The Royal Wolverhampton NHS Trust

CP10
Withdrawing or Withholding Clinically Assisted Nutrition and Hydration in Adult Patients Who Lack Capacity to Consent to Treatment

Contents

1.0 Policy Statement (Purpose / Objectives of the policy)

Clinically Assisted Nutrition and Hydration (CANH) was defined by the courts as a medical treatment in 1992. Until July 2018, decisions to withdraw CANH from patients with a prolonged disorder of consciousness (see below) had to be authorised by the Court of Protection, but the Supreme Court ruled that court approval is not required if there is full agreement between the healthcare team and people close to the patient who have an interest in his or her welfare provided that we follow the Mental Capacity Act 2005 and good practice guidance. The judgement emphasises 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 invoking the court in such cases.

The British Medical Association (BMA) and the Royal College of Physicians (RCP) published joint guidance on withdrawing or withholding CANH in 2018. The General Medical Council (GMC) has endorsed the guidance to be legally and ethically sound and consistent with their guidance on consent and end of life care.

This policy is an iteration of the joint guidance and directs the processes that must be followed at the Royal Wolverhampton NHS Trust (RWT) when making decisions about administering CANH. It is important to state that there is no legal or moral difference between withholding and withdrawing CANH, and that withdrawing or withholding life-sustaining treatment is not euthanasia. Decisions not to give CANH do not breach the Human Rights Act 1998 if they are made according to the requirements of the Mental Capacity Act 2005 (MCA).

All aspects of this document regarding potential Conflicts of Interest should refer first to the Conflicts of Interest Policy (OP109). In adhering to this policy, all applicable aspects of the Conflicts of Interest Policy must be considered and addressed. In the case of any inconsistency, the Conflict-of-Interest Policy is to be considered the primary and overriding policy.

2.0 Definitions

Clinically Assisted Nutrition and Hydration (CANH): the administration of either or both food and water by artificial means including nasogastric (NG) and nasojenunal (NJ) tube feeding; feeding through a percutaneous endoscopic gastrostomy (PEG), a percutaneous endoscopic jejunostomy (PEJ) or a surgically placed gastrostomy or jejunostomy or one placed under radiological control and intravenous parenteral nutrition (PN). CANH is more than just helping patients to ingest food and, or fluids by mouth.

LPA: lasting power of attorney.

MCA: Mental Capacity Act 2005.

MCS: minimally conscious state.

NG: nasogastric.

NJ: nasojejunal.

PN (parenteral nutrition): an intravenous infusion of water, electrolytes and nutritional substances.

PDOC: prolonged disorder of consciousness sub-divided into MCS and VS.

PEJ: percutaneous endoscopic jejunostomy.

VS: permanent vegetative state.

3.0 Accountabilities

3.1 The Chief Medical Officer is the Executive Director for the policy and has overall responsibility for medical staff.

3.2 The Lead Clinician for CANH is responsible for implementation of this policy in liaison with the Clinical Directors, matrons and clinicians in directorates that will provide care and treatment for patients covered by this policy. The Lead Clinician will be responsible for auditing the application of the policy and any necessary revisions.

3.3 All clinicians who are involved in the care of patients covered by this policy must comply with its contents.

4.0 Policy Detail

4.1 This Policy only applies to adults who have a legitimate clinical indication for and no contraindications to CANH and who lack capacity to consent to treatment and for whom CANH is their only life-sustaining treatment. It directs decisions to withhold or to stop CANH.

4.2 The patients to whom this Policy applies will have one of the following: a PDOC following acute brain injury (e.g. trauma, stroke or hypoxia), progressive neuro-degenerative disease, or an acute or rapidly progressing brain injury in the presence of life-limiting co-morbidities (including frailty). Most PDOC patients will have been previously fit; some of them will recover consciousness with or without residual disability while others will be in a VS or a MCS for years with a poor prognosis for functional recovery.

4.3 Our legal and ethical responsibilities are to determine if CANH is in the patient's best interests. We must consider the patient's rights to life and to self-determination but the latter will outweigh the right to life if there is good evidence that CANH would not provide a quality of life that the patient would find acceptable.

4.4 The MCA dictates the processes that we must follow to make best interests decisions for patients who lack capacity. Decisions must focus on the care and treatment that is holistically correct for that individual. We must consult with others (see below) in reaching best interest judgements. The fatal consequence of not giving CANH means that we must comply precisely with the MCA, document all our decision-making, and review and audit our processes.

4.5 Who makes the decision about CANH? In rank order, the following individuals:

- The Patient, by an Advance Decision
- A Health and Welfare Attorney, or
- A Senior Clinician (Consultant in Charge of the care of an inpatient or GP attending a patient in the community). If the patient is on a ward that uses a "Consultant of

the Week System", there must be one consultant identified as the lead for the patient in question.

4.6 A valid and applicable Advance Decision to refuse CANH must be honoured if it fulfils these criteria (if you are unsure about it, contact the Trust Legal Team):

- It was made when the patient had capacity and was over 18
- It clearly applies to CANH in the present circumstances
- It is in writing, signed and witnessed
- There is an explicit statement that it applies if there is a risk to life
- It has not subsequently been withdrawn
- The patient has not appointed a health and welfare attorney to make this specific decision **after** making the Advance Decision; an Advance Decision made after appointing a health and welfare attorney is valid

- The individual has done nothing that would be inconsistent with the Advance Decision remaining a fixed decision.

4.7 Lasting power of attorney for health and welfare.

4.7.1 The patient may have granted an LPA for health and welfare with the specific authority to give or refuse consent to life-sustaining treatment. An LPA is only valid if it has been registered with the Office of the Public Guardian. You must see either the original LPA document (embossed with 'validated–OPG' at the bottom of each page) or a certified copy to ensure that it authorizes decisions about life-prolonging treatment. If these stipulations are met, The Attorney is the lawful decision-maker with the power to consent to or refuse CANH if it is clinically indicated.

4.7.2 If you doubt the attorney is acting in the patient's best interests, you must discuss it with them, and, if that does not resolve the issue, you must seek advice from the Trust Legal team.

4.8 Decision-making by a senior clinician

4.8.1 If there is neither an applicable and valid Advance Decision nor a suitable Health and Welfare Attorney, the decision rests with a Senior Clinician, who must make a best interests decision on behalf of the patient following the process laid down in the MCA (see Attachment 1 – Assessment of Best Interests).

4.8.2 If a unanimous best interests decision about CANH cannot be agreed between the healthcare team and those close to the patient, or if the best interests decision is finely balanced, the case must be taken to the Court of Protection. CANH should continue to be provided while awaiting the decision of the court.

4.8.3 If the decision is made not to give CANH to a patient whose life expectancy is more than a few days, a second clinical opinion must be sought unless there is a valid, applicable Advanced Directive or a health and welfare attorney with the appropriate powers (except if the attorney requests a second opinion). Getting a second opinion

should be a high priority (see Attachment 2 – Getting a Second Clinical Opinion).

4.9 Managing disagreement and uncertainty.

4.9.1 Once made, the best interests decision should be shared with everyone who has contributed to the assessment. If all parties agree with the decision, it can be enacted. If there is a disagreement or uncertainty about the patient's best interests then further discussion, a case conference or another clinical opinion can be used to try to resolve the issue. If there is no resolution, Legal Services must be contacted to discuss an application to the Court of Protection. The Trust (the CCG for community patients) will fund the legal proceedings). Those close to the patient must be kept abreast of the process.

4.9.2 Applications to the course must set out what treatment is being provided and any decisions that have been made about ceilings of care (including both potentially beneficial treatments that are thought not to be in the patient's best interests and those that are not indicated because they hold no potential benefit or cannot be done for clinical reasons).

4.9.3 If a disagreement about CANH is taken to the Court of Protection, the healthcare team must not pre-empt the court's judgment. For example: if the patient's feeding tube becomes blocked or displaced and an immediate decision is needed about how to proceed, an urgent application to the court must be made, out of hours if necessary; however, if time does not allow for that, all necessary steps must be taken to secure the patient's life.

4.9.4 If, while awaiting a Court of Protection decision, there is a material change in the situation (e.g. the clinical team and those close to the patient reach agreement or the clinical uncertainty is resolved), the application can be withdrawn.

4.9.5 Once the decision is made to stop CANH, it must be done as soon as is reasonably practicable. There must be a detailed plan to withdraw CANH and provide end-of-life care, including palliation of symptoms (with help from the Palliative Care Team if needed) and to support those close to the patient (e.g. counselling and bereavement support service).

4.10 Death certification

4.10.1 The Senior Clinician in charge of the patient's care must ensure that the death is properly certified and reported. Following withdrawal of CANH, the immediate, direct cause of death (Ia) will probably be multiorgan failure or bronchopneumonia, and the underlying cause of death will be the original brain injury or medical condition.

4.10.2 The usual rules will apply for determining if the patient's death needs to be reported to the coroner and will depend on the cause of the brain injury or condition. Medical Examiners will scrutinize deaths that are not reported to the coroner.

5.0 Financial Risk Assessment

1	Does the implementation of this policy require any additional Capital resources	No
2	Does the implementation revenue resources of this policy require additional	No
3	Doe the implementation of this policy require additional manpower	No
4	Does the implementation of this policy release any manpower costs through a change in practice	No
5	Are there additional staff training costs associated with implementing this policy which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments	

6.0 Equality Impact Assessment

An equality analysis has been carried out and it indicates that:

Tick	Options
X	A. There is no impact in relation to Personal Protected Characteristics as defined by the Equality Act 2010.
	B. There is some likely impact as identified in the equality analysis. Examples of issues identified, and the proposed actions include: • • •

7.0 Maintenance

The Lead Clinician for CANH will maintain this policy.

8.0 Communication and Training*

This policy will be shared with all appropriate clinicians and managers in the Trust. Any training deficits will be addressed by the Lead Clinician and the management triumvirate in the Directorates.

9.0 Audit Process

Criterion	Lead	Monitoring method	Frequency	Committee
CANH decisions must be audited to ensure they have been made in line with the MCA and this Policy. NB the documentation must be available for review by the Care Quality Commission (CQC).	CANH lead	Clinical records review to verify that there are regular and effective best interests assessments for patients receiving CANH.	Ad hoc according to the presence of a patient in the Trust for whom a decision must be made.	QSIG

10.0 References - Legal, professional or national guidelines must underpin policies and be referenced here. Where appropriate cross references must be made to other policies.

All references to appendices and attachments within the body of the document must be highlighted in blue and all hyperlinks inserted.

BMA & Royal College of Physicians (2018) Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in England and Wales.

BMA (2007) Withholding and withdrawing life-prolonging medical treatment: guidance for decision making. 3rd ed. Blackwell Publishing: London

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

Royal College of Physicians (2010) Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life.

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

The Mental Capacity Act 2005.

NICE (2018) guideline NG97 Dementia: assessment, management and support for people living with dementia and their carers.

An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellants) (2018) UKSC46.

Part A - Document Control

<table>
<tr><td>Policy number and Policy version:

CP10

V2.0</td><td>Policy Title

Policy for Withdrawing or Withholding Clinically Assisted Nutrition and Hydration in Adult Patients Who Lack Capacity to Consent to Treatment</td><td colspan="2">Status:

Final</td><td>Author: Consultant Surgeon

Director Sponsor: Chief Medical Officer</td></tr>
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<tr><td>1.0</td><td>Jan. 2020</td><td>Consultant Surgeon</td><td>Implementation of new policy.</td></tr>
<tr><td>1.1</td><td>Aug. 2023</td><td>Divisional Medical Director</td><td>Extension</td></tr>
<tr><td>2.0</td><td>August 2023</td><td>Consultant Surgeon</td><td>Reviewed ad Updated</td></tr>
<tr><td colspan="5">Intended Recipients: All clinical staff who care for adults who have a legitimate clinical indication for and no contraindications to Clinically Assisted Nutrition & Hydration (CANH) and who lack capacity to consent to treatment and for whom CANH is their only life-sustaining treatment.</td></tr>
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<tr><td colspan="2">Monitoring arrangements and Committee</td><td colspan="3"></td></tr>
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Document summary/key issues covered. This policy is an iteration of the joint guidance from the British Medical Association and the Royal College of Physicians to direct the processes that must be followed at the Royal Wolverhampton NHS Trust when making decisions about administering CANH to comply with the requirements of the Mental Capacity Act and the ruling of the Supreme Court.	
Key words for intranet searching purposes	Clinically Assisted Nutrition & Hydration. CANH. Mental Capacity Act.

Attachment One Assessment of Best Interests: Guidance for the Decision-making Senior Clinician

1.0 CANH should only be started or continued if it is in the best interests of the patient (and not those of their family, friends or the healthcare team). You must decide what the patient would have wanted if they had retained capacity. The impact of the decision on others, including family members, is only relevant to the extent that the patient would have taken this into account if they had capacity. The appropriateness of giving CANH must be reviewed by the patient's senior responsible clinician every 6 months (or more often) and whenever the patient's condition changes. CANH is life sustaining, and its withdrawal will be fatal.

1.1 The courts have used a "balance-sheet" approach for decision-making: they weigh the pros and cons of each possible option in light of what is known about the patient's likely wishes on a balance sheet. It is the weight of the arguments for and against CANH and not their number that is used to identify the patient's best interests. There may be some 'factors of magnetic importance' that are of such overriding importance to the patient that they will have a decisive influence on the outcome.

2.0 **Whom must you consult**?

2.1 The MCA demands consultation with those '…engaged in caring for the patient or interested in his or her welfare,' to make a best interests decision; these people include:

- anyone named by the patient as someone to be consulted on the matter in question or on matters of that kind,
- family,
- friends,
- neighbours,
- carers,
- colleagues, and
- a Court of Protection appointed deputy (if there is one); these deputies must be consulted about best interests assessments, but they do not have the power to refuse CANH.

2.2 These individuals must be invited to discuss the best interests assessment and you must explain how those decisions are made and the part they will play, but that the responsibility for decision-making does not rest with them. They may prefer to submit written statements, which have some advantages compared with oral statements, because they may allow a more thoughtful

summary and they provide an accurate record of the statements in the author's own words. If they decline to participate, document that in the patient's medical record. The decision about whom to consult must not be influenced by a desire to achieve agreement on a particular course of action.

2.3 You must be aware that those consulted may be unable to separate their own views and preferences 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 supporting evidence for the views expressed helps to ensure that decisions are focused on the patient.

2.4 Unbefriended patients will need an Independent Mental Capacity Advocate (IMCAs) to be consulted about best interests assessment.

2.5 You must also involve all members of the healthcare team, particularly those who have spent some considerable time with the patient.

3.0 Essential information.

3.1 The key pieces of medical information that everyone involved in the decision-making process needs to know are:

- The current clinical status and the prognosis for functional recovery – best, worst and likeliest outcomes;
- The level of uncertainty about the prognosis – the prospects for recovery may be more easy to determine after a period of observation;
- The patient's quality of life: how much pleasure (and if it could be enhanced) and how much suffering, physical and psychological (and if it could be reduced);
- Their likely survival time;
- The patient's level of awareness of self and of their environment;
- A holistic assessment of their medical, social and psychological welfare;
- The palliative and end of life care that will be given (and involvement of a Palliative Care Physician) if CANH is stopped.

3.2 The best interests assessment must take account of the patient's wishes, feelings, beliefs and values, both generally and how they would relate to the current situation. To assess these factors, the senior clinician must consult those close to the patient (see 2.1 above). The patient may be able to contribute to the decision-making process: if communication is a problem, speech and language therapists may be able to help. Also, any relevant written statement made by the patient when they had capacity might be important.

3.3 The principles regarding decisions about CANH pertain to a pregnant woman whose death would kill the foetus. The decision must be for the best interests of the woman not her baby (Article 2 of the European Convention on Human Rights says that the right to life does not extend to a foetus), but the gestational age of the foetus, and the woman's views about the pregnancy are relevant to the best interests assessment. If the foetus is viable and you

propose to stop CANH, you must contact the Trust Legal team.

4.0 **Best interests meetings**.

4.1 Formal best interests meetings are not mandatory in the MCA, but they are a good way of making important decisions to demonstrate that the appropriate processes have been followed.

4.2 Formal meetings are of particular value in patients whose life expectancy with CANH is long and if the cohort of people consulted is large or complex or if they have very different views on what the patient would have chosen had capacity not been lost.

4.3 They are usually initiated by the decision-making senior clinician, but they can be convened if requested by those close to the patient.

4.4. A suitable venue is essential – large enough to accommodate the expected attendance and quiet enough to allow an effective discussion.

4.5 There must not be a predominance of healthcare staff over those close to the patient.

4.6 There must be a formal agenda.

4.7 A detailed minute of the meeting must be circulated to all those in attendance to check its accuracy before it is finalized; if facilities allow, a digital recording can be made and shared with all relevant parties.

5.0 **Documentation**

5.1 However the best interest assessment is made, the MCA Code of Practice requires that a detailed record must be kept in the patient's medical case notes of all best interests decisions. This record must include:

- The decision taken about CANH
- How the decision about the patient's best interests was reached
- The reasons for reaching the decision
- The identities of the people consulted during the assessment
- The particular factors that were taken into account
- The name and position of the decision-making senior clinician
- A detailed record of all significant discussions and best interests meetings
- Any written submissions made by those close to the patient
- The agreed minutes, or digital recordings, of all best interests meetings

5.2 If the patient goes to another healthcare unit, a copy of the best interests assessments must go with them; if he or she goes home or to a nursing or care home, a copy should be sent to their GP.

Attachment Two
Getting a Second Clinical Opinion

1.0 The second-opinion must be from a senior clinician with experience in managing the condition from which the patient is suffering but who is not currently directly involved in their care. This can be any Senior Doctor, Nurse or Consultant Allied Health Professional with the relevant clinical knowledge and experience of the patient's disease and experience of best interests decision-making.

2.0 If the patient's underlying condition is a prolonged disorder of consciousness (PDOC), one of the senior clinicians involved in the best interests assessment must be a specialist in that area.

3.0 If the patient was previously healthy but is in a permanent vegetative state (VS) or minimally conscious state (MCS) after a sudden-onset brain injury, the second opinion clinician must have had no prior involvement in the patient's care, and he or she should be from another Trust or organization unless no such clinician can be found.

4.0 If the patient's life expectancy could be long, the second opinion clinician should be from outside the Trust, unless no such clinician can be found, and have had no prior involvement in the patient's care.

5.0 People close to the patient or interested in the patient's welfare must be given an opportunity to meet the second-opinion clinician, to be present during the examination of the patient and to discuss the case with the second-opinion clinician.

6.0 In all cases the second-opinion clinician must examine the patient and their notes to ensure that the right investigations and tests have been done and interpreted accurately.

7.0 He or she does not need to make their own best-interests assessment but must review the information about the assessment; including the identities of the people who have been involved in it (the names of those individuals must have been documented).

8.0 The second-opinion clinician must submit a written report summarizing their findings and specifying if the expected functional prognosis has been defined accurately (with appropriate caveats) and if the patient's prior wishes, feelings, beliefs and values, and their likely opinion regarding CANH have been explored and documented. The report must state whether a decision to withdraw or withhold CANH is in the best interests of the patient.

9.0 If the second-opinion clinician disagrees with the original decision or has concerns about any part of it, he or she must discuss these issues with the original decision maker.

Appendix One
Decisions About CANH in Specific Groups

1.0 **Neurodegenerative conditions.**

1.1 It is appropriate to advise patients with neurodegenerative conditions to consider making Advance Decisions about CANH and other aspects of their care before they lose capacity and, or to give an LPA to a health and welfare attorney with specific authority to make decisions about CANH. Information about advance care planning is available online (Office of the Public Guardianwww.gov.uk/government/organisations/office-of-the-publicguardian; Compassion in Dying www.compassionindying.org.uk; My Living Will at www.mylivingwill.org.uk).

1.2 CANH is not usually indicated when inadequate intake of nutrition is due to progression of dementia, but it may be indicated for a short period to allow treatment of a potentially reversible comorbidity, such as acute infection.

2.0 **Patients with life-limiting comorbidities or frailty who have suffered a brain injury.**

2.1 In this group of patients, the assessment of best interests must encompass all their medical problems and not just the indication for CANH. If the patient's life expectancy is short even with CANH, a less extensive assessment will be appropriate.

3.0 **Previously healthy patients in a vegetative state (VS) or a minimally conscious state (MCS) following a sudden-onset brain injury.**

3.1 Patients with VS or MCS can live for years with CANH, so an extensive assessment of best interests must be done.

3.2 Formal best interests meetings must be held. Ideally, the first one should be within four weeks of the brain injury, even it is highly likely that no decision will be made; to ensure that those close to the patient know what options are available. Sedating drugs can hamper assessing awareness, but stopping them may be unpleasant for the patient. This potential harm must be weighed against the benefits of distinguishing between VS and MCS, and whether that will enhance the assessment of best interests (which depends more on the prognosis for functional recovery). The prognosis will become clearer with time as the patient's condition stabilizes. Structured assessment tools (such as the Coma Recovery Scale and the Wessex Head Injury Matrix) may help the assessments.

3.3 Palliative care for patients with PDOC from whom CANH is being withdrawn must be planned and delivered in line with the Royal College of Physicians guidelines, seeking advice from a centre with specialist experience in this area if needed.

Appendix Two
Recording Best Interests Assessments

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

- The nature, cause and severity of the injury or illness that has caused the need for CANH.
- The clinical assessments and investigations that have been undertaken.
- The current functional status (e.g. movements, language, speech, responses etc.).
- The clinical assessment of the best, worst and most likely prognosis, including life expectancy if CANH is continued.
- The patient's level of awareness of themselves and their environment, and, where appropriate, the tests done to assess this in line with the RCP guidelines on PDOC or an account of the reasons for not doing so (e.g. the impact of a reduction in sedating drugs).
- The patient's ability to experience pain, pleasure and enjoyment.
- The treatment that has been provided to date.
- A summary of the evidence about the patient's likely wishes, feelings, beliefs, values and views on having CANH in their current situation and the named sources of that evidence (e.g. from the patient (if relevant), the healthcare team and those interested in his or her welfare).
- 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.
- The decision made about CANH and the reasons for that decision.
- The planned date to review a decision that CANH is in the patient's best interests.
- The second opinion clinician's report if the decision has been made that CANH is not in the patient's best interests.
- Details of the end-of-life care plan including any preferences expressed by the patient.