening the mouth and providing good oral hygiene. The plan should detail where end-of-life care will be managed, who will be responsible, and how symptoms will be managed.

Consideration should also be given to how family members and friends will be supported after the decision to withdraw (or not to provide) CANH has been made, for example by signposting them to relevant counselling, bereavement or support services available in the area.

2.11. Record-keeping

The GMC requires that doctors keep an accurate record of decisions about a patient’s treatment and care and of who was consulted in relation to those decisions.⁵⁰ The MCA Code of Practice also requires that a detailed record should be kept of all best interests decisions made and how they were reached.⁵¹

In all cases where a decision about CANH has been made (whether to continue or to stop), the reasons for the decision and the decision-making process must be carefully recorded, contemporaneously, in the patient’s medical record.

In addition to the decision itself, the record should include:

- 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.

This should include a detailed record of all significant discussions, best interests meetings, advice sought and resources consulted. The structured best interests assessment conducted must be clearly recorded and should be available for both internal and external review. To facilitate this, a detailed clinical record should be kept in a format that can be easily extracted from the rest of the medical record. A model proforma can be found at [Appendix 2](#).

More detailed guidance about what information should be recorded in specific circumstances is provided in [part 2](#).

Recording and reporting the death

It is the responsibility of the senior clinician in charge of the patient’s care to ensure that the death is properly certified and reported, following established procedures.

Office for National Statistics and General Register Office Guidance for doctors on completing the Medical Certificate of Cause of Death (MCCD) states that:

50 General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London. Para 75.

51 Mental Capacity Act 2005 Code of Practice. Para 5.15.

'You are asked to start with the immediate, direct cause of death on line Ia, then to go back through the sequence of events or conditions that led to death on subsequent lines, until you reach the one that started the fatal sequence.

If the certificate has been completed properly, the condition on the lowest completed line of part I will have caused all of the conditions on the lines above it. This initiating condition, on the lowest line of part I will usually be selected as the underlying cause of death.

Any other diseases, injuries, conditions, or events that contributed to the death, but were not part of the direct sequence, should be entered in part two of the certificate.⁵²

Following withdrawal of CANH, the immediate, direct cause of death will usually be multi-organ failure or bronchopneumonia, whereas the underlying cause of death will be the original brain injury or medical condition.

Example of death certification in a patient from whom CANH was withdrawn following severe brain injury

		Example
I	(a) <i>Disease or condition leading directly to death</i>	Multi-organ failure
	(b) <i>other disease or condition, if any, leading to I(a)</i>	Hypoxic brain injury
	(c) <i>other disease or condition, if any, leading to I(b)</i>	Myocardial infarction resulting in cardiac arrest
II	<i>Other significant conditions Contributing to death but not related to the disease or condition causing it</i>	Type II diabetes mellitus

The usual rules will apply for determining whether a particular death needs to be reported to the coroner and will depend on the cause of the brain injury or condition.⁵³ If the senior clinician is uncertain as to whether a death should be reported to the coroner or not, he or she should contact the coroner's office.

The role of the coroner is to investigate where the deceased died a violent or unnatural death, the cause of death is unknown, or the deceased died while in custody or otherwise in state detention.

In due course the Medical Examiner will look at all such deaths following the withdrawal of clinically-assisted nutrition and hydration, including consideration of whether a particular death should be reported to the coroner.

52 Office for National Statistics' Death Certification Advisory Group (2010) Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales, section 5.1. Available at: http://www.gro.gov.uk/images/medcert_July_2010.pdf

53 Office for National Statistics' Death Certification Advisory Group (2010) Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales, section 5.1. Available at: http://www.gro.gov.uk/images/medcert_July_2010.pdf

2.12. 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.

Internal governance

Internal review and audit are now a formal part of all healthcare provision and most hospitals, Trusts and Health Boards have formal mechanisms for reviewing deaths – whether as part of a formal Trust policy or through regular multi-disciplinary morbidity and mortality meetings. In England, for example, this is a requirement of the ‘Learning from Deaths’ agenda which imposes obligations on Trusts and their Boards to collect, publish and review data on all in-patient deaths.⁵⁴ In Wales this is part of the ‘Universal Mortality Review’ (UMR).⁵⁵ Trusts and Health Boards should ensure that decisions not to start or re-start, or to withdraw, CANH, in the circumstances covered by this guidance, are identified for review through these mechanisms.

CCGs and Health Boards, which fund care and treatment for patients in whom decisions about CANH are made, should ensure that deaths following withdrawal of CANH from patients who are not imminently dying are reviewed, including where deaths occur in the community. This should include reviewing the clinical investigations that were undertaken by the treating team and how they were interpreted and the process that was followed to assess the patient’s best interests, as well as reviewing the report provided by the second-opinion clinician.

External regulatory review

Information about the decisions covered by this guidance should be recorded in a format that allows it to be easily extracted, when requested, for external review and audit, by bodies such as the Care Quality Commission (CQC), Healthcare Inspectorate Wales (HIW), and Care Inspectorate Wales (CIW). Such reviews should include ensuring that regular and effective best interests assessments are being undertaken where patients are receiving CANH in nursing and care homes, as well as ensuring that appropriate processes are in place, and are followed, in hospitals to decide whether or not CANH should be provided.

National data collection

National data collection provides an important overview of practice across the country and can help improve practice as well as identifying trends that may need further investigation. Where relevant national data collection and audit exist, health professionals should contribute to them in order to make them as effective and inclusive as possible. This includes databases both directly related to the decisions covered in this guidance (such as the UK Rehabilitation Outcomes Collaborative for patients in VS or MCS⁵⁶) and those that are indirectly related (such as the general ICU audit undertaken by the Intensive Care National Audit and Research Centre).⁵⁷

54 National Quality Board (2017) National Guidance on Learning from Deaths. A framework for NHS Trusts and NHS Foundation Trusts on identifying, reporting, 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>.

55 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>.

56 For more information see: www.ukroc.org

57 For more information see: www.icnarc.org

Medical Examiners

The UK Government has announced that a national network of ‘Medical Examiners’ for England and Wales will be in place from April 2019.⁵⁸ Medical Examiners will scrutinise and review all deaths that are not reported to the coroner and will therefore have a role in reviewing deaths following decisions not to provide, or not to continue, CANH.

Box 9: Governance and audit – key points

1. Trusts and Health Boards should ensure that decisions not to start, re-start or to stop CANH are identified for review through existing formal mechanisms for reviewing deaths.
2. CCGs and Health Boards should ensure that deaths following the withdrawal of CANH from patients in the community are formally reviewed.
3. Decisions about CANH should be subject to review and audit by bodies such as the Care Quality Commission, Healthcare Inspectorate Wales and Care Inspectorate Wales.
4. Where relevant national data collection and audit exist, health professionals should contribute to them to make them as effective and inclusive as possible.
5. From April 2019 Medical Examiners will have a role in reviewing deaths following decisions not to provide or not to continue CANH.

58 Department of Health and Social Care (2018) *Introduction of Medical Examiners and Reforms to Death Certification in England and Wales: Government response to consultation*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/715224/death-certification-reforms-government-response.pdf.

Part two: guidance for specific scenarios

3. Decisions about clinically-assisted nutrition and hydration (CANH) in the context of neurodegenerative conditions

Ideally, all patients with neurodegenerative conditions for whom CANH may become an option should be encouraged to include discussion about CANH as part of their advance care planning before they lose capacity. This gives them the opportunity to consider for themselves whether there would come a stage at which they would not wish CANH to be provided or continued. Any such views should be recorded in the medical records, and used as part of the best interests assessment and patients should be advised of the possibility of formalising these views in an advance decision to refuse treatment (ADRT) or by appointing a health and welfare attorney with the power to consent to or refuse CANH.⁵⁹ Similarly, anyone who wants to express a wish to continue to receive CANH should be encouraged to make these views known, so they can be documented in their medical record.

Where the patient has not made an ADRT, the scheduled review of the patient's care and treatment should routinely include considering whether providing or maintaining CANH would be in the patient's best interests.

Throughout this guidance we have emphasised the need to adopt a proportionate approach to decision-making. Each case needs to be considered with a view to assessing the patient's current condition, prognosis and the level of certainty about this, both in terms of the potential for improvement and the length of time for which the patient may live with the consequences of any decision to give, continue or stop CANH.

3.1 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,⁶⁰ 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 those cases, this guidance provides a framework for making decisions about whether continuing CANH would be in the patient's best interests.

Where patients have been diagnosed with a progressive neurological disorder, experienced clinicians will be familiar with the standard clinical progression of the disease and will be able to share this information with those close to the patient. Information provided should include both their current condition (including, as far as this can be determined, how this is likely to impact on the experiences of the patient) and prognostic information in terms of estimated life expectancy.

59 Information for patients about advance care planning is available from a range of organisations including: the Office of the Public Guardian at <https://www.gov.uk/government/organisations/office-of-the-public-guardian>; Compassion in Dying at: <https://compassionindying.org.uk/>; and My Living Will at: <https://www.mylivingwill.org.uk/>. Please note that some of these services may incur a fee.

60 National Institute for Health and Care Excellence (2018) *Dementia: assessment, management and support for people living with dementia and their carers* (NICE guideline NG97) NICE: London. Recommendation 1.10.8; Royal College of Physicians (2010) *Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life*. RCP: London.

3.2 Best interests assessments

Given the focus throughout this guidance on adopting a proportionate approach to decision-making, the extent of the best interests assessment will depend upon the stage of the illness and the estimated life expectancy. 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 wider consultation with those close to the patient, and 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, although lacking capacity, will have a level of awareness and every effort should be made to communicate with them – including through the use of speech and language therapists – in order to glean any information they are able to contribute to the best interests assessment.

Decisions to provide or continue CANH should be reviewed on a regular basis, including at significant points such as where the patient’s clinical condition deteriorates, the anticipated life expectancy changes or another significant event occurs.

3.3 Second opinions

If agreement is reached that CANH is not in the patient’s best interests, 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 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.

Where a GP is the responsible decision-maker (where the patient is living in a nursing or care home, for example), the CCG or Health Board should identify and pay for a suitably qualified and experienced clinician to provide the second opinion.

3.4 Record-keeping

A detailed clinical record should be kept in a format that can be easily extracted from the rest of the medical record for internal and external review. It should include the following information:

1. the diagnosis;
2. clinical assessments that have been undertaken;
3. the treatment that has been provided to date;
4. the stage of the patient’s disease and estimated life expectancy;
5. evidence of the patient’s ability to experience pain;
6. evidence of the patient’s ability to experience pleasure or enjoyment;
7. summary of views and evidence collected from those engaged in caring for the patient or interested in his or her welfare about the past and present wishes, feelings, beliefs and values of the patient and the patient’s likely views regarding the continuation of CANH in their current situation;
8. a detailed summary of all best interests meetings, including any written statements made by those who care for, or are interested in the welfare of, the patient;
9. the reasons for the decision made;
10. if the decision is that the provision of CANH is in the patient’s best interests, the date the decision should be reviewed;
11. if the decision is to withdraw CANH, the second-opinion report giving details of the review undertaken and outlining the second-opinion clinician’s judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient;
12. a record of any discussions relating to the patient’s preference for end-of-life care, including preferred place of death, and any known spiritual or religious beliefs or pre-stated wishes that should be taken into account; and
13. details of the end-of-life care plan put in place.

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

This group includes those 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.

The court has made clear, in the case of PL (who had suffered a catastrophic stroke), that irrespective of the level of awareness and the cause of the condition, the same approach should be taken and that the decision of whether to continue CANH is ultimately a matter of best interests.

'It would be wrong in my view to conclude that where the patient is not diagnosed as MCS or VS, a significantly different approach to the determination of the case should be taken. Quite apart from anything else, as is well-recognised, the diagnosis is often difficult, and may indeed change over time. So just as it would not necessarily follow that someone who is in a 'vegetative state' would be bound to have life-sustaining treatment discontinued, the fact that someone retains consciousness and can answer questions is not in itself a reason not to consider discontinuance of life-sustaining treatment: see *An NHS Trust v A* [2006] 2 Lloyds Rep Med 29. It all depends, as I have indicated, on the individual facts, and every decision must ultimately be governed by what is in a patient's best interests.'⁶¹

Mr Justice Cobb, *PL*

As with other patient groups, the focus should be on adopting a proportionate approach to decision-making. Each case needs to be considered with a view to assessing the patient's current condition, prognosis and the level of certainty about this, both in terms of the potential for improvement and the length of time for which the patient may live with the consequences of any decision to give, continue or stop CANH.

4.1 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.

Factors such as the extent to which the patient is able to experience pain or pleasure, the awareness of self and environment and ability to interact with others are likely to have a bearing on the individual's perception of their quality of life and will form an important part of the best interests assessment. Views from the full multi-disciplinary team about the patient's level of awareness will form an important part of such assessments.

⁶¹ *PL v Sutton Clinical Commissioning Group & Anor* [2017] EWCOP 22. 29. Available at: <http://www.bailii.org/ew/cases/EWCOP/2017/22.html>

4.2 Best interests assessments

The extent 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 for the patient – whether that is to continue or to withdraw CANH – should be used to determine the appropriate investigations. Less extensive best interests investigations will be appropriate for a patient who has a life expectancy of a few months, as opposed to one with a similar clinical condition who could survive for many years, for whom the risks of making the 'wrong' decision for that individual are very significant. Where the patient could survive for a significant period of time, with CANH, an 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 – including through the use of speech and language therapists – in order to glean any information they are able to contribute to the best interests assessment.

4.3 Second opinions

If there is agreement that CANH should not be started, or re-started, or that it should be stopped, 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.

Where a GP is the responsible decision-maker (where the patient is living in a nursing or care home, for example), the CCG or Health Board should identify and pay for a suitably qualified and experienced clinician to provide the second opinion.

4.4 Record-keeping

A detailed clinical record should be kept in a format that can be easily extracted from the rest of the medical record for internal and external review. It should include the following information:

1. the nature, cause and severity of the injury or illness;
2. the clinical assessments that have been undertaken;
3. information about the patient's level of awareness;
4. the treatment that has been provided to date;
5. the patient's presentation and abilities: movements, language, speech, responses etc., and the reproducibility of these findings;
6. evidence of the patient's ability to experience pain;
7. evidence of the patient's ability to experience pleasure or enjoyment;
8. clinical assessment of best, worst and most likely prognosis including life expectancy if CANH is continued;
9. summary of views and evidence collected from the patient, and those engaged in caring for the patient or interested in his or her welfare, about their past and present wishes, feelings, beliefs and values and likely views regarding the continuation of CANH in their current and likely future situation;
10. a detailed summary of all best interests meetings, including any written statements made by those who care for, or are interested in the welfare of, the patient;
11. the reasons for the decision made;
12. if the decision is that the provision of CANH is in the patient's best interests, the date the decision should be reviewed;
13. if the decision is not to start, re-start or to withdraw CANH, the second-opinion report giving details of the review undertaken and outlining the second-opinion clinician's judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient;
14. a record of any discussions relating to the patient's preference for end-of-life care, including preferred place of death, and any known spiritual or religious beliefs or pre-stated wishes that should be taken into account; and
15. details of the end-of-life care plan put in place.

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

This section provides specific guidance for decision-making in patients who were previously healthy (or have ongoing medical conditions that are effectively managed) and have suffered a sudden-onset brain injury leaving them in a vegetative, or minimally conscious, state (collectively referred to as prolonged disorders of consciousness, or PDOC). This is the patient group that is covered by the RCP's clinical guidelines on prolonged disorders of consciousness, and includes those that have traditionally been referred to the Court of Protection.

Some of the patients covered by this section will have been in this condition for many years, possibly without having had a recent best interests assessment that covers CANH. Raising the question of whether CANH continues to be in the patient's best interests can be difficult, but is an important part of the duty of care to the patient. Appropriate support should be provided to enable families to understand why the question is being asked and to inform them that the aim is to ensure that the patient is receiving the treatment that is right for them.

5.1 Clinical assessments

Where patients are in PDOC (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. Assessing levels of awareness – and in particular the prospect of it increasing – however, is not a simple task and there is no single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame intentions and interact with others. These observations need to be repeated over a period of time, with specialist analysis of the results. It is essential, therefore, that these patients have a thorough, expert assessment according to the RCP guidelines to provide a detailed evaluation of their level of awareness of themselves or their environment and to record any trajectory towards future recovery or deterioration.

There may be some cases in which there is clear evidence that the findings of detailed assessments will not affect the outcome of the best interests decision because, for example, even the most optimistic prediction of recovery would not constitute a quality of life they would find acceptable. Where this is the case, a decision can be made before these assessments have been completed.

In most cases, while these investigations are being made, careful consideration should be given to reducing or stopping sedating drugs, to ascertain the extent to which they are reducing responsiveness (if at all). This may involve risks, for example of pain or seizures, which can be distressing for those close to the patient. It is crucial that doctors clearly explain the steps they are taking, why they are taking them and what to expect during that time. If withdrawal or reduction of medication is likely to have significant consequences for the patient, the doctor will need to weigh up the balance of benefits and harms between optimal assessment conditions and adequate symptom-control. This will include an assessment of how important a clear diagnosis of permanent VS versus MCS would be for the patient in terms of the best interests assessment.

Diagnosis and prognosis

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.

Many patients would want CANH continued until there is a clear sense of the level of functional recovery that they are likely to experience. For these patients, the prognosis is important because it provides information necessary to make best interests decisions about their treatment. For example, they might have wished to refuse treatment if the tests used for diagnosing PDOC show they are likely to be permanently unconscious but not if they are likely to regain consciousness.

It is important to know whether patients have any awareness of themselves and/or their environment, because this may affect the quality of their experiences – both positive and negative. Additionally, there is evidence that permanent VS and MCS have different prognoses in respect of recovery of consciousness: generally speaking, the higher the level of responsiveness, the greater the potential for recovering consciousness. So, the tests used for diagnosing PDOC continue to be important for informing the prediction of the best level of recovery that could be expected, although the importance of placing the patient within a specific category (e.g. permanent VS rather than MCS) is reduced.

The RCP guidelines should be followed in terms of 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 need for specialist evaluation

Misdiagnosis of VS and MCS is very common in non-specialist settings so, particularly for patients in the post-acute phase following brain injury, the RCP guidelines recommend a detailed assessment conducted over a period of time (usually 3-4 months) in a designated PDOC assessment unit, in order to establish not only the patient's level of awareness but also their prognosis for recovery.

The longer a patient remains in VS or MCS following sudden-onset brain injury, the less likely they are to emerge and the shorter their life expectancy. In time, therefore, patients will stabilise, and the situation becomes clear. At this point, outcome may be predicted with a greater level of certainty, so a shorter and less detailed assessment is warranted. Specialist nursing homes are increasingly familiar with two of the structured assessment tools recommended by the RCP (the Coma Recovery Scale (CRS-R) and the Wessex Head Injury Matrix (WHIM)). In the stable phase the application of these tools, supported by evaluation by a physician experienced in PDOC on an outreach basis, will often be sufficient to provide a reliable assessment of the patient's level of awareness and interaction.

5.2 Best interests assessments

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. This is because the risks of making the 'wrong' decision for that individual – whether that is to continue or to withdraw CANH – are very significant.

Formal best interests meetings should be conducted as a matter of routine practice for this group of patients to enable the clinical team and those close to the patient to develop a shared understanding of:

- **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
- **life expectancy:** the period of time for which the patient would live with the benefits or harms of continued CANH.

Timing of best interests discussions

The RCP guidelines recommend that best interests discussions should begin as soon as possible and within four weeks of the original injury. 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, and discuss with family and friends, what the patient would want and to share those views with the treating team.

Such important decisions should not be rushed and sufficient time should be allowed to ensure that accurate information can be provided about the expected likelihood and extent of any recovery. The importance of 'not rushing' a decision, however, should not be used as a justification for unnecessary delay or prevarication and information should be collated, and assessed, in a timely manner.

'It needs to be stated that the avoidance of delay in medical treatment cases is an important imperative, as I have now said in a number of judgments. This is not to say that assessments ought to be rushed or that delays may not sometimes be clinically purposive, but respect for a patient's autonomy, dignity and integrity requires all involved in these difficult cases to keep in focus that these important rights are compromised in consequence of avoidable delay. Those who are beyond pain, understanding or without any true consciousness require vigilant protection of their rights and interests, all the more so because of their unique level of vulnerability.'⁶²

Mr Justice Hayden, *Cumbria CCG v Miss S & Ors*

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.

'I acknowledge that there is no evidence that Mr Briggs ever specifically addressed that best case scenario but, in my view, if he was able to do so, he would be horrified by that prospect for himself and his family. This is because he would consider that he and they would have to lead lives in which because of his very limited cognitive and physical abilities he could not take an active and meaningful part in anything that they had previously enjoyed and valued as individuals and had hoped and expected to enjoy together during and after the childhood of his daughter. In my opinion his views, values and beliefs about how life should be lived would cause him to conclude that for him such a life was intolerable.'⁶³

Mr Justice Charles, *Briggs v Briggs*

62 *Cumbria NHS Clinical Commissioning Group v Miss S & Ors* [2016] EWCOP 32. 13. <http://www.bailii.org/ew/cases/EWCOP/2016/32.html>

63 *Briggs v Briggs* [2016] EWCOP 53. 119. <http://www.bailii.org/ew/cases/EWCOP/2016/53.html>.

5.3 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 be, 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, and would take responsibility for ensuring that all of the necessary assessments, in line with the RCP guidelines, have been properly conducted and interpreted.

So far as is reasonably practicable 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.

Where a GP is the responsible decision-maker (where the patient is living in a nursing or care home, for example), the CCG or Health Board should identify and pay for a specialist PDOC physician to provide the second opinion.

The clinician providing the opinion should expect the following information to be provided.

- A clear short introduction to the case highlighting:
 - any clinical doubts in terms of brain damage;
 - any clinical doubts/disagreements about level of responsiveness;
 - any disagreements about the best interests decision; and
 - any other matters of concern.
- A structured and reasonably detailed summary covering:
 - nature, cause and extent of brain damage;
 - relevant neurological investigations (positive and negative);
 - clinical course covering:
 - complications and significant events;
 - changes in level of responsiveness;
 - level of responsiveness observed/recorded over last four weeks;
 - any formal assessments of awareness (copies must be provided); and
 - prognosis used when discussing best interests.
- A copy of the documents recording the relevant best interests meeting(s).
- A clear note of the reasons for the decision made.
- Immediate and easy access to any notes they wish to review including:
 - reports on brain imaging and assessments of responsiveness.
- A private quiet room to see people, read notes, etc.
- Opportunity to talk to:
 - clinical staff familiar with the patient;
 - family and/or friends (if they wish); and
 - anyone who disagrees.

A detailed report should be provided setting out details of the second-opinion clinician's review and their judgement as to whether the decision to withdraw CANH is in the best interests of the patient. Any doubts or reservations about the original decision reached should be included. To assist with this, a model proforma has been developed as part of the process of developing this guidance. This can be accessed via the BMA website.

5.4 The withdrawal of CANH

Palliative care in the context of CANH withdrawal in PDOC is not necessarily the same as other end-of-life care. For these patients, the end-of-life care plan should follow the guidance set out in the RCP guidelines. 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 arranged.

5.5 Record-keeping

A detailed clinical record should be kept in a format that can be easily extracted from the rest of the medical record for internal and external review. It should include the following information:

1. the nature, cause and severity of the brain injury;
2. the clinical assessments that have been undertaken;
3. the treatment that has been provided to date;
4. the results and interpretation of formal tests to assess the patient's level of awareness, carried out in line with the RCP guidelines on prolonged disorders of consciousness;
5. the reasons for any decision not to carry out certain tests or assessments (e.g. because of the impact on the patient of a reduction, or withdrawal, of medication that would be needed);
6. the patient's presentation and abilities: movements, language, speech, responses etc., and the reproducibility of these findings;
7. evidence of the patient's ability to experience pain;
8. evidence of the patient's ability to experience pleasure or enjoyment;
9. clinical assessment of best, worst and most likely prognosis including life expectancy if CANH is continued;
10. 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, feelings, beliefs and values of the patient and the patient's likely views regarding the continuation of CANH in their current and likely future situation;
11. a detailed summary of all best interests meetings, including any written statements made by those who care for, or are interested in the welfare of, the patient;
12. the reasons for the decision made;
13. if the decision is that the provision of CANH is in the patient's best interests, the date the decision should be reviewed;
14. if the decision is not to start, re-start or to withdraw CANH, the second-opinion report giving details of the review undertaken and outlining the second-opinion clinician's judgement as to whether the decision to withdraw (or not to start) CANH is in the best interests of the patient;
15. a record of any discussions relating to the patient's preference for end-of-life care, including preferred place of death, and any known spiritual or religious beliefs or pre-stated wishes that should be taken into account; and
16. details of the end-of-life care plan put in place.

A model proforma for collecting information about decisions to withdraw CANH has been developed as part of the process of developing this guidance, which can be accessed via the BMA website. This sets out all of 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. Its use will also ensure that the information is recorded in such a way as to facilitate both internal and external review.

5.6 National review and audit

There is an urgent need to address the dearth of data on the number of previously healthy patients diagnosed as being in a prolonged disorder of consciousness following a sudden-onset brain injury. In 2013 the RCP recommended that a national database should be established, within UKROC (the UK Rehabilitation Outcomes Collaborative),⁶⁴ to collect data on these patients and the BMA strongly supported this recommendation. Whilst some progress has been made, it is essential that this work is expedited in order to provide a robust national system for collecting and reviewing this information.

In addition to providing national data, such a database would facilitate the establishment of a formal clinical outcome review programme to audit the decision-making process. This should include individual review of a selection of cases where CANH has been withdrawn, to ensure that the appropriate assessments were undertaken in line with the RCP clinical guidelines, and that the appropriate decision-making process was followed.

Once this database is established, all individual clinicians and medical establishments treating these patients should contribute information and make medical records available for review and audit when requested. The disclosure of medical records to a formal clinical outcome review programme would not breach the GDPR (General Data Protection Regulation) – which does not apply after death – and would be in line with the GMC's guidance on confidentiality.⁶⁵

64 For more information see: <http://www.ukroc.org>

65 General Medical Council (2018) *Confidentiality: good practice in handling patient information*. GMC: London. Para 137.

Appendix 1 – practical guidance for best interests decision-making

Decisions for adults who lack the capacity to consent to medical treatment in England and Wales are governed by the Mental Capacity Act 2005 (MCA). The MCA specifies that any act done, or decision made, for a patient who lacks capacity, and does not have a valid and applicable advance decision to refuse treatment (ADRT), 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. The MCA requires that the decision should be that which, objectively, is in the best interests of the patient. The best interests test is therefore not, formally, what is called a 'substituted judgment' test (i.e. a 'what the person would have done test'). However, the courts have held that in the context of decisions about life-sustaining treatment, where it is clear what decision the patient would have taken had they had capacity, then this will almost invariably give the answer as to what is in their best interests.⁶⁶

The MCA deliberately avoids defining best interests, and instead sets out a process to be followed when making a decision. In some cases, this process will be reasonably straightforward. In making more serious decisions about life-sustaining treatment, such as clinically assisted nutrition and hydration (CANH), it will be more extensive and formal. This section provides some practical guidance and tips for best interests decision-making.

Is a best interests decision required?

A best interests decision is not required if the patient has made a valid and applicable advance decision to refuse treatment (ADRT), which applies in the patient's clinical situation. Here the patient has already decided to decline treatment, and that decision must be respected. If there is any doubt about the capacity of the patient at the time of making the ADRT, or about its validity or applicability, legal advice should be sought and the Court of Protection may be asked to decide.

If the patient has made a lasting power of attorney (LPA) appointing a health and welfare attorney with the power to consent to, or refuse, life-sustaining treatment, and the LPA has been registered with the Office of the Public Guardian, the health and welfare attorney is the lawful decision-maker and is required to act in the patient's best interests. If there is genuine doubt that the attorney is acting in the best interests of the patient, this should be resolved as soon as possible. The Court of Protection should be asked to decide if that doubt or disagreement persists.

Where there is no ADRT or health and welfare attorney, the decision-maker will be the person with overall responsibility for the patient's care, usually the consultant or GP, who must make a decision based on the best interests of the patient.

Who should be consulted as part of best interests decision-making?

The Mental Capacity Act sets out who should, where practicable and appropriate, be consulted as part of the assessment of best interests. This includes:

- anyone named by the individual as someone to be consulted on such matters;
- anyone engaged in caring for the patient or interested in his or her welfare; and
- any court-appointed deputy.

Where there is nobody that fits into the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.

66 *Salford Royal NHS Foundation Trust v Mrs P* [2017] EWCOP 23. <https://www.bailii.org/ew/cases/EWCOP/2017/23.html>

The second of the categories above is potentially very broad and open to interpretation. How extensive this consultation should be will depend on what is 'practicable and appropriate' in the individual circumstances and should be proportionate to the consequences of the decision being made. So, for example, if a patient is in the end-stage of a degenerative neurological condition and is known to be approaching the end of their life, consultation with a smaller group of people may be appropriate. Where someone has suffered a sudden-onset brain injury, but is otherwise healthy, more consultation will be needed. The nature, and complexity, of the family relationships may also be relevant factors in this decision. The person responsible for making the decision should ultimately decide how wide this consultation should be, but should take account of the views of other members of the healthcare team in reaching that decision. The decision of who to consult must not be influenced by a desire to achieve agreement on a particular course of action.

For the most significant decisions, it is important to ensure that attempts are made to identify all relevant people to be consulted about whether CANH would be in the patient's best interests. Those consulted usually include family members and could also include friends, colleagues etc., who have known the patient well and may be aware of their views and values. In some cases a neighbour or close friend may have been more involved in the patient's day-to-day life and have a clearer view of the patient's wishes than family members, and so it is important to look beyond the immediate family to gain as much information as possible to feed into the decision-making process. Identifying those who can contribute this information – and ensuring that a range of views is heard – can be difficult. Some strategies that have proved helpful are:

- asking those who are closest to the patient whether there are other family members, friends, carers, colleagues or associates who may have information about the patient to contribute to the best interests assessment;
- asking those who have provided information if they are aware of any other people who hold, or might hold, a different view to their own – it is important that these people are consulted; and
- identifying those who visit the patient to assess whether they should be consulted.

If a decision is made specifically not to consult with a particular individual, the reasons for this should be recorded in the medical notes.

'I want to make it clear that his wife was a great support to him and she stayed with him in the hospital. She was there for him on a daily basis for some three years. She found the situation extremely difficult and, eventually, she came to the conclusion that she had to move on with her life. I am told she has not seen Christopher for some 19 to 20 years. Their marriage broke down and a decree absolute has been pronounced [and ...] in those circumstances, I take the clear view that it was not necessary to inform her of this application.'⁶⁷

Mr Justice Moor, *Re CL*

Best interests discussions should also involve 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 a considerable period of time with the patient and those close to them. Those responsible for commissioning healthcare for the patient should also be consulted.

67 *Abertawe Bro Morgannwg University Local Health Board v CL* [2017] EWCOP 31. 6. www.bailii.org/ew/cases/EWCOP/2017/31.html

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. Even where there are family members and/or others available and positively engaged in the discussion, where the resource is available, it can also be helpful to involve an independent advocate (who may be an IMCA or other experienced advocate) to help with decision-making. An advocate can, for example, help to identify others who need to be consulted and help with the collection of information to be taken into account in the best interests assessments. Some families have reported finding it helpful to have an advocate to help them to navigate their way through the system and to ensure that the patient's views and likely wishes are heard.

Whilst, in the vast majority of cases, those consulted want what is best for the patient, not all family relationships are straightforward; there may be some cases where the views presented are not focused on the best interests of the patient. This may simply be because those consulted find it hard to separate their own views and preferences from those of the patient. They may, for example, have religious views that the patient did not share (or they may lack or oppose the religious views which the patient held) which, subconsciously, influence the information they provide; or there may be financial considerations or concerns which influence their views about either continuing or stopping CANH. Health professionals need to be conscious of the possibility that relatives may have ulterior motives for the views they express.

'In many cases I have found family and friends to be, as I have set out above, the only real conduit through which P's wishes can be communicated. In this case RY's 'voice' has remained resistantly silent [...] I have felt unable to rely on CP's account of her father's wishes for a number of reasons. I do not doubt that she loves him dearly, even though I suspect that their relationship has not always been equable. I also consider that she has a strong faith. She told me that her wishes were indistinguishable from those she has advanced as her father's i.e. even a wholly compromised life, punctuated by pain, would be better than no life. It is also quite plain that she has not accepted the medical evidence and that her belief both in her father's present abilities and future prognosis is very unrealistic.'⁶⁸

Mr Justice Hayden, Re RY

Seeking views from a number of different people and seeking examples or evidence to back up statements made, or views expressed, is a good way of testing the information provided and ensuring that decisions are focused on what is in the best interests of the patient, not in the best interests of others.

68 *Abertawe Bro Morgannwg University Local Health Board v RY & Anor* [2017] EWCOP 2. 34-38. <http://www.bailii.org/ew/cases/EWCOP/2017/2.html>

Box 10: Practical guidance on who should be consulted about best interests – key points:

1. When making best interests decisions, decision-makers should as far as 'practicable and appropriate' consult with:
 - anyone named by the individual as someone to be consulted on such matters;
 - anyone engaged in caring for the patient or interested in his or her welfare; and
 - any court-appointed deputy.
2. The consultation should include family, friends, colleagues, neighbours etc. who have relevant information about the patient, his or her wishes, feelings, beliefs and values, that could help to inform the decision of whether CANH would be in the patient's best interests.
3. The scope and extent of this consultation will depend on the individual circumstances and should be proportionate to the consequences of the decision to be made; the nature and complexity of family relationships will also be a relevant factor. The decision of who to consult must not be influenced by a desire to achieve agreement on a particular course of action.
4. Best interests discussions should involve all members of the healthcare team, particularly those who have spent some considerable time with the patient and those close to them. Those responsible for commissioning healthcare for the patient should also be consulted.
5. If there is no family, or other person to represent the patient, or there is nobody it is appropriate to consult, an IMCA must be appointed.
6. Health professionals need to be conscious of the possibility that those consulted may find it hard to separate their own views and preferences – such as religious or non-religious beliefs or financial interests – from those of the patient, or may have ulterior motives for the views they express. Seeking views from a range of people and asking for examples or supporting evidence for the views expressed helps to ensure that decisions are focused on the patient.

Initiating best interests discussions

Discussions about treatment options, and whether treatment that is possible is in the best interests of the patient, are a standard part of good-quality care and form part of an ongoing dialogue with those close to patients who lack capacity to give consent. Where CANH is provided, it should be reviewed as a standard part of future care-planning. When discussions take place and decisions are made about other interventions, such as providing antibiotics, or CPR, CANH should also feature in the discussion.

The concept of best interests should be introduced at an early stage of the patient's treatment and care, with an initial discussion about the views, beliefs, wishes, feelings and values of the patient. This may not be the point at which a decision about how to proceed is made, but the concept of best interests and an initial discussion about the patient's beliefs, wishes, feelings and views in relation to CANH can begin very early on. Clinicians should make clear what the nature and purpose of this discussion is, and at what stage decisions will be made.

Discussions about whether it is in the patient's best interests to receive or to continue to receive CANH can be challenging and complex, and require sensitivity. This is particularly so where the patient has been receiving CANH for a long time and it is the primary form of life-sustaining treatment being provided. If nothing has changed clinically, some family members will wonder why this question is being raised now. Health professionals can find it particularly challenging to initiate these conversations, lest those close to the patient interpret this as the healthcare team 'giving up' on the patient. As the provision of CANH can only be justified if it is in the best interests of the patient, however, it is crucial that these discussions take place.

A change in condition, prognosis, or care setting can prompt a discussion about whether continuing CANH will be in a patient's best interests. In some cases, the prompt for a discussion about best interests may come from a question from the patient's family – but the responsibility for initiating best interests discussions should not fall to them. The senior clinician should ensure that discussions about best interests in relation to CANH take place on a regular basis.

Best interests meetings

Where decisions are complex, or are likely to have serious consequences for the patient (as is the case with decisions about CANH), it is good practice to convene formal best interests meetings to share and exchange information and to discuss how the patient's best interests can be met. This is not a requirement of the Mental Capacity Act but is a good way of making important decisions and can also help health professionals to demonstrate that the proper process has been followed. As has been made clear throughout this document, best interests decision-making is part of a process rather than a single determinative event. Best interests meetings, therefore, should be viewed as one step in that process – in reality, discussions about what is in the best interests of a patient should begin before this point. It is usually the responsibility of the decision-maker to initiate best interests meetings but they should also be set up when requested by those close to the patient. All parties have the same goal: to determine the best interests of the patient. It is, therefore, in everyone's interest that these meetings are as productive as possible, with everyone feeling they have had the opportunity to have their information and views heard and considered.

Careful planning can maximise the effectiveness of best interests meetings: allowing sufficient time, a quiet space, ensuring that the numbers are manageable and that those close to the patient do not feel intimidated, 'outnumbered', or overwhelmed by the clinical staff. Family members should be encouraged to attend with someone who will be able to support them.

In the meeting itself, someone should be designated to chair the meeting and facilitate discussion. In many cases, this will be the decision-maker themselves, but in some circumstances it may be deemed more appropriate to have some separation between the decision-maker and the chair or facilitator. Whoever is responsible for chairing or facilitating the meeting should ensure that everyone is clear about:

- the purpose of the meeting;
- the decisions that need to be made;
- who is responsible for making the decisions;
- when they will be made; and
- when participants will be informed.

They should also be conscious of the risk of inadvertent pressure or coercion, where the treating team all agree on a decision and those close to the patient find it difficult to question, challenge or disagree, and ensure that everyone has the opportunity to share their views.

A detailed record should be kept of all best interests meetings, summarising the information exchanged and clearly documenting any decisions reached. Notes should be circulated to all parties present, who should be given the opportunity to dispute any points of factual accuracy before they are finalised. In addition, it may be helpful to make a digital recording of formal best interests meetings and share a copy with all relevant parties. This enables family members to listen again to the information in their own time and enables those who could not attend to hear at first hand what was said; it also ensures that a full and accurate record of the meeting is available to all parties.

Box 11: Practical guidance about best interests meetings – key points:

1. Best interests meetings are not required by the MCA but are a good way of making important decisions and for health professionals to demonstrate that the appropriate process has been followed.
2. They are usually convened by the decision-maker but should also be set up when requested by those close to the patient.
3. In order to maximise the effectiveness of best interests meetings, sufficient time and a quiet space should be provided and steps should be taken to help those close to the patient to contribute effectively and to ensure they do not feel overwhelmed by the clinical staff.
4. A detailed note of the meeting should be circulated to all those in attendance to check its accuracy before it is finalised; it may also be helpful to make a digital recording to be shared with all relevant parties.

Assessing best interests

Section 4 of the MCA sets out a checklist of common factors which should be considered when making a decision about best interests. This checklist is not exhaustive, and there may be additional factors which should be taken into consideration.

Mental Capacity Act 2005, section 4

6. He must consider, so far as is reasonably ascertainable—
 - a. the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
 - b. the beliefs and values that would be likely to influence his decision if he had capacity, and
 - c. the other factors that he would be likely to consider if he were able to do so.
7. He must take into account, if it is practicable and appropriate to consult them, the views of—
 - a. anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
 - b. anyone engaged in caring for the person or interested in his welfare,
 - c. any donee of a lasting power of attorney granted by the person, and
 - d. any deputy appointed for the person by the court,

as to what would be in the person’s best interests, and, in particular, as to the matters mentioned in subsection (6).

The type of information to be considered**Clinical information**

Unless the patient had previously indicated that information is not to be shared with others, it is reasonable to assume he or she would want relevant information shared with those who may be asked to contribute to the decision-making process.

In discussions with those close to the patient, the clinical team should therefore:

- explain, in simple terms, the patient’s clinical condition, diagnosis and prognosis including the level of uncertainty surrounding this information;
- provide realistic information about what the future holds for the patient, including the long-term care options available;
- avoid making general statements about the likely extent of the patient’s disability but, instead, focus on specific activities 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;

- provide accurate information about what they should expect following the withdrawal of CANH; and
- explain how the withdrawal of CANH would be managed and the end-of-life care that would be provided.

Information about the patient

The role of those close to the patient is to provide the decision-maker with information about the patient. This might include:

- the nature and length of their relationship with the individual;
- a description of what the patient was like before becoming ill – work, hobbies, likes, dislikes, what was important to them etc.;
- any examples of things the patient said or did that might indicate the view that they are likely to have of their current situation;
- anything relevant the patient wrote down – in a diary, letters, on social media or in e-mails, for example;
- any religious, spiritual or ethical beliefs the patient held and how these might impact on the decision;
- aspects of the patient’s personality that might be relevant to the decision; and
- whether they believe the patient would want CANH provided/continued and their rationale for that assessment.⁶⁹

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 the capacity to make the decision.

‘The purpose of the best interests test is to consider matters from the patient’s point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient’s wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that ‘It was likely that Mr James would want treatment up to the point where it became hopeless’. But insofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.’⁷⁰

Lady Hale, *Aintree v James*

69 The need to be satisfied that a suitably clear indication can be gleaned from such information was stressed by Mr Justice Baker in *W v M* [2011] EWHC 2443 (Fam) 107.

70 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 39. <http://www.bailii.org/uk/cases/UKSC/2013/67.html>

What types of information have the courts taken into consideration in decisions about CANH?

'Prior to his injury he told his cousin that he did not agree that people should be assisted to die, and that a life was no less valuable or worth living if a person was chronically disabled or ill. P was a deeply religious man. He strongly believed that life was sacred given by God and could only be taken away by God. As a Sunni Muslim he believed that suffering was a component of predestination and someone else should not play an assisting role in shortening life merely because of the subjective quality of that life. It is against the tenet of his faith to do anything to shorten a life... All these matters point strongly towards P wishing to ensure that life preserving treatment should continue whatever may befall him.'⁷¹

Mr Justice Newton, *St George's Healthcare NHS Trust v P*, 2015

'Mrs N, all agreed, 'lived to shop'. She loved clothes, she was extremely attentive to her appearance. M told me her mother never left the house without 'her hair and nails being immaculate... [she] kept the family home immaculately clean; she was as obsessive about its appearance as she was regarding her own presentation... It would be easy to criticize these occupations as shallow; it would require discounting her feistiness, her pride and her commitment to her children...

'I am left with little doubt that Mrs N would have been appalled to contemplate the early pain, increasing dependency and remorseless degeneration that has now characterised her life for so long.'⁷²

Mr Justice Hayden, *M v Mrs N*, 2015

'I acknowledge that there is no evidence that Mr Briggs ever specifically addressed that best case scenario but, in my view, if he was able to do so, he would be horrified by that prospect for himself and his family. This is because he would consider that that he and they would have to lead lives in which because of his very limited cognitive and physical abilities he could not take an active and meaningful part in anything that they had previously enjoyed and valued as individuals and had hoped and expected to enjoy together during and after the childhood of his daughter. In my opinion his views, values and beliefs about how life should be lived would cause him to conclude that for him such a life was intolerable.

'As a risk taker and a man of courage I consider that he would not take a different view based on the possibilities that as a result of the ending of his CANH alone, or together with the treatment of his PSH and dystonia, would cause him pain and him and others distress. In my view, he would consider that his family would take comfort from knowing that this arose from what he wanted.'⁷³

Mr Justice Charles, *Briggs v Briggs*, 2016

'The views which PL expressed to her family and friends about the prospects of being dependent on life support, or receiving artificial assistance in order to survive, are clear. She simply would not want this...

SL told me he recalls a conversation with his mother in which she had told him expressly that she would not wish to be 'kept alive artificially'. By that time she had had first-hand experience of the death of a good friend who had passed away in a local hospice. She told him: 'If I can't have a full life, I just want to go.'⁷⁴

Mr Justice Cobb, *PL v Sutton Clinical Commissioning Group*, 2017

71 *St George's Healthcare NHS Trust v P* [2015] EWCOP 42. 38. <https://www.bailii.org/ew/cases/EWCOP/2015/42.html>

72 *M v Mrs N* [2015] EWCOP 76. 53-60. <https://www.bailii.org/ew/cases/EWCOP/2015/76.html>.

73 *Briggs v Briggs* [2016] EWCOP 53. 119-120. <https://www.bailii.org/ew/cases/EWCOP/2016/53.html>

74 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22. 38-39. <https://www.bailii.org/ew/cases/EWCOP/2017/22.html>

'Mrs P was headstrong, frequently combative, effervescing with ideas and projects... Her partner Z told me how he missed sitting up with Mrs P late into the night, drinking whilst he, largely unsuccessfully (he told me) tried to change her opinions on the political issues of the day...

'... she was immensely private about her own health. She never, for example, took her medication in front of people. One of her sisters told me how she would always take her medication discretely [sic] in the bedroom. She would not talk about her health issues... All agreed that her insistence on privacy was a feature of Mrs P's determination to present a strong face to the world...

'Q told me in evidence that there had been a number of occasions when her mother had made it clear to her that she would not have wanted to prolong her life through medical treatment. Her religious beliefs, which changed and developed throughout her life, left her with a sense of consolation that she would be reunited with people dear to her after death. She told Q that she was not afraid of dying. Given that she and her mother were in regular email correspondence Q was confident that some of these views might have been expressed in her undeleted emails from her mother. Accordingly, she began a search. She told me that this was extensive and took her a long time. She found an email dated 13 May 2013. Following some superficial domestic exchanges is the following, which I record in full:

'Did you see that thing on dementia? Made me think of Dad and what a travesty of life his last years were and all the sadder as he had such incredible talent. You know I miss Mum everyday and still talk to her but it is a comfort that she went quickly and I am still haunted by how he ended up... Get the pillow ready if I get that way!... Love Mum'

'... The context of this email seems to me to be significant. It was written by Mrs P having watched a television programme about dementia. This triggered her recollection of her father's death which it is agreed remained a source of great sadness to her. The communication does not therefore exist in a vacuum but in the specific context of her view of life without consciousness or thought. That she identifies, as 'a travesty'. Moreover, so confident was Q that her mother would have expressed this view in writing at some point that she trawled three years of undiscarded emails before finding it. This to my mind gives great credibility to Q's assertion that this was an issue that Mrs P had mentioned with some regularity. It is in this context that I find it to be a powerful indicator of Mrs P's own wishes. Reinforcing this are her own actions, concealing her health issues and deliberately not informing her family about them.⁷⁵

Mr Justice Hayden, [Salford Royal NHS Foundation Trust v Mrs P, 2017](#)

More detailed information about these cases, and how they have influenced the development of the law in this area can be found in [Appendix 4](#).

Written statements about the patient

It can be difficult for those close to the patient to articulate all of the information required in a short space of time in a face-to-face meeting and it is often more productive to ask those who are providing information to do so in writing, to be submitted as part of the best interests process. Taking this approach allows those providing information to produce the statement at their own pace and allows decision-makers to seek views from a much wider group of people than would be possible if all the information was provided orally at a best interests meeting. It also means that there is an accurate record of the statements in the authors' own words rather than the information being paraphrased by the individual taking notes of the discussion.

75 [Salford Royal NHS Foundation Trust v Mrs P \[2017\] EWHC EWCOP 23, 30; 35-37. https://www.bailii.org/ew/cases/EWCOP/2017/23.html](https://www.bailii.org/ew/cases/EWCOP/2017/23.html)

Some health professionals also find it helpful to provide their contribution to the best interests assessments as a written statement, to allow family members to take it away to read and digest in their own time.

Box 12: Practical guidance about the information to be considered in best interest assessments – key points

1. The clinical team should provide accurate and factual information, in a way those close to the patient can understand, expressed as practical examples of what the patient may be able to experience, do or achieve, rather than general statements about levels of disability.
2. Those close to the patient should provide information about the patient as a person, what he or she was like before the injury, interests, beliefs, feelings, values and anything the patient said, did or wrote down that might be relevant to the decision.
3. It can be helpful to ask those who know the patient – family, friends, colleagues etc. – to provide written statements about the patient, including whether they think the patient would want CANH to be provided and why they think that.

Using the information

All of the information and evidence provided about the patient's past and present wishes, feelings, beliefs and values, including the balance of current positive and negative experiences, should be carefully assessed in relation to the most realistic prognostic evidence available.

The decision needed is whether the information provided about the patient, combined with the clinical information about the patient's likely prognosis, would provide clear evidence to rebut the strong presumption that it will be in the patient's best interests to prolong his or her life.

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

Assessing best interests in relation to CANH can be complex, involving the balancing and weighing of a range of divergent and competing factors – both clinical and personal. The courts have promoted a 'balance-sheet approach' to this task which some clinicians also find helpful as a tool for decision-making.⁷⁶ This approach is where the potential benefits and risks of each option are set out side by side. This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the patient's best interests. As part of this process any 'factors of magnetic importance' should be identified; these are factors that might have a decisive influence on the outcome. The balance sheet does not provide 'the answer'; but it is a way of ensuring that all relevant factors have been carefully considered and of demonstrating how the decision has been reached.

'In determining where the best interests lies, it is helpful to draw up a balance sheet of the various factors... In doing so, however, the court must bear in mind the warning given by McFarlane LJ in *Re F (A Child) (International Relocation Cases)* which, although, as the title of the case shows, given in a different context, applies to the judicial use of balance sheets generally:

'Whilst I entirely agree that some form of balance sheet may be of assistance to judges, its use should be no more than an aide memoire of the key factors and how they match up against each other. If a balance sheet is used it should be a route to judgment and not a substitution for the judgment itself. A key step in any welfare evaluation is the attribution of weight, or lack of it, to each of the relevant considerations; one danger that may arise from setting out all the relevant factors in tabular format, is that the attribution of weight may be lost, with all elements of the table having equal value as in a map without contours."⁷⁷

Mr Justice Baker, *Re D*

The 'balance-sheet approach' to decision-making was first alluded to by the Law Lords in *Bland* where, at the same time, they also held that such an approach would be inappropriate in that case: as he was in VS, continuing treatment had no therapeutic benefit and was therefore 'futile'.⁷⁸

The BMA has always taken the view that a balance-sheet approach should be applied across all categories of patients,⁷⁹ and considers that this follows from the approach of the Supreme Court in *Aintree v James*. Even for patients who are in VS, there may be benefits to put in the 'benefits side' of the balance sheet: for example, if a patient believed strongly in the principle of sanctity of life and in there being intrinsic value in being alive this should be given serious consideration in making a decision on whether to prolong his or her life. It will always be a decision about what is in the best interests of that individual patient, and not a blanket approach to particular categories or groups of patients.

⁷⁷ *Re D* [2017] EWCOP 15. 40. <https://www.bailii.org/ew/cases/EWCOP/2017/15.html>.

⁷⁸ *Airedale NHS Trust v Bland* [1993] AC 789. 868. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>.

⁷⁹ British Medical Association (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making*. 3rd Ed. Blackwell Publishing: London. 62.

Box 13: Practical guidance about using the information to assess best interests – key points:

1. The decision that needs to be made is whether the information provided about the patient, combined with the clinical information about the patient's likely prognosis, would provide clear evidence to rebut the strong presumption that it will be in the patient's best interests to prolong his or her life.
2. A 'balance-sheet approach' can help to ensure that all relevant factors have been carefully considered and to demonstrate how the decision has been reached.
3. This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the patient's best interests.

Whilst the decision must be focused on what is right for the individual patient, there is scope to consider the effect of the decision on other people, such as family members, to the extent that the individual him or herself would have been likely to consider that factor if he or she were able to do so.

'I start with the assumption that an instinct for life beats strongly in all human beings. However, I am entirely satisfied that Mrs N would have found her circumstances to be profoundly humiliating and that she would have been acutely alert to the distress caused to her family, which she would very much have wanted to avoid.'⁸⁰ (Emphasis Mr Justice Hayden's own).

Mr Justice Hayden in *Re Mrs N*

The Mental Capacity Act places significant emphasis on identifying the patient's prior and current wishes, feelings and beliefs as part of any best interests assessment. In some cases, this will not be problematic. There may be times, however, where a person's prior, capacitous wishes, feelings and beliefs are, or appear to be, in conflict with their current behaviour. Similarly, it may not always be easy to identify consistent or reliable wishes, feelings and beliefs. The emphasis is on decision-makers taking all reasonable and appropriate steps to identify the choice that is right for the individual. The greater the uncertainty about the correct decision, the greater the degree of scrutiny that will need to be applied including, in some cases, seeking legal advice or applying to the Court of Protection.

'...it is not correct to assume that because a P, and others in an equivalent position, demonstrate contentment and happiness that their present wishes or feelings are that they wish to, and so if they had capacity to do so they would now consent to life-sustaining treatment.'⁸¹

Mr Justice Charles, *Briggs v Briggs*

80 *Re Mrs N* [2015] EWCOP 70. 71. <http://www.bailii.org/ew/cases/EWCOP/2015/76.html>.

81 *Briggs v Briggs* [2016] EWCOP 53. 52. <https://www.bailii.org/ew/cases/EWCOP/2016/53.html>

Patients who have never had capacity

Where the patient has never had capacity, a similar process needs to be followed to enable the decision-maker to gain an accurate picture of the patient, as a person, including any likes or dislikes and to gain an understanding of his or her life, even though not all of the information will be available. The decision about whether to provide, or continue to provide, life-sustaining treatment in patients who have never had capacity to make decisions also depends on the patient's best interests.

This issue has not been considered in the courts in relation to adults, but in cases involving young children, the courts have made clear that: 'the starting point is to consider the matter from the assumed position of the patient' and that 'the paramount consideration is best interests'.⁸²

'There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.'⁸³

Mr Justice MacDonald, *Kings College Healthcare NHS Trust v Thomas and Haastrup*

There will be some adult patients who have never had capacity, but who have still been able to express wishes and feelings. These should be taken into consideration as part of best interests decision-making in the same way as for patients who have lost capacity. Where the patient has never been able to express wishes and feelings, it is likely to be more difficult to assess best interests with any degree of certainty and so these cases are more likely to require court review.

Recording best interests decisions

The GMC requires that doctors keep an accurate record of decisions about a patient's treatment and care and of who was consulted in relation to those decisions.⁸⁴ The MCA Code of Practice also requires that a detailed record should be kept of all best interests decisions made and how they were reached. In addition to the decision itself, the record should include:

- 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.⁸⁵

A model proforma is attached as [Appendix 2](#), which provides a way of ensuring that a thorough best interests assessment has been undertaken and documenting the process. Once completed, the form and accompanying information (including any written submissions made by those close to the patient and the agreed minutes, or digital recording, of all best interests meetings) should be included as part of the medical record.

82 *Kings College NHS Foundation Trust v Haastrup* [2018] EWHC 127 (Fam). 69. <http://www.bailii.org/ew/cases/EWHC/Fam/2018/127.html>

83 *Kings College NHS Foundation Trust v Haastrup* [2018] EWHC 127 (Fam). 69. <http://www.bailii.org/ew/cases/EWHC/Fam/2018/127.html>

84 General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London. Para 75.

85 Mental Capacity Act 2005 Code of Practice, para 5.15.

Appendix 2 – checklist of evidence for best interests decision-making in relation to 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.

<p>Patient Details</p> <p>Name:</p> <p>DOB:</p> <p>Ref/NHS no:</p>	<p>Treating Team</p> <p>Clinician in charge of patient’s care:</p> <p>Specialty:</p>
---	---

Minimum requirement	Detail/comment (optional)	Completed and Signed/ Date of signing
<p>1. PRE-STATED WISHES/PROXY DECISION-MAKING</p> <p>Is there a valid and applicable ADRT with respect to life sustaining treatment?</p> <p>Is there a health and welfare attorney authorised to make decisions regarding CANH?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
<p>2. BEST INTERESTS DECISION-MAKING MEETINGS</p> <p>Have best interests decision-making meetings been conducted with the relevant people including family/friends and any health and welfare attorney/deputy?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Dates of meetings:</p>	
<p>Were the family members/friends made aware of:</p> <ul style="list-style-type: none"> – the patient’s likely prognosis for recovery (or range of possible outcomes); and – the patient’s estimated life expectancy if CANH is continued? 	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	
<p>Have the best interests discussions taken into account the patient’s likely wishes so far as these can be known?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	

Appendix 3 – recommendations for implementation, training and support

Guidance can only improve practice if it is known about and there is a commitment to making it work. This appendix sets out some of the steps that should be considered by other organisations to help health professionals to follow this guidance and to help ensure high-quality care for patients and open and transparent decision-making that maintains public confidence.

This information is also provided in a separate, more in-depth document on the BMA website, for Trusts, Health Boards, Clinical Commissioning Groups and anyone else involved in commissioning or providing services to patients receiving, or who may benefit from, CANH.

The role of Trusts, Health Boards and CCGs

Trusts, Health Boards and CCGs should develop an implementation plan to ensure that there is widespread awareness of this guidance and that health professionals are given the training and support they need to follow it. 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.

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 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 this guidance. Although decision-making will be the responsibility of the most senior clinicians, ensuring that junior doctors are exposed to the clinical care, and the decision-making process, around CANH at an early stage will help them to develop the practical skills to make these decisions appropriately in the future. 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. There may be a role for Health Education England and the Medical Royal Colleges here.

Support

The support that is needed includes providing the resources and practical steps 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 support needed also includes ensuring that there is personal and professional support for decision-makers, who need support to build up their expertise and confidence – particularly for cases where, in the past, the Court of Protection would have been the final decision-maker.

Research carried out by the BMA⁸⁶ 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, not

86 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.

just family members. 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.

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, which might include the following.

- Identifying those individuals, teams and departments that are most likely to need to make decisions about CANH and ensuring that they are notified of the guidance.
- Setting up specific training courses on decisions about CANH and ensuring that staff know where and how to access guidance when they need it.
- Modifying existing training on the Mental Capacity Act to increase the focus on patient-centred best interests decision-making as set out in this 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 are able to comply with this guidance (e.g. ensuring that 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 this guidance, to provide advice and support to others in the hospital/Trust/Health Board as required.
- Setting up a local or regional multi-disciplinary special interest group to support the implementation and use of this 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' (in England)⁸⁷ and the 'Universal Mortality Review' (in Wales)⁸⁸ to ensure that decisions to withdraw CANH are subject to internal audit and review and 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

87 National Quality Board (2017) National Guidance on Learning from Deaths. A framework for NHS Trusts and NHS Foundation Trusts on identifying, reporting, 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>.

88 1000 Lives/NHS Wales. *Supporting NHS Wales to Develop Mortality Reviews*. Available at: <https://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/PHW%20Mortality%20Reviews%285%29.pdf>.

- 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 the availability of other sources of support, advice and guidance that might be utilised 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 this 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 a process for alternative arrangements to be made.

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 of the law, regulation, and this 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).

The role of the Care Quality Commission, Healthcare Inspectorate Wales, and Care Inspectorate Wales

The Care Quality Commission (CQC) and Healthcare Inspectorate Wales (HIW) have an important role to play in ensuring that appropriate processes are followed.

Part of the inspection process for hospitals which are making decisions about CANH should include a review of the decision-making process followed, and the decisions reached, in these cases.

Where patients are being cared for in the community – either at home or in a nursing or care home – part of the inspection process for primary and social care sectors should include checks to ensure that:

- formal best interests assessments are being carried out, for all patients receiving CANH, on a regular basis, and that the decisions are acted upon in a timely fashion; and
- deaths following a decision to stop CANH are reviewed to ensure that the proper process was followed, including a second opinion being sought.

The CQC should also consider asking a range of questions in relation to CANH as part of its annual provider information return (PIR).

The role of NHS England and the Welsh Government

There is an urgent need to expedite the development of a national database to record information about all previously healthy patients who are diagnosed as being in VS or MCS following a sudden-onset brain injury. This database should also be used to facilitate a formal clinical outcomes review programme involving scrutiny of a selection of medical records of cases where CANH has been stopped, to ensure that the correct process was followed. The database should also be used to ensure that regular best interests assessments – including the provision of CANH – are undertaken.

Appendix 4 – decisions about clinically-assisted nutrition and hydration (CANH) – the legal background

- 1993 ● *Airedale NHS Trust v Bland*
CANH is a medical treatment which can be withdrawn if it is no longer in the patient's best interests to receive it. For the time being, such cases should be brought before the court.
- 2001 ● *M and H*
The principles in *Bland* do not violate the Human Rights Act 1998.
- 2005 ● *Mental Capacity Act 2005*
Provides the statutory legal framework for making decisions on behalf of individuals who lack mental capacity in their best interests.
- *Burke v General Medical Council*
An advance request to receive CANH should carry significant weight as evidence of a patient's past wishes and preferences, but cannot be determinative of the doctor's decision on best interests.
- 2007 ● *Mental Capacity Act 2005 Code of Practice*
States that decisions about the proposed withholding or withdrawal of CANH should be approved by the Court of Protection.
- *Practice Direction 9E*
States that decisions about the proposed withholding or withdrawal of CANH from a patient in permanent vegetative state (VS) or minimally conscious state (MCS) should be brought to the Court of Protection.
- 2011 ● *W v M*
First case to involve an application to withdraw CANH from a patient in MCS. Judge holds it is in best interests to continue CANH.
- 2012 ● *Re D*
Advance decisions to refuse treatment must comply strictly with requirements in Mental Capacity Act in order to be valid.
- 2013 ● *Aintree v James*
Best interests incorporates not just medical interests, but the patient's welfare in the widest sense.
- 2015 ● *Re Mrs N*
First case to involve MCS as a result of a neurodegenerative illness, not a sudden-onset brain injury. First case involving an MCS patient where judge authorises withdrawal of CANH.
- *Lambert v France* (European Court of Human Rights)
Individual member states of the EU can set their own standards about the appropriate processes to be followed when considering withdrawal of life-sustaining treatment.
- 2016 ● *Cumbria NHS Clinical Commissioning Group v Miss S*
Delays in resolving cases through the court can be harmful.

2017	<p><i>Briggs v Briggs</i> Emphasises importance of decision-making which gives effect to patient's own wishes, feelings, thoughts and values. Judge authorises withdrawal.</p> <p><i>Director of Legal Aid Casework v Briggs</i> Court of Appeal suggests that Practice Direction 9E does not create a legal obligation for decisions about CANH to go to court.</p> <p><i>M v A Hospital</i> Court suggests again that there are no formally binding measures which make a court decision necessary. Practice Direction 9E is withdrawn</p> <p><i>PL v Sutton Clinical Commissioning Group</i> Court supports withdrawal of CANH for woman following catastrophic stroke.</p> <p><i>Salford Royal NHS Foundation Trust v Mrs P</i> Court supports withdrawal of CANH for woman in MCS following head injury.</p> <p><i>NHS Trust v Mr Y</i> Declaration granted that there is no legal requirement for decisions about CANH to be approved by a court.</p>
2018	<p><i>NHS Trust v Mr Y</i> Supreme Court confirms that there is no requirement for decisions about CANH to go to court, where there is agreement as to what is in the best interests of the patient, and the law and professional guidance have been correctly followed.</p>

Introduction

Decisions about whether to start, continue, or stop clinically-assisted nutrition and hydration (CANH) are some of the most clinically, ethically, and professionally challenging decisions to make in medical practice. The law has historically singled out decisions about CANH in a specific group of patients (those in permanent vegetative state (VS) or minimally conscious state (MCS)) as warranting separate treatment. In these patients, decisions to withhold or withdraw CANH were seen as requiring approval from the Court of Protection – even though other decisions to withdraw CANH from a much larger group of patients with other diagnoses were made on a regular basis without this requirement. Although the rationale for treating these conditions differently from others has been disputed for a long time, the Courts found the distinction, at least initially, fairly straightforward to apply.

As medical understanding of the diagnosis and classification of prolonged disorders of consciousness (PDOC) has developed, these clear lines have become increasingly blurred: in particular, the boundary between MCS in the context of a sudden-onset brain injury and other states of low awareness which result from a progressive neurodegenerative condition, or as part of a terminal decline towards the end of life. We started to see the Court of Protection asked to adjudicate on the withdrawal of CANH from patients with multiple sclerosis,⁸⁹ Huntington's Disease,⁹⁰ and following catastrophic stroke.⁹¹

As this was going on, through the case law we also started to see a change in emphasis on the importance of making a clear diagnosis of either VS or MCS. Withdrawal of CANH was routinely supported in patients in VS, but very rarely in patients in MCS. However, the courts increasingly took the view that a clear distinction is artificial and in practice, unnecessary.

89 *Re Mrs N* [2015] EWCOP 76.

90 *M v A Hospital* [2017] EWCOP 19.

91 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22.

They made clear that the decision in every case came down to what would be in the best interests of the patient – and for many, the precise classification of their condition will be irrelevant in their consideration of an acceptable quality of life.^{92,93}

At the same time, we started to see a shift in the way the Court of Protection approached these cases. Although the strong starting presumption is that life should be prolonged, that presumption can be displaced if the patient’s views, wishes or feelings on receiving life-prolonging treatment can be ascertained with sufficient certainty. A number of judgments have emphasised the importance of decision-making which gives effect to the wishes, feelings, beliefs and values of the patient, and of seeking to reach a decision which the patient would have made for him or herself, had they had capacity.⁹⁴

These developments culminated in a case heard by the Supreme Court in 2018, where it was confirmed that there is no requirement to seek approval from the court before withdrawing or withholding CANH, providing that 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.⁹⁵

About this document

These legal developments underpin this guidance on CANH, where we quote extensively from legal judgments in relevant cases. This document outlines the key legal developments in England and Wales relating to decisions about CANH, and provides more detail about the case law referred to throughout the guidance. It is intended to provide more context about the legal background for decisions about CANH. It can be read in conjunction with the guidance document or, for those with a more academic interest, as a separate document. The legal developments are set out in chronological order. Not every single issue in each case is summarised: the focus is on statements and decisions which are relevant to decision-making about CANH.

This paper does not constitute legal advice which, if necessary, should be sought on the facts of any specific individual case.

1. *Airedale NHS Trust v Bland* – [1993] AC 789

Tony Bland was 17 years old when he was injured in the Hillsborough Disaster in April 1989. As the result of severe injuries sustained in the crush, the supply of oxygen to his brain was interrupted. He suffered catastrophic and irreversible brain damage to the higher centres of the brain, leaving him in a permanent vegetative state (VS). He could breathe unaided, but had no cognitive function and was unable to see, hear, taste, smell, speak or communicate in any way.

All those involved in his care were of the opinion that there was no hope of improvement or recovery, but that he could live for many years in his current state as long as medical care and treatment continued to be provided. With the agreement of his family, the hospital caring for Tony sought a declaration that they could discontinue the life-sustaining medical treatment, including CANH, being provided to him – knowing that this would inevitably result in his death.

The House of Lords granted this declaration, holding that as there was no therapeutic, medical or other benefit being provided to Tony Bland, it could no longer be said to be in his best interests to continue to receive CANH.

92 *Re Mrs N* [2015] EWCOP 76.

93 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22.

94 *Briggs v Briggs* [2016] EWCOP 53.

95 *An NHS Trust v Y* [2018] UKSC 46.

Bland established several key principles which are fundamental to the development of the law in this area:

1. CANH is a medical intervention, not basic care;⁹⁶
2. although the principle of sanctity of life is fundamental, it is not absolute and may yield in certain circumstances;⁹⁷
3. a decision about whether CANH should be initiated or withdrawn must be determined by what is in the best interests of the patient;⁹⁸
4. providing, or continuing to provide, medical treatment to someone without their consent could amount to a tort and crime of battery;⁹⁹
5. in some cases, the decision about whether to withhold CANH would be made by weighing up relevant and competing considerations, but in the case of Tony Bland who was in permanent VS, such an approach was inappropriate as the treatment had no therapeutic benefit and was therefore 'futile';¹⁰⁰ and
6. until a body of expertise and practice had been built up, decisions about withdrawing CANH should 'as a matter of routine' be brought before the court.¹⁰¹

A note on euthanasia and assisted suicide

Some people and jurisdictions refer to withdrawing or withholding life-sustaining treatment as 'passive euthanasia'. This is not the position in the UK, where euthanasia has been given a very specific meaning: the taking of active steps with the intention of terminating the patient's life.

The courts in England and Wales proceed on the basis that there is a fundamental distinction between decisions not to provide, or not to continue, life-sustaining treatment and euthanasia.¹⁰²

Euthanasia or assisted suicide involves taking active steps with the intention of terminating the patient's life. The intention behind a decision to withdraw treatment, however, is to stop providing medical treatments or interventions that are not able to benefit the patient, allowing them to die from their pre-existing condition. In the words of Lord Goff of Chieveley in *Bland*:

'...the doctor's conduct in discontinuing life support can properly be categorised as an omission. It is true that it may be difficult to describe what the doctor actually does as an omission, for example where he takes some positive step to bring the life support to an end. But discontinuation of life support is, for present purposes, no different from not initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition; and as a matter of general principle an omission such as this will not be unlawful unless it constitutes a breach of duty to the patient.'¹⁰³

All forms of assisted dying are unlawful in the United Kingdom.

96 *Airedale NHS Trust v Bland* [1993] AC 789, 870.

97 *Airedale NHS Trust v Bland* [1993] AC 789, 864.

98 *Airedale NHS Trust v Bland* [1993] AC 789, 866.

99 *Airedale NHS Trust v Bland* [1993] AC 789, 857.

100 *Airedale NHS Trust v Bland* [1993] AC 789, 868.

101 *Airedale NHS Trust v Bland* [1993] AC 789, 873.

102 *Airedale NHS Trust v Bland* [1993] AC 789, 866.

103 *Airedale NHS Trust v Bland* [1993] AC 789, 866.

2. *NHS Trust A v M and NHS Trust B v H* – [2001] Fam 348

Mrs M was a 49-year-old woman who had a cardiorespiratory arrest in September 1997 while under general anaesthetic during surgery, and suffered a hypoxic brain injury. She was later diagnosed as being in VS. Mrs H was a 36-year-old woman who suffered anoxic brain damage following an asystolic cardiac arrest in January 2000 whilst receiving treatment in hospital for pancreatitis. She too was later diagnosed as being in VS.

The hospital trusts caring for each woman sought a declaration that would allow them to withdraw CANH. These applications were supported by the clinical teams caring for the women, and their families.

Dame Elizabeth Butler-Sloss held that the principles set out in *Bland* had to be considered in light of the implementation of the European Convention on Human Rights (ECHR) into UK law through the Human Rights Act 1998, particularly in relation to the right to life (protected by Article 2) and the right to freedom from cruel, inhuman or degrading treatment (protected by Article 3).

The court held that:

- although Article 2 did impose a positive obligation to provide medical treatment, it did not apply where treatment would not be in the best interests of the patient;
- discontinuing treatment would not be an intentional deprivation of life under Article 2, as it was an omission rather than an act, and the death of the patient would be the result of their underlying illness or injury and not any other act; and
- provided the patient would be unaware of pain or suffering, there would be no breach of Article 3.

The court authorised withdrawal of CANH on the basis that it was in the best interests of Mrs M and Mrs H.

Although *Bland* was heard before the Human Rights Act came into force, it is clear that the judges in *Bland* were cognisant of the human rights elements of the case, particularly in relation to the right to life (protected by Article 2 of the ECHR).¹⁰⁴

Following the introduction of the Human Rights Act, it was not immediately obvious that anything in the *Bland* judgment conflicted with the new legislation. *M* and *H* confirmed that the principles set out in *Bland* were unaffected by the Human Rights Act.

3. Mental Capacity Act 2005 and the Mental Capacity Act 2005 Code of Practice

The Mental Capacity Act 2005 brought together the common law on decision-making for patients who lack capacity by way of a composite code. The Act, which applies in England and Wales, provides the legal framework for acting, and making decisions, on behalf of individuals who lack the mental capacity to make decisions for themselves.

One of the key principles of the Act is that any decision made on behalf of a person who lacks capacity must be made in their best interests, and Section 4 sets out the factors to be taken into consideration when making such a decision. The key principles are that every case must be dealt with on an individual basis; that the person making the decision must take into account all relevant factors that it would be reasonable to consider; and that the test is whether treatment is in the best interests of the person in question, not what the decision-maker would want if they were in that position.

¹⁰⁴ *Airedale NHS Trust v Bland* [1993] AC 789. 863H.

S.4(6) and (7) also set out a checklist of factors which should be taken into consideration when making a best interests decision.

6. *He must consider, so far as is reasonably ascertainable—*
 - a. *the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
 - b. *the beliefs and values that would be likely to influence his decision if he had capacity, and*
 - c. *the other factors that he would be likely to consider if he were able to do so.*
7. *He must take into account, if it is practicable and appropriate to consult them, the views of—*
 - a. *anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,*
 - b. *anyone engaged in caring for the person or interested in his welfare,*
 - c. *any donee of a lasting power of attorney granted by the person, and*
 - d. *any deputy appointed for the person by the court,**as to what would be in the person’s best interests, and, in particular, as to the matters mentioned in subsection (6).*

The Act itself is silent on the subject of process or procedure to be followed when decisions about withdrawing or withholding CANH from a patient lacking capacity are to be made. The Act’s accompanying Code of Practice, however, contains provisions which contributed to an ongoing debate on whether an application to the Court of Protection is a legal requirement, or simply a matter of good practice. Section 6.18 of the Code states that:

Some treatment decisions are so serious that the court has to make them – unless the person has previously made a Lasting Power of Attorney appointing an attorney to make such healthcare decisions for them or they have made a valid advance decision to refuse the proposed treatment. The Court of Protection must be asked to make decisions relating to:

- *the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from a patient in a permanent vegetative state (PVS)*
- *cases where it is proposed that a person who lacks capacity to consent should donate an organ or bone marrow to another person*
- *the proposed non-therapeutic sterilisation of a person who lacks capacity to consent (for example, for contraceptive purposes)*
- *cases where there is a dispute about whether a particular treatment will be in a person’s best interests.*

Sections 8.18 and 8.19 elaborate:

8.18 Prior to the Act coming into force, the courts decided that some decisions relating to the provision of medical treatment were so serious that in each case, an application should be made to the court for a declaration that the proposed action was lawful before that action was taken. Cases involving any of the following decisions should therefore be brought before a court:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS)
- cases involving organ or bone marrow donation by a person who lacks capacity to consent
- cases involving the proposed non-therapeutic sterilisation of a person who lacks capacity to consent to this (e.g. for contraceptive purposes)
- all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.

8.19 The case law requirement to seek a declaration in cases involving the withholding or withdrawing of artificial nutrition and hydration to people in a permanent vegetative state is unaffected by the Act, and as a matter of practice, these cases should be put to the Court of Protection for approval.

Following the Supreme Court ruling in *Y* in 2018 (see below), the requirement in the Code of Practice for decisions involving withdrawal of CANH to go before a court is no longer valid where there is agreement as to what is in the person's best interests.

4. *Burke v General Medical Council* – [2005] EWCA Civ 1003

Mr Burke was a 45-year-old man suffering from spino-cerebellar ataxia with peripheral neuropathy, a progressively degenerative condition with a similar course of degeneration to multiple sclerosis. Although he was likely to maintain full cognitive faculties (including mental capacity) as his condition worsened, he would be unable to swallow and would require CANH to meet his nutritional and hydration needs.

Mr Burke became concerned that the General Medical Council (GMC) guidance would permit a doctor to decide whether CANH should be provided and allow them to withdraw CANH, even if his death was not imminent. He sought judicial review of the GMC's guidance, claiming that it was incompatible with the Human Rights Act.

In the first instance, Mr Justice Munby upheld his claim, ruling that some parts of the GMC's guidance were incompatible with the Human Rights Act. This decision was overturned, however, by the Court of Appeal, where it was held that: 'where life depends on the continued provision of CANH, there can be no question of it not being clinically indicated unless a clinical decision has been taken that the life in question should come to an end. This is not a decision that can lawfully be taken in the case of a competent patient who expresses the wish to remain alive.'¹⁰⁵

The law as it currently stood addressed Mr Burke's concerns.

It was already a well-established principle that adults with capacity can refuse treatment, even if treatment is clearly in their best interests.¹⁰⁶ *Burke* made clear, however, that patients cannot insist on receiving a medical treatment that is clinically inappropriate and that an advance request to receive CANH should carry significant weight as evidence of a patient's past wishes and preferences, although it cannot be determinative of the doctor's decision on best interests.

The source of a doctor's duty to provide CANH lies in the normal duty of care that doctors owe to patients to keep someone alive, not because a patient demands it. A patient's wish will, however, underline that duty, and a doctor who deliberately interrupted life-prolonging treatment with the intention of ending the patient's life, in the face of a competent patient's wish to be kept alive, would be open to a charge of murder.¹⁰⁷

Lord Phillips also commented on the apparent requirement to go to court, as set out in *Bland*, stating that the court has no power to authorise treatment that would otherwise be unlawful. He noted that good practice 'may' require medical practitioners to seek a court declaration where the legality of the proposed treatment was in doubt, but that they were not 'required to do so as a matter of law'.¹⁰⁸

5. Practice Direction 9E

In 2007, the Court of Protection Rules, supplemented by various Practice Directions, were published, setting out practice and procedure to be followed in the new Court of Protection.

Section 5 of Practice Direction 9E (PD9E) restated the 'requirement' to seek court approval prior to withdrawing CANH from patients in VS, and also extended it to patients in MCS.

Cases involving any of the following decisions should be regarded as serious medical treatment for the purpose of the Rules and this practice direction, and should be brought to the court:

- a. *decisions about the proposed withholding or withdrawing of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state;*
- b. *cases involving organ or bone marrow donation by a person who lacks capacity to consent; and*
- c. *cases involving non-therapeutic sterilisation of a person who lacks capacity to consent.*

In December 2017 Practice Direction 9E was withdrawn and not replaced.

¹⁰⁶ *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449.

¹⁰⁷ *Burke v General Medical Council* [2005] EWCA Civ 1003. 34.

¹⁰⁸ *Burke v General Medical Council* [2005] EWCA Civ 1003. 80.

6. *W v M* – [2011] EWHC 2443 (Fam)

M was a 43-year-old woman who, in 2003, was due to leave for a skiing holiday when her partner found her in a drowsy and confused state. She was taken to hospital where she fell into a coma. It was discovered that she had suffered viral encephalitis which left her with extensive and irreparable brain damage. After emerging from coma, she was diagnosed as being in VS.

It was only when her family decided, with the support of the treating doctors, to begin proceedings to withdraw CANH, that it was discovered she was in MCS rather than VS. The family subsequently decided to proceed with the court application without the support of the medical team.

There was dispute between the parties as to the quality of life experienced by M. Medical experts for the family reported that they were *'unable to identify any aspect of M's life that gave her positive pleasure or satisfaction.'*¹⁰⁹ M's family gave evidence that she had made comments prior to becoming ill about her grandmother's care in a nursing home, and following media coverage of Tony Bland's case, which they believed demonstrated that she would not want to be kept alive in her current situation. Other medical experts reported that she had a life expectancy of around a further ten years and had at present a quality of life that was reasonable, and that could certainly be improved with recommendations for future management. Staff who cared for her in the nursing home reported that she seemed to get enjoyment from things like listening to music, or feeling the sun on her face whilst outside.

In making the decision, Mr Justice Baker held that the law required the court to identify factors relevant to the patient's best interests and carry out a balancing exercise. Following such an exercise, he held that it was in M's best interests for CANH to be continued, and so rejected the family's application.

Following *Bland*, the approach set out by the judges continued to be followed in relation to patients in permanent VS – and the outcomes were invariably the same. Once the court was satisfied that the patient was in permanent VS, with no prospect of recovery, and subsequently that treatment was regarded as 'futile', it followed that no weighing exercise of best interests was necessary and treatment could be withdrawn.

The case of *M* was the first case to involve an application to withdraw CANH from a patient in MCS. Mr Justice Baker adopted a 'balance-sheet' approach, which involved carefully considering and weighing all of the factors for and against continued treatment. This involves considering not just medical issues, but wider factors concerning the individual. Accordingly, the patient's previously expressed wishes, beliefs, values and feelings, and other factors which would have influenced his or her decision had they been able to make it, are at the heart of decision-making.

Mr Justice Baker accepted the arguments that M experienced pain and discomfort, and that her disability severely restricted what she could do. Having considered all the available evidence, however, he concluded that M's experiences were not completely negative, and that there was a reasonable prospect that more positive experiences could be included and extended by a planned programme of increased stimulation. He noted that although M's previously expressed wishes were important, he could not attach significant weight to them as they were not a clear indication of what M would want now, eight years into her condition.

Mr Justice Baker made various other observations about decisions to withhold or withdraw CANH from patients in VS and MCS:

1. in his view, PD9E created a requirement to refer decisions about whether to withdraw or withhold CANH from a person in VS or MCS to the court;
2. no application for an order to withhold or withdraw CANH should be made unless an assessment to provide a diagnosis of VS or MCS had been carried out (in his view, disputes between family members and clinical staff about whether M was in VS or MCS had contributed to delays in the case); and
3. he expressed concern that public funding had not been made available to the family to pursue their case.

7. *Re D* – [2012] EWHC 885 (COP)

D was 54 years old when he developed a swelling in his thyroid gland that was suspected to be malignant. He underwent an initial operation in May 2011 which was successful, but further tests indicated that another operation was necessary. A subsequent operation in July 2011 led to complications, at which time D suffered a cardiac arrest, leaving him with severe and irreparable brain damage, and in VS.

Before his first operation D had discussed his fears and concerns with his family and friends and had left a signed letter to his sister-in-law, which made it clear he wished to refuse any medical treatment of an invasive nature ('including but not restricted to placing a feeding tube in [his] stomach')¹¹⁰ that would only extend a reduced quality of life. Although this was a clear refusal of treatment being made by a patient with capacity, it was not legally binding under the Mental Capacity Act as it did not include a specific statement that the decision was to apply to the specified treatment even if his life was at risk, and because the signature had not been witnessed. The case was taken to court months later as a withdrawal of treatment from a patient in VS case meaning that a decision had to proceed on the basis of best interests.

The court held that as D was in VS, the decision was legally straightforward and CANH could be withdrawn while D was receiving 'carefully planned palliative care'.¹¹¹

Although by the time the case reached the court the decision was relatively straightforward, this case highlights the issue of the applicability of advance decisions in relation to CANH. Mr Justice Peter Jackson noted that the fundamental importance of the decision to withdraw life-sustaining treatment meant that the need for advance decisions to comply with the form specified by statute was all the greater.

ADRTs are addressed by sections 24 to 26 of the Mental Capacity Act, where a distinction is drawn between treatments that are life-sustaining, and treatments that are not. For treatments that are life-sustaining, the criteria for validity are more stringent: the advance decision must be verified by a statement to the effect that it is to apply to that treatment even if life is at risk, and be made in writing and signed and witnessed.

¹¹⁰ *Re D* [2012] EWHC 885 (COP). 15.

¹¹¹ *Re D* [2012] EWHC 885 (COP). 18.

8. *Aintree University Hospitals NHS Foundation Trust v James* – [2013] UKSC 67

Mr James was a 68-year-old man who was admitted to hospital in May 2012 following complications with a stoma fitted during successful treatment for cancer of the colon. The problem was soon resolved, but he acquired an infection which was complicated by the development of chronic obstructive pulmonary disease, an acute kidney injury, and persistent low blood pressure. He was admitted to the critical care unit where he was placed on a ventilator and received CANH through a nasogastric tube. By July, Mr James' condition had deteriorated markedly, and he was considered to lack the capacity to make decisions about his medical treatment.

A declaration was sought by the Trust that it would be in Mr James's best interests for three specified treatments (invasive support for circulatory problems, renal replacement therapy, and cardiopulmonary resuscitation (CPR)) to be withheld in the event of a clinical deterioration. There was disagreement between his clinical team and his family: the clinical team felt it would not be in Mr James's best interests for him to receive these interventions should his condition deteriorate to the extent that he needed them, while his family believed that, although he would never recover to his previous health, he still received great enjoyment from life.

In the first instance, Mr Justice Peter Jackson refused to make the declaration sought by the Trust, on the basis that he was not persuaded that treatment would be futile or overly burdensome, or that there was no prospect of recovery (criteria set out in s.5.31 of the Mental Capacity Act Code of Practice). The judge also held that Mr James' family life was of the 'closest and most meaningful kind', which carried great weight in his assessment of best interests.

By the time the Trust appealed the decision, Mr James's condition had deteriorated significantly; the Court of Appeal overturned the previous decision and granted the declaration sought by the Trust. The Court of Appeal judges held that the treatment proposed would be futile, as per the Mental Capacity Act Code of Practice, and that this being the case, the patient's wishes must give way to what is in his best *medical* interests. Although Mr James had died shortly before the Court of Appeal handed down their judgment, the Court granted his widow permission to appeal in view of the importance of the issues and the different approaches taken by the trial judge and the Court of Appeal as to the assessment of best interests.

The Supreme Court upheld the decision of the Court of Appeal, on the basis of the fresh evidence of Mr James's condition which was before them. However, they supported the approach to the best interests assessment taken by Mr Justice Peter Jackson, and overturned the approach of the Court of Appeal.

Although this case did not concern the withdrawal of CANH, it set out at the highest level of legal authority a number of important statements concerning the Mental Capacity Act and decision-making in medical treatment:

1. the correct question to be addressed in determining the best interests of a patient is whether it is in the patient's best interests to receive or continue to receive treatment, not whether it is in his best interests to withhold or withdraw it;¹¹² best interests incorporates not just medical interests, but the patient's welfare in the widest sense:

*'decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.'*¹¹³

2. Decision-makers must identify what is in the best interests of a patient by considering matters from the patient's point of view, and not reach a decision based on what the 'reasonable patient' would want;¹¹⁴ and
3. treatment is not 'futile' if it brings some benefit to the patient, even if it has no effect on the underlying disease or disability. Similarly, recovery does not mean a return to full health, but returning to a quality of life that is acceptable to the patient.¹¹⁵

¹¹² *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 22.

¹¹³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 39.

¹¹⁴ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 45.

¹¹⁵ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 43-44.

9. *Lambert v France* – (2015) ECHR 185

Vincent Lambert sustained serious head injuries in a road traffic accident in 2008, which left him tetraplegic and in a state of complete dependency, including receiving CANH. In 2011 his condition was characterised as minimally conscious, and in 2014 as vegetative.

In line with French law, the clinical team caring for him initiated the procedure for the withdrawal of CANH, in agreement with his wife. This decision was challenged by his parents, by way of an urgent application to the court, which they continued to do until the case reached the European Court of Human Rights. They argued that withdrawing CANH would be in breach of the state's obligations under Article 2 (the right to life) of the European Convention on Human Rights, and that depriving him of nutrition and hydration would constitute ill-treatment amounting to cruel, inhuman or degrading treatment (as prohibited by Article 3).

In considering the issue, the European Court took the following factors into account:

- the existence in domestic law and practice of a legislative framework compatible with the requirements of Article 2;
- whether account had been taken of Mr Lambert's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel; and
- the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's best interests.

The Court observed that there was no consensus among the Council of Europe member states on the withdrawal of life-sustaining treatment and that accordingly, there must be a large margin of appreciation given to each state.¹¹⁶ It is for each individual member state to verify whether the decision to withdraw treatment had been made appropriately and in compliance with any domestic legislation or regulation.

This European case builds on consideration of the relationship between withdrawal of life-sustaining treatment and issues of human rights. Just as the UK case *M and H*¹¹⁷ confirmed that there is nothing incompatible with the Human Rights Act about the approach of the UK to withdrawal of CANH, the case of *Lambert* made clear that as long as there is a clear regulatory framework for how these decisions are made, the requirements of Article 2 will be satisfied.

¹¹⁶ *Lambert and Others v France* [2015] ECHR 545.

¹¹⁷ *NHS Trust A v M and NHS Trust B v H* [2001] Fam 348.

10. *Re Mrs N* – [2015] EWCOP 76

Mrs N was a 68-year-old woman who had been diagnosed with multiple sclerosis (MS) 23 years previously. Initially the physiological development of the disease was slow, but within six years of the diagnosis, Mrs N's speech had deteriorated, she required a wheelchair, struggled with concentration and experienced rapid mood changes. She struggled to adapt to her diagnosis and arrangements for her care and her behaviour was 'challenging, unpredictable and increasingly difficult for her family to cope with.'¹¹⁸

By 2015, Mrs N was severely cognitively impaired, her ability to communicate had deteriorated rapidly, and she was receiving nutrition and hydration through a percutaneous endoscopic gastrostomy (PEG) tube. Her daughter, M, sought a declaration that it was not in Mrs N's best interests to continue to receive CANH. The Official Solicitor originally opposed the application but, having heard evidence from the family about Mrs N's past wishes, values, feelings and beliefs, withdrew that opposition.

There was disagreement between the experts consulted about whether Mrs N was in VS or in MCS. The court held that Mrs N was in MCS, and that it would not be in her best interests to continue to receive CANH. Accordingly, a declaration was granted authorising Mrs N to be moved to a hospice where CANH would be withdrawn and care provided in accordance with a structured palliative care plan.

Re Mrs N was the first case to come before the courts which concerned MCS as the result of a progressive neurodegenerative condition, and also the first case in which withdrawal of treatment was authorised from a patient in MCS.

Mr Justice Hayden followed the balance-sheet approach set out by Mr Justice Baker in *W v M*, identifying and weighing the advantages and disadvantages of each proposed course of action. In doing so, he placed great importance on the principle of sanctity of life but concluded that respect for Mrs N's autonomy should take priority: Mrs N would have found her circumstances 'profoundly humiliating' and would not have wanted to inflict distress on her family.¹¹⁹

Mrs N's case is also notable for the discussion about the diagnosis and classification of her condition. Although all three clinical experts consulted agreed that Mrs N had a life expectancy of around 3 to 5 years, two were of the opinion that she was in MCS and the other that she was in VS. The court took the view that she was in MCS, although Mr Justice Hayden suggested that 'any bright line delineation between VS and MCS is largely, perhaps even entirely, artificial.'¹²⁰

11. *Cumbria NHS Clinical Commissioning Group v Miss S & Ors* – [2016] EWCOP 32

Miss S was a 38-year-old woman who in 2012, suffered catastrophic brain damage following an overdose of medication used to treat diabetes. She was later determined to be in VS, and in 2013, her family initiated discussions about the possibility of further life-extending treatments being stopped.

The judge was clear that this should have prompted serious consideration about whether it was in Miss S's best interests to continue CANH and, if it was deemed not to be, this should have triggered preparation to make an application for withdrawal to the Court of Protection. This did not happen, and it was another three years before a court hearing took place and treatment was subsequently withdrawn from Miss S.

118 *Re Mrs N* [2015] EWCOP 76. 4.

119 *Re Mrs N* [2015] EWCOP 70. 71.

120 *Re Mrs N* [2015] EWCOP 76. 73.

Although not a key judgment with regard to the development of the law on decision-making in VS and MCS cases, it is useful to reflect on the case of Miss S, a case involving a woman in confirmed VS for four years before an application was made to the Court of Protection. Mr Justice Hayden was critical of the delay in the case being resolved, stating that:

'I have found it difficult to understand entirely why this process has taken quite as long as it has. Given that, ultimately, all the parties have been able to agree on the way forward, I have not been required to investigate the reasons. It needs to be stated that the avoidance of delay in medical treatment cases is an important imperative, as I have now said in a number of judgments. That is not to say that assessments ought to be rushed or that delays may not sometimes be clinically purposive, but respect for a patient's autonomy, dignity and integrity requires all involved in these difficult cases to keep in focus that these important rights are compromised in consequence of avoidable delay. Those who are beyond pain, understanding, or without any true consciousness require vigilant protection of their rights and interests, all the more so because of their unique level of vulnerability.'¹²¹

12. *Briggs v Briggs* – [2016] EWCOP 53

Paul Briggs was a police officer who was seriously injured in a road traffic incident as he travelled to work on his motorcycle in July 2015. He suffered serious brain injury and other multiple injuries and was rendered unconscious. He was later determined to be in MCS, and was kept alive by the package of care and treatment provided to him in hospital, including CANH.

Seventeen months after the incident, Mr Briggs's treating team was of the opinion that he could be moved from the hospital to a rehabilitation unit, where his progress could be monitored and promoted. His wife and family, however, were of the opinion that this was not what he would want, since even the best and most realistic assessment of the quality of life he could achieve after rehabilitation would not result in a quality of life that he would value. Their view was that he should be transferred to a hospice where he would no longer be treated by CANH, and instead receive palliative care, allowing him to die as painlessly and as peacefully as possible. His wife sought a declaration that continuing CANH was not in his best interests and so should be withdrawn.

The court held that it would not be in Mr Briggs's best interests to continue to receive CANH and granted the declaration. Mr Briggs died in a hospice receiving palliative care in January 2017.

In his judgment, Mr Justice Charles devoted considerable discussion to the issue of how a patient's best interests should be considered, and, in particular, how much prominence should be given to the patient's own wishes for what they would want to happen in these circumstances.

He was clear that the result of *Aintree v James* was not that a conclusion about what the patient would have done was decisive in determining best interests. Rather, the best interests test required the decision-maker to take that into consideration while performing a balancing exercise with a number of other competing factors.

He held that the default position is for a strong presumption in favour of the sanctity of life – but that this can come into direct conflict with the principle of self-determination. He made two observations about the way forward when this is the case:

1. that the decision-maker (in this case, the judge) must be wary of giving too much weight to what he or she would want in similar circumstances, or what ‘a reasonable person’ would want; and
2. that if the wishes of the patient can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.¹²²

In making his decision, Mr Justice Charles took a holistic approach to understanding Mr Briggs’s views about his current situation. He considered not just what Mr Briggs had said about his wishes in relation to similar circumstances (for example, his support for his mother-in-law’s refusal of a feeding tube at an advanced stage of cancer), but also how he lived his life and embodied his values through the choices he made in life (for example, his career in the army and police force, his hobby of riding motorcycles, and his love for and commitment to his family). This led him to conclude that it was not in Mr Briggs’s best interests to continue to receive CANH.

13. Director of Legal Aid Casework & Ors v Briggs – [2017] EWCA Civ 1169

Mrs Briggs had taken the initial case under s.21(a) of the Mental Capacity Act 2005, as non-means-tested legal aid was available in proceedings taken by this route – unlike a conventional serious medical treatment application made under s.16, in accordance with Practice Direction 9E. In resolving this issue, the Court of Appeal made several significant *obiter* comments about the role of the court in these proceedings.

The judges suggested that the so-called ‘requirement’ to go to court did not create a legal obligation to do so, but simply provided guidance on good practice. The court did, however, have a role to play in cases where there was disagreement as to what was in a patient’s best interests. Lady Justice King noted that the reality of these decisions were that they were made by agreement between clinical teams and those close to the patient, and that suggesting that every case should go before the court ‘would not only be an unnecessary pressure on the overstretched resources of NHS Trusts and add to the burden on the courts but, most importantly, would greatly add to the strain on the families.’¹²³

¹²² *Briggs v Briggs* [2016] EW COP 53. 62.

¹²³ *Director of Legal Aid Casework & Ors v Briggs* [2017] EWCA Civ 1169. 26.

14. *PL v Sutton Clinical Commissioning Group* – [2017] EWCOP 22

PL was a 79-year-old woman who suffered a catastrophic stroke which left her severely physically disabled, brain damaged, and significantly incapacitated. She was being kept alive only through the provision of CANH through a PEG tube.

PL's son made an application to the court to ask them to consider whether it was in PL's best interests to continue to receive CANH.

The court held that the views PL had previously expressed to family and friends about the prospect of being kept alive on life support were clear, and that she would not have wanted to continue to receive CANH in her current condition. Withdrawal was authorised, alongside a palliative care plan designed to give PL 'the dignity which she would crave, and a passing which involves the minimum of distress.'¹²⁴

It should be noted that PL was not diagnosed or described by medical experts as being in MCS, although she did display some features of MCS. Mr Justice Cobb made some comments which suggested that a clear diagnosis or distinction between disorders of consciousness was unnecessary, holding that:

'It would be wrong in my view to conclude that where the patient is not diagnosed as MCS or VS a significantly different approach to the determination of the case should be taken. Quite apart from anything else, as is well-recognised, the diagnosis is often difficult and may indeed change over time. So just as it would not necessarily follow that someone who is in a 'vegetative state' would be bound to have life-sustaining treatment discontinued, the fact that someone retains consciousness and can answer questions is not in itself a reason not to consider discontinuance of life-sustaining treatment ... It all depends, as I have indicated, on the individual facts, and every decision must ultimately be governed by what is in a patient's best interests.'¹²⁵

15. *Salford Royal NHS Foundation Trust v Mrs P* – [2017] EWCOP 23

Mrs P was a 72-year-old woman who, in late 2016, started to experience severe and worsening headaches. Attending hospital after a fall in a car-park where she hit her head, a CT brain scan suggested (although not definitively) a resolving subarachnoid haemorrhage. She was admitted to hospital where her condition began to deteriorate and she was later diagnosed as being in MCS.

The hospital Trust caring for Mrs P made an application to the court and sought a declaration that it would be in Mrs P's best interests to continue to receive CANH.

Taking into consideration Mrs P's previously expressed views, feelings and values, Mr Justice Hayden concluded that Mrs P 'would have found her present circumstances not only intolerable but humiliating... Her present high level of dependency and minimal awareness would, to her, have been 'a travesty of life', to adopt her own phrase.'¹²⁶ He subsequently declined the Trust's application to continue CANH.

124 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22. 75.

125 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22. 29.

126 *Salford Royal NHS Foundation Trust v Mrs P* [2017] EWCOP 23. 39.

16. *M v A Hospital* - [2017] EWCOP 19

M was a 50-year-old woman who had been diagnosed with Huntington's Disease some decades prior. Her condition deteriorated, and in 1994 she became permanently resident in hospital although she was still able to go out for short periods. By 2003, she was no longer able to go out at all, and required CANH to meet her nutritional and hydration needs. For the last ten years of her life she was confined to bed.

An application was made to the Court of Protection asking for a declaration that it was not in M's best interests to continue to receive CANH, supported by M's family, the clinical team caring for her, and an external specialist second opinion.

Mr Justice Peter Jackson held that, based on the evidence of family members and clinicians, M would not 'have wanted to go on living like as she was [*sic*], nor endure the inevitable continued decline in her terminal condition'.¹²⁷ He granted a declaration that CANH should be withdrawn and replaced by palliative care.

The parties to the case also asked Mr Justice Peter Jackson to clarify whether legal proceedings were necessary when there was agreement between M's family and her clinicians that CANH was no longer in her best interests. On this point, he held that he did not consider there to be a legal requirement for a decision about CANH to come before the court. In his view:

'a decision to withdraw CANH, taken in accordance with the prevailing professional guidance...will be lawful. The court is always available where there is disagreement, or where it is felt for some other reason that an application should be made.'¹²⁸

127 *M v A Hospital* [2017] EWCOP 19. 26.

128 *M v A Hospital* [2017] EWCOP 19. 37.

17. *An NHS Trust v Y* – [2018] UKSC 46

Mr Y, a 52-year-old man, suffered a cardiac arrest after a myocardial infarction as a result of coronary artery disease. It was not possible to resuscitate him for well over 10 minutes, resulting in severe cerebral hypoxia and causing extensive brain damage. Although it was not possible to make a diagnosis of VS, as he had not been in a disorder of consciousness for 6 months, there was medical agreement that it was highly improbable that he would re-emerge into consciousness.

Mr Y's family were in agreement that he would not want to be kept alive given his poor prognosis, and that it would be in his best interests for CANH to be withdrawn. Both Mr Y's family and the treating Trust sought a declaration specifically that there was no mandatory requirement to seek consent to the withdrawal of CANH from the court.

In the first instance, Mrs Justice O'Farrell granted a declaration that it was not mandatory for applications for withdrawal of CANH to come before the court, in circumstances where the clinical team and the family are in agreement that it is not in the patient's best interests to continue to receive it.¹²⁹ Mr Y died a month later, having developed acute respiratory sepsis.

In light of the importance of the issues involved, permission was granted for the appeal to proceed and 'leapfrog' the Court of Appeal and go straight to the Supreme Court for consideration. The Supreme Court handed down its judgment on 30 July 2018, which confirmed that there is no requirement to go to court to seek approval for the withdrawal of CANH, providing:

- the provisions of the Mental Capacity Act 2005 have been followed;
- the relevant guidance has been observed; and
- there is agreement as to what is in the best interests of the patient.

The issue of whether there was a requirement for every decision about CANH in cases to withdraw or withhold to be approved by the court was settled definitively by the Supreme Court in *Y*. In delivering the decision of the Court, Lady Black rejected the notion that diagnosis is determinative of the approach to be taken in each case, and underlined the centrality of best interests:

'In any event, I have difficulty accepting that there are readily apparent and watertight categories of patient, with PDOC patients clearly differentiated from, say, patients with a degenerative neurological condition or critically ill patients, in such a way as to justify judicial involvement being required for the PDOC patients but not for others... In all cases, the medical team take their decisions as to treatment, whether it is CANH or some other form of treatment such as artificial ventilation or cardiopulmonary resuscitation or the administration of antibiotics, by determining what is in the patient's best interests.'¹³⁰

¹²⁹ *NHS Trust v Mr Y* [2017] EWHC 2866 (QB)

¹³⁰ *An NHS Trust and others v Y* [2018] UKSC 46. 119.

She further outlined the correct approach to decision-making, highlighting the importance of a second opinion as a crucial and essential part of scrutiny in safeguarding the interests of patients and their families, protecting against errors in diagnosis and evaluation, and premature decisions.¹³¹

She was clear that where there was disagreement as to the proposed course of action, or where the approach was 'finely balanced', an application to the court 'can and should be made.'¹³² However, she concluded that:

'I do not consider that it has been established that the common law or the ECHR, in combination or separately, give rise to the mandatory requirement for which the Official Solicitor contends, to involve the court to decide upon the best interests of every patient with a prolonged disorder of consciousness before CANH can be withdrawn. If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court.'¹³³

131 *An NHS Trust and other v Y* [2018] UKSC 46. 124.

132 *An NHS Trust and other v Y* [2018] UKSC 46. 125.

133 *An NHS Trust and other v Y* [2018] UKSC 46. 126.

British Medical Association
BMA House, Tavistock Square,
London WC1H 9JP
bma.org.uk

© British Medical Association, 2018

BMA 20180748