

Supporting information for decisions to withdraw clinically-assisted nutrition and hydration (CANH) in previously healthy patients with prolonged disorders of consciousness due to sudden onset brain injury.

<p>Patient Details</p> <p>Name:</p> <p>DOB:</p> <p>Hospital no:</p> <p>NHS No</p>	<p>Treating Team Consultant in Charge:</p> <p>Specialty:</p> <p>Experience in managing PDOC patients: Years</p> <p>Meets the requirements for PDOC Expert Physician (see below)?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
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Please read first

1. This form is designed for health professionals to document all relevant supporting information for decisions to withdraw CANH in previously healthy patients in prolonged disorders of consciousness following sudden onset brain injury only.
 2. It is intended to provide a standard approach to record keeping in these cases, in order to facilitate internal and external review and audit of decisions.
 3. When completing this form you will need to be familiar with the Royal College of Physicians' Guidelines for Prolonged Disorder of Consciousness (2013) (henceforth "the RCP National Guidelines") and any subsequent updates to or amendments of it. The RCP National Guidelines are available here: <https://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines>
 4. This form serves as a summary and is not a substitute for the evidence. Full evidence must be considered and provided as specified in the RCP National Guidelines. This should be appended to the form or summarised in a detailed report as appropriate to the individual case.
 5. This form is completed by two experienced physicians, one of whom may be the treating physician and the other an independent clinician.
 - Both should have experience in end of life decisions and best interests decision-making, and should be familiar with the RCP PDOC guidelines.
 - At least one of these must be a physician with experience in assessment and management of patients in prolonged disorders of consciousness, whose experience and training fulfils the requirements set out in Annex 2b of the RCP National Guidelines (PDOC Expert Physician).
- Sections 1a,1c and 1d are completed/compiled by the treating team, to confirm assessment and decision-making according to the RCP guidelines;
 - Section 1b is completed by the PDOC Expert Physician (who may be part of the treating team or the independent clinician). This expert also completes section 2 unless the equivalent Form 2f from the RCP guidelines has already been completed.
 - Section 3 is completed by the treating team, to confirm that an appropriate best interests assessment has been carried out.
 - Section 4 is completed by both physicians.

Proforma prepared as part of the development of BMA/RCP guidance – see www.bma.org.uk/CANH

N.B. 'Family' is used in this document 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.

Section 1: Clinical background

1a: History and current condition (To be completed by the treating team)

Pre-morbid condition

- Briefly describe the patient's situation prior to the brain injury
 - Work / social situation
 - Hobbies / interests
- Any relevant past medical history and its impact on function, if any

Type to expand dialogue box

Details of brain injury and medical treatment to date

- All relevant past medical history
- Type, severity, duration and course of injury
- Immediate treatment, including surgery, recovery, locations of care etc.
- Comorbidities

Type to expand dialogue box

Current physical condition and care needs

- Dependency
- PEG/NG fed
- Tracheostomy?
- Incontinence - Catheter
- Skin integrity
- Current medication

Type to expand dialogue box

1b: PDOC diagnosis and prognosis

(To be completed by the PDOC expert physician who meets the Annex 2b requirements)

Diagnosis of PDOC

Details of clinical evaluation of PDOC according to the RCP guidelines

- Where was this evaluation conducted?
- Results of assessment
 - Clinical evaluation – including confirmation of intact primary pathways
 - Pre-requisites
 - Exclusion of remediable causes through imaging/ EEG etc
 - Medication review to withdraw/minimise sedative medications
 - Suitable controlled sensory environment /targeted sensory stimulation programme
- How was consciousness assessed?
 - Clinical evaluation and behavioural observations over time
 - Standardised tests to assess responsiveness and interaction
 - Serial WHIM, CRS-R and or SMART
 - Give results in table / charts with interpretation
- What is the PDOC diagnosis?
 - i.e. VS, MCS- or MCE+ (each being either continuing or permanent)
- What is the trajectory towards change?
Deteriorating / flat / rising slowly / rising fast / fluctuating

Type to expand dialogue box

Prognosis, uncertainty and life expectancy

- What are the likely best and worst scenarios for the patient's recovery of consciousness and functional independence:
 - Worst condition
 - Best possible condition
- How certain are we regarding the patient's chances of emerging into consciousness
 - Probable, possible, unlikely, very unlikely
- How certain are we regarding the patient's chances of recovering independence?
 - Probably, possible, unlikely, very unlikely
- How long would the patient be likely to live if CANH were not to be withdrawn?
 - Existing ceiling of treatment arrangements

Type to expand dialogue box

1c: Decision making process (To be completed by the treating team)

Pre-stated wishes and proxy decision makers

- Is there a valid and applicable ADRT refusing CANH? If so, provide details
- Is there a health and welfare attorney with decision-making power regarding life-sustaining treatment?

Type to expand dialogue box

Summary of Best Interests meetings

- How were these conducted?
- Dates
- Who was involved?
- Conclusions from the meetings

Type to expand dialogue box

Summary of essential clinical questions

- 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 yes, how can this be maximised?
- Does he/she experience pain and/or distress and if so how is that 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?
- How would the end-of-life care be managed?
- How are the family and team to be supported?
- Are plans in place to manage the situation after the death of the patient?

Type to expand dialogue box

Agreement

- Are the family and treating team in agreement about the patient's best interests in relation to CANH withdrawal?
 - Is there anyone else in the family who would take a different view?
- Has there been any dispute about the patient's wishes, condition or prognosis?
- If yes, how was the disagreement resolved?

Type to expand dialogue box

Overall conclusion and reasons for the decision

Type to expand dialogue box

1d: Palliative care plan

(To be completed by the treating team)

End-of-life care programme

- What is the proposed end-of-life care plan if CANH is withdrawn? (Describe with special emphasis on a terminal care plan and prescribing)
 - Where will the patient be cared for?
 - Who will oversee the end-of-life care (Named Consultant)
 - Principles of care

Type to expand dialogue box

Section 2. Checklist of evidence for diagnosis of PDOC

(To be completed by an expert PDOC assessor who meets the Annex 2b requirements)

This section provides a checklist summarising the requirements for diagnosis of a PDOC, according to the RCP guidelines for patients in PDOC following sudden-onset brain injury.

If a full PDOC assessment has already been conducted according to the RCP guidelines, the form in annex 2f of the guidelines should already have been completed by the person responsible for the specialist PDOC evaluation, and should be accompanied by a copies of the original assessment forms, care plans, investigation reports etc. or a formal assessment report.

This will enable the expert physician to confirm that each requirement has been met.

If a 2f form has not yet been completed, then the equivalent form below, should be completed by the Expert PDOC physician

Minimum requirement		Detail/comment (optional)	Completed and Signed/ Date of signing
1.	<p>TIME FRAME</p> <p>Time since injury:</p> <p>Cause: Traumatic/Hypoxic /Vascular / Toxic or Metabolic/ Other.....</p> <p>Nature of injury: Focal/ / Diffuse</p>		
2.	<p>APPROPRIATE ASSESSMENT PROGRAMME</p> <p>Has undergone an appropriate period of PDOC management and formal assessment by clinician(s) with expertise in PDOC who meet the Annex 2b requirements in one of the following (please tick):</p> <p><input type="checkbox"/> In-patient assessment programme in a designated specialised PDOC Unit</p> <p><input type="checkbox"/> In-patient unit - usually Level 1 or 2 neurorehabilitation setting - with a PDOC assessor who meets the Annex 2b requirements.</p> <p><input type="checkbox"/> A suitable care setting (eg acute hospital, rehabilitation unit, care home, the patient's own home) where staff are familiar with the needs of PDOC patients, under the supervision of a PDOC specialist outreach team for an appropriate period of time minimum 6 weeks but more usually 3-4 months (depending on the time elapsed since onset and the stability of the patient's condition)</p>	Name of Unit / Assessor	

	<input type="checkbox"/> In the case of very long-standing stable PDOC (>3 years post injury), assessed on an outreach basis by a PDOC assessor who meets the Annex 2b requirements, using at least one of the validated tools (WHIM, CRS-R or SMART) administered in conjunction with the family / care team		
3.	MEDICAL MANAGEMENT General medical condition has been stabilised as far as possible, including sepsis and other conditions that may affect consciousness		
a.	Medications have been reviewed to minimise sedation		
b.	Clinical examination of sensory pathways has been undertaken		
c.	Imaging / Investigations: As appropriate to eliminate remediable cause of PDOC		
4	SPECIALIST MANAGEMENT PROGRAMME All essential requirements for management are addressed:		
a.	Tone: Active spasticity management in place, including medication		
b.	Positioning: A 24 hour a day programme of positioning is in place with a range of positions available including bed and chair (unless contra-indicated)		
c.	Has appropriate seating system and sitting tolerance at least 1 hour at a time – preferably up to several hours/day OR, if in bed, at least sitting up in profile in midline for one hour		
d.	Arousal levels recorded: Measures have been taken to maximise arousal		
e.	Optimised environment: Consideration has been given to optimising the environment for interaction (adequate light, avoidance of distraction/overstimulation, rest periods)		
f.	Communication: Has been assessed by clinicians experienced in PDOC to explore ability to access switches / use of communication aids etc. (Only usually applicable in higher levels of MCS)		

g.	Controlled sensory stimulation programme: Patient has been exposed to a range of controlled stimuli		
5	FAMILY/IMPORTANT RELATIONSHIPS Family informed re sensory stimulation and responses etc, and actively involved in the programme (if possible).		

6.	FORMAL ASSESSMENTS One or more of the conditions under 6 a, b and c have been met		
a.	Wessex Head Injury Matrix The patient has had a minimum of 10 WHIM ratings (At least 2-3 per week over a minimum of 4 weeks)		
b.	Coma Recovery Scale – Revised (CRS-R) The patient has had a minimum of 10 CRS-R ratings (At least 2-3 per week over a minimum of 4 weeks)		
c.	Sensory Modality Assessment and Rehabilitation Technique The patient has had a full SMART assessment completed by a trained and accredited SMART assessor		
7.	LEVEL OF CONSCIOUSNESS Current Level of consciousness: <ul style="list-style-type: none"> • Vegetative state/ MCS-minus/ MCS-plus • Is this likely to be permanent? Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> 		
8.	Approximate life expectancy <u>but for</u> withdrawal of CANH <ul style="list-style-type: none"> ○ *Months / years *(Delete as applicable) 		
9.	Uncertainty of prognosis and life expectancy Moderately certain/ significantly uncertain / very uncertain		
10.	Completed by: (Print name and signature) I am/am not (<i>delete as appropriate</i>) a member of the treating team	Date	

Section 3. Checklist of evidence for best interests decision-making

(To be completed by the treating team)

This section provides a checklist summarising the requirements for best interests decision making.

- This will enable the physicians to confirm that they have seen evidence to satisfy them that each requirement has been met.
- This form should be accompanied by a tabbed file, or electronic record, with copies of the notes from best interests meetings.

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 family/friends and any health and welfare attorney or deputy?</p>	<p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Dates of meetings:</p>	
<p>Were the family members made aware of</p> <ul style="list-style-type: none"> • The patient's likely prognosis for recovery (or range of possible outcomes)? • 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>	
<p>3. FAMILY MEMBERS/FRIENDS INVOLVED</p> <p>The following family and friends have been involved in best interests decision making:</p>		

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

Section 4: Clinician Statements

Two physician statements are required, both of whom should have experience in end of life decisions and best interests decision-making, and be familiar with the RCP PDOC guidelines.

- One of them may be the treating consultant.
- One of them must be an independent clinician, who should also provide a written report summarising his/her findings and views.
- One of them must be an expert in PDOC assessment according to Annex 2b of the Royal College of Physicians' Guidelines for Prolonged Disorders of Consciousness, who should also complete the section below confirming diagnosis of the disorder of consciousness

Confirmation of Diagnosis of Disorder of Consciousness

To be completed by the physician expert who meets the person specification in Annex 2b of the Royal College of Physicians' Guidelines for Prolonged Disorders of Consciousness

Name and Initials:.....

Employing Authority:.....

I am an experienced physician who meets the person specification in Annex 2b of the Royal College of Physicians' Guidelines for Prolonged Disorders of Consciousness?

Time Frame

Date of onset of brain injury

The patient has been in a continuing Disorder of Consciousness for months following a [traumatic / non-traumatic*] brain injury (*Delete as applicable)

Medical management

There is no evidence of a remediable medical condition contributing to the patient's low level of responsiveness

Specialist management

The patient has had an adequate period of specialist management and assessment, lasting months* meeting the conditions laid out in the RCP National Guidelines.

*Depending on the time since injury, stability of condition etc. the specialist assessment period should be a minimum of 6 weeks but more usually 3-4 months

OR

In the case of very long-standing stable PDOC (>3 years post injury):

The patient has been assessed on an outreach basis by a PDOC assessor who meets the Annex 2b requirements, using at least one of the validated tools (WHIM, CRS-R or SMART) administered in conjunction with the family / care team for a sufficient period to reach a diagnosis of VS/MCS

Formal assessment

- One or more of the approved structured tools have been used to confirm the diagnosis (e.g. WHIM, CRS-R or SMART)
- The tool(s) have been applied by staff who have been trained in their use
- Formal assessment using one or more of these have been conducted on a sufficient number of occasions to identify any trajectory towards improvement
- I confirm that the diagnosis of [continuing/permanent]* [vegetative / minimally conscious]* state has been made in accordance with the RCP National guidelines

**Delete as applicable*

Prognosis and uncertainty

- I agree the patient is unlikely to recover to a level of functional independence and autonomy that he/she would regard as a reasonable quality of life
- If CANH is continued I estimate that he/she is likely to live for a further.....[months/years*]

**Delete as applicable*

The uncertainty with regard to prognosis for recovery of consciousness, function and life expectancy is:

- Very certain Moderately Certain Significantly uncertain Very uncertain

Signed (Print name and sign)

.....Date.....

Statement from Experienced Physician 1

Name and Initials:.....

Employing Authority:.....

I am an experienced physician who:

a) meets the person specification in Annex 2b of the Royal College of Physicians' Guidelines for Prolonged Disorders of Consciousness?

Yes No

b) is part of the patient's current treating team?

Yes No

c) is from a separate organisation to that responsible for the patient's care.

Yes No

(If both experts are from the same organisation, please specify why this is unavoidable).

I confirm that:

I am familiar with end of life decisions and best interests decision-making

I am familiar with the requirements of the RCP National Guidelines for Prolonged Disorders of Consciousness

My CV with evidence of my training and experience is attached

I have examined the patient.

I have considered and evaluated this form and the patient's medical records to check that the appropriate investigations and tests have been conducted and to assess the interpretation of the results.

I have reviewed the best interests assessments undertaken.

Best interests decision-making meetings

- I have seen the documentation of best interests meetings and confirm that they have been conducted appropriately.
- The appropriate persons, including family members, have been consulted.
- The patient's likely wishes, feelings, beliefs and values have been taken into account so far as these are known.
- All parties are agreed that it is not in the patient's best interests to continue to receive life-sustaining treatment in the form of clinically assisted nutrition and hydration.

Plans for end of life care

- I have seen the plans for end-of life care and confirm that appropriate arrangements have been made for management in accordance with the guidelines

- Having reviewed all relevant information, I have reached the judgement that withdrawing CANH is in the patient's best interest.

(Any concerns or reservations about the initial decision of the treating team, and details of how they were resolved, should be attached).

Signed (Print name and sign)

.....Date.....

Position

Statement from Experienced Physician 2

Name and Initials:.....

Employing Authority:.....

I am an experienced physician who:

a) meets the person specification in Annex 2b of the Royal College of Physicians' Guidelines for Prolonged Disorders of Consciousness?

Yes No

b) is part of the patient's treating team?

Yes No

c) is from a separate organisation to that responsible for the patient's care.

Yes No

(If both experts are from the same organisation, please specify why this is unavoidable).

I confirm that:

I am familiar with end of life decisions and best interests decision-making

I am familiar with the requirements of the RCP National Guidelines for Prolonged Disorders of Consciousness

My CV with evidence of my training and experience is attached

I have examined the patient.

I have considered and evaluated this form and the patient's medical records to check that the appropriate investigations and tests have been conducted and to assess the interpretation of the results.

I have reviewed the best interests assessments undertaken.

Best interests decision-making meetings

- I have seen the documentation of best interests meetings and confirm that they have been conducted appropriately.
- The appropriate persons, including family members, have been consulted.
- The patient's likely wishes, feelings, beliefs and values have been taken into account so far as these are known.
- All parties are agreed that it is not in the patient's best interests to continue to receive life-sustaining treatment in the form of clinically assisted nutrition and hydration.

Plans for end of life care

- I have seen the plans for end-of life care and confirm that appropriate arrangements have been made for management in accordance with the guidelines

- Having reviewed all relevant information, I have reached the judgement that withdrawing CANH is in the patient's best interest.

(Any concerns or reservations about the initial decision of the treating team, and details of how they were resolved, should be attached).

Signed (Print name and sign)

.....Date.....

Position