End-of-life care for patients with prolonged disorders of consciousness following withdrawal of life-sustaining treatment: Experience and lessons from an 8-year cohort

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ABSTRACT

National guidelines provide advice for end-of-life care in patients with prolonged disorders of consciousness (PDOC). Following a Supreme Court judgment in July 2018, updated guidelines set out requirements to ensure that decisions to withdraw clinically assisted nutrition and hydration (CANH) are made responsibly in the absence of a mandatory application to the court.

This retrospective 8-year cohort analysis of prospectively collected clinical data examines the experience and lessons learned from implementing the guidelines in the 80 PDOC patients who have died in one tertiary centre since 2014. It also reports performance against the standards for elective withdrawal of CANH outside of court since July 2018.

CANH was withdrawn in 39/80 (49%) of the patients, over half of whom were already imminently dying. Even in a centre where patients are referred for this purpose, elective CANH withdrawal is comparatively rare (just 14 patients since 2018). The requirements were met in all cases.

KEYWORDS: disorders of consciousness, vegetative state, minimally conscious state, end-of-life care, palliative care

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Introduction

With recent improvements in acute care services (eg major trauma networks, defibrillators in public places), we get ever better at saving lives. Although some patients will recover well from severe brain injury, others have unsurvivable injuries or remain in a 'prolonged disorder of consciousness' (PDOC) – ie in a vegetative or minimally conscious state (VS or MCS). In the immediate stages post-injury, a range of life-sustaining treatments are initiated in the hope of a good recovery. However, the longer patients remain in PDOC, the less likely they are to regain consciousness or return to independence and autonomy.

By definition, patients in PDOC lack capacity to decide on their own care and treatment. In England, the Mental Capacity Act (MCA) 2005[1] requires that treatment must only be given on the basis of their best interests (see Section 4 of the MCA 2005 for full definition), taking account of their individual circumstances and past and present wishes, feelings, beliefs and values (so far as these can be ascertained).[2] While decision-making must start from the strong presumption that it is in the patient's best interests to stay alive,[3] that presumption can be rebutted if there is clear evidence that a patient would not want life-sustaining treatment provided in the circumstances that have arisen.[2]

Clinically assisted nutrition and hydration (CANH) is classed as a medical treatment rather than a facet of basic care,[4] but it has historically been treated differently to decisions about other forms of life-sustaining treatment.[2] Following a Supreme Court Judgment in July 2018, decisions to withdraw CANH no longer require an application to the Court of Protection 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.[5]

First published in 2013 by the Royal College of Physicians, the National Clinical Guidelines for PDOC were updated in 2020[6] to set out the conditions to ensure timely and responsible clinical decision-making to replace court procedures (see supplementary material S1, part 1, for details). In brief, they recommend a system of proportionate external scrutiny in six categories (see supplementary material S1, Table S1). Elective withdrawal of CANH in medically stable patients (categories 3 and 4) carries the highest requirements, including: a) formal evaluation of the level of consciousness, b) documented best interests discussions, c) an independent second opinion from an experienced consultant, and d) a written plan for appropriate end of life (EoL) palliative care after CANH is withdrawn to ensure effective symptom management. The guidelines also provide practical advice and tools to support these processes and recommend using a proforma to document them.

Patients in PDOC are often medically unstable and may be given a range of life-sustaining treatments. For those who are dying as a consequence of profound brain injury and its complications

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(or other comorbidities), CANH is sometimes withdrawn because it increases the risk of vomiting and other complications and, if continued, could actually hasten death. If CANH alone is withdrawn in otherwise medically stable patients (categories 3–5), this will lead through dehydration to multi-organ failure (including renal failure, with acidosis, uraemia and other metabolic and electrolyte disturbances), ending ultimately in cardiorespiratory arrest.[6] This typically takes about 2–3 weeks, during which they will visibly lose weight. Reduced tissue perfusion may also affect absorption of subcutaneous medications.[6]

Although the majority of patients appear to die peacefully, a few may show a strong physiological reaction due to dysautonomia, leading to 'undamped' homeostatic responses. In this situation, reflex physiological signs and hyperactivity in the brainstem can be extreme and unstable, resulting in sweating, tachycardia, agitation, and hyperventilation. Other spontaneous and reflex movements that the person ordinarily displays (such as roving eye movements, grimacing, crying, vocalisation, teeth-grinding, etc) may become much more pronounced. Even if the patient him/herself is unaware, to the onlooker these can give the impression that they are experiencing distress, resulting in significant burden of witness for families and care staff.[6] The guidelines recommend a four-stage palliative care protocol given by continuous subcutaneous or intravenous infusion with bolus doses carefully titrated to maintain the patient in 'calm coma' (see supplementary material S1, part 2).

To our knowledge there is no published literature on the management of patients who are dying in PDOC, and no shared experience of implementing the RCP guidance. Some authors have highlighted concerns about the absence of central monitoring in this situation,[7] which sets out a challenge to clinical teams to publish their experience.

The aim of this retrospective cohort analysis of prospectively-collected routine clinical data, was to review our unit's experience of implementing the RCP palliative care protocol in the cohort of patients who have died in the 8 years since the first 2013 guidelines were published.[8] Patients who died following withdrawal of CANH are compared with those in whom it was continued. The effectiveness of symptom control is reported as well as other lessons learned. We also report our performance against the expected standards for documentation and decision-making in cases of elective withdrawal of CANH since the law changed in July 2018.[5]

Methods

Setting

The Regional Hyperacute Rehabilitation Unit (RHRU) at Northwick Park Hospital is a 24-bedded tertiary specialist inpatient neurorehabilitation unit in north-west London. It takes unstable patients directly out of intensive care units from major trauma and neurosciences centres across south-east England. The unit is one of just three designated units in the UK for the assessment and management of patients admitted in PDOC, who make up approximately half the unit's caseload and carry the highest mortality. The unit also provides end of life terminal neuro-palliative care for patients dying from catastrophic brain injury, including following withdrawal of CANH where appropriate.

Process

In line with the national PDOC guidelines,[6] best interests (BI) discussions are routinely conducted from an early stage in the patient's admission. This includes a review of each medical treatment to consider whether it is clinically appropriate and, if so, to discuss with the patient's family whether or not it is in the patient's BI to continue to give it. We seek to ascertain the patient's own wishes through open discussion with family/friends. BI decision-making is an iterative process that carries on throughout the admission.

The unit's palliative and EoL programme is also provided in accordance with the PDOC Guidelines.[6,8] The majority of patients who die do so from inter-current illness, such as sepsis, respiratory failure, or a further cerebral or cardiac event. Since 2018, if withdrawal of CANH is considered electively in a patient who is not imminently dying from other conditions/comorbidities, the unit uses the recommended proforma to document the process of BI decision-making and independent external scrutiny. Some patients are now referred electively, specifically for this purpose. Once the proforma has been prepared, this is passed to the Trust's senior management for review and approval before CANH is withdrawn. (Note that legally, a decision is made 'not to continue' CANH if this is no longer in the patient's BI, rather than 'to withdraw CANH'. However, from the clinical perspective there is still a very active process of decision-making, documentation, and seeking of a second opinion which the term 'discontinuation of CANH' does not fully capture. The guidelines use the term 'CANH withdrawal' to describe this process, so we have used it here for clarity.)

As part of reflective practice, clinical governance and monitoring for quality improvement, the team conducts a detailed multidisciplinary review for every patient who dies on the unit. Mortality review data are now collated on the unit's clinical database and systematically reported to the Trust's 'Learning from Deaths' Committee. Patients expect health professionals to undertake audit and service evaluation as part of quality assurance, and secondary analysis of de-identified data collected in the course of routine clinical practice does not require research ethics permission in England, but, for the avoidance of doubt, local research ethics permission has been granted to use routinely collected anonymised clinical data for our patients who lack the capacity to consent for the purpose of research and service evaluation (Harrow Research Ethics Committee 04/Q0405/47). Families are routinely informed that clinical data may be used anonymously for research, evaluation and education purposes and that they may opt out if they wish. None of the families in this series did so.

Extraction and data analysis

A systematic search of our unit's clinical database was conducted to identify those who died on the unit's EoL pathway during the period 1 April 2014 to 31 March 2022. De-identified data were extracted and transferred to Microsoft Excel for cleaning and validation. Analysis was conducted using the Statistics Package for Social Sciences (SPSS) v27. Descriptive statistics include the n (%), mean, range, and 95% confidence intervals (CI) calculated with boot strapping in samples of n=1,000. A median and inter-quartile range (IQR) are given for severely skewed data. Where relevant, between-groups differences were examined using Chi-Squared statistics (for categorical data) or independent T tests for continuous data. Non-parametric tests were used to confirm significant differences or correlations for highly-skewed data.

Results

Out of 728 admissions to the unit during the 8-year period, 320 (44%) were admitted in PDOC, of whom 80 (25%) died on our unit. CANH was withdrawn in 39/80 (49%) of these patients. Demographics are shown in Table 1. The overall mean age of the cohort was 52 years (range 17–79). The mean time from injury to death was approximately 10 months (95% CI 6–17). Just over half (55%) had diffuse brain injury. A total of 87% were still in PDOC at death; 13% had emerged into consciousness, but had severe cognitive communicative deficits or were 'locked in'.

The demographic profile of those in whom CANH was, and was not, withdrawn was broadly similar with no significant difference between the two groups for age, time from onset to death, and PDOC diagnosis. By definition, all those in whom CANH was not withdrawn fell within guidelines category 1 (ie imminently dying of within hours or days). As expected, the commonest mode of death (as recorded on Part 1a on the death certificate) in this group was 'bronchopneumonia' (73%), while it was 'multi-organ failure' (59%) for patients in whom CANH was withdrawn. Palliative medication was administered intravenously (IV) in 46%, and subcutaneously (SC) in 21% (both in 15%). All those with SC administration only were imminently dying (Category 1). The mean maximum doses of morphine and midazolam were significantly higher in the patients from whom CANH was withdrawn. T-tests confirm the mean dose differences to be 30 mg/24 hours (95%CI 10, 49; $p=0.007$) and 36 mg/24 hours (95%CI 23, 49; $p<0.001$) respectively.

Of those who died following CANH withdrawal, over half (56%) were in the guidelines Category 1. In 16 (73%) of these, giving CANH was not possible (either because an enteral feeding tube could not be sited (n=4), or because CANH was contraindicated due to abdominal pathology causing obstruction/vomiting etc (n=12)). Six were already dying of other conditions (Table 2). The median time from withdrawal of CANH to death was 7 days (IQR 4–11).

Seven patients who had CANH withdrawn were in Category 2 (ie they were not imminently dying, but had other co-morbidities or frailty that were the main limiting factor for life expectancy). 10 previously healthy patients had elective withdrawal of CANH following either a clinical best-interests decision-making process (category 3 (n=8) or 4 (n=1)) or Court approval (category 5 (n=1)). The modes of death within each of these categories are shown in Table 2.

RCP Guidelines palliative care protocol

The four-stage RCP Guidelines protocol was used in 65 patients (81%): all but two of those in whom CANH was withdrawn (ie 37), and over two-thirds (n=28/41) of those in whom it was not (see Table 3). Overall, the large majority (83%) required Stage 1 only; 11 patients required Stage 2 (12%) or Stage 3 (5%). Eight patients reached or exceeded the maximum recommended dose of morphine and/or midazolam. Higher doses were typically used in the run-up to Stage 2, when bolus doses continued to be given with diminishing effect while transition was arranged. (Delays included waiting for prescription or a second infusion pump or IV line, as phenobarbitone cannot be given through the same line as other agents). In addition, six patients required levomepromazine (maximum dose 50 mg/24 hours), and five required phenobarbitone (maximum dose 1200 mg/24 hours). Anti-emetics (mainly cyclizine) were used in 23% to control vomiting, and drying agents (mainly glycopyrronium) in 9% for secretion management. Spearman rank correlations showed no significant relationship between dosage of analgesia/sedation and time from withdrawal of CANH to death.

The multidisciplinary team review after each death includes an overall consensus on whether symptom control had been 'good' or 'difficult'. Symptom control was good in three-quarters of the patients, but was difficult in the remaining n=15 (23%). Table 3 shows the protocol features in each group. Of those with good control, 94% required only Stage 1 of the protocol, with just three patients requiring Stages 2 or 3 to reach 'calm coma'. By contrast, fewer than half of the patients with difficult symptom control required only Stage 1; 40% required Stage 2 and 13% Stage 3.

As may be expected, the 15 patients whose symptoms were difficult to control required significantly higher doses of morphine than those who achieved good control (mean difference 56mg (95% CI 26, 89) $p<0.001$). They also required higher doses of midazolam (mean difference 42 (95% CI 23, 58), $p<0.001$) (significant differences also seen on non-parametric testing $p<0.001$). These patients were no different in terms of age, gender, time since onset of brain injury or PDOC diagnosis – but two thirds (66%) of this group died a respiratory death (bronchopneumonia or respiratory failure). The proportion of patients with difficult-to-control symptoms has reduced over time as the team has become more experienced in managing symptoms through proactive prescribing and forward planning of transition (see Discussion).

Table 4 provides an aggregated analysis of the 14 patients for whom CANH has been withdrawn electively since the Supreme Court Judgment on 31 July 2018; 57% of the patients were in MCS and 43% in VS. Over half of them (57%) were previously healthy, while 43% had frailty/comorbidity. All had unanimous agreement on best interests. The proforma documentation was completed in all of them and approved by the Trust's management. In 28% of cases the RHRU acted as second opinion – the first consultant having signed from the referring hospital. Of the remainder, five were in Category 2 (frailty/comorbidity) and required only an internal second opinion, which was provided by a consultant from the Trust's palliative care department. Five were in Category 3 or 4, all of whom had the requisite second opinion from an external PDOC expert physician. The median time from withdrawal of CANH to death in this group was 8 days (IQR 6–10, range 2–26). All of them were managed with IV medication and all had 'good' symptom control.

Discussion

Although the principles of neuro-palliative care for patients with PDOC have been previously described,[6,9] to our knowledge this is the first published series of the experience of providing practical EoL care in this group – and especially following elective withdrawal of CANH. Despite the fact that our unit is one of a very small number of tertiary services in England providing EoL care following elective withdrawal of CANH, it is still a comparatively rare event – occurring in just 14/80 (18%) of those who died. Much more commonly, CANH was withdrawn either as part of palliative care in patients who were already dying as a result of a deteriorating condition, or because it was no longer possible to continue feeding.

Overall, there was little difference between the groups in whom CANH was, and was not, withdrawn other than that the former

Table 1. Demographics of the whole cohort, and split by clinically assisted nutrition and hydration (CANH) withdrawal

	CANH withdrawn N=39	CANH not withdrawn N=41	All N=80
M:F ratio	62:38%	61:39%	61:39%
Age (years)			
Mean (95% CI)	53.2 (49.3, 57.3)	50.7 (45.5, 55.5)	51.9 (48.7, 55.1)
Range	24–79	17–77	17–79
Time onset of brain injury to death (months)			
Mean (95% CI)	10.6 (6.0, 17.3)	9.9 (4.3, 20.4)	10.2 (5.8, 17.4)
Median	5.7	4.5	4.6
Range	2–112	1–208	1–208
Aetiology of brain injury			
Trauma	9 (23%)	5 (12%)	14 (18%)
Diffuse[a]	23 (59%)	21 (51%)	44 (55%)
Cerebrovascular accident	7 (18%)	15 (37%)	22 (28%)
PDOC diagnosis at death			
Vegetative state	19 (49%)	20 (49%)	39 (49%)
Minimally conscious state	15 (38%)	14 (34%)	29 (36%)
Coma	2 (5%)	-	2 (3%)
Emerged into consciousness	3 (8%)	7 (17%)	10 (13%)
Guidelines category[b]			
1	22 (56%)	41 (100%)	63 (79%)
2	7 (18%)	-	7 (9%)
3	8 (21%)	-	8 (10%)
4	1 (3%)	-	1 (1%)
5	1 (3%)	-	1(1%)
Guidelines protocol stage			
0	2 (5%)	13 (32%)	15 (19%)
1	29 (74%)	25 (61%)	54 (68%)
2	5 (13%)	3 (7%)	8 (10%)
3	3 (8%)	-	3 (4%)
Maximum dosages/24 hours			
Morphine, mean (95% CI)	55.8 (44.6, 68.4)	25.7 (13.8, 42.3)	41.0 (31.7, 50.8)
Midazolam, mean (95% CI)	55.9 (46.5, 65.9)	19.5 (11.9, 28.9)	38.0 (30.4, 45.4)
Route of administration			
IV	26 (67%)	11 (27%)	37 (46%)
SC	2 (5%)	15 (37%)	17 (21%)
IV and SC	9 (23%)	3 (7%)	12 (15%)
Mode of death[c]			
Bronchopneumonia	11 (28%)	30 (73%)	41 (51%)
Multi-organ failure	23 (59%)	2 (5%)	25 (31%)
Cardiac event/failure	-	3 (7%)	3 (4%)
Respiratory failure	3 (8%)	3 (8%)	6 (8%)
Sepsis	1 (3%)	2 (5%)	3 (4%)
New cerebral event	1 (3%)	1 (2%)	2 (3%)

[a]Diffuse brain injury includes hypoxic/hypoglycaemic/inflammatory/metabolic aetiologies.
[b]Category for proportionate external scrutiny (see page Table 4.2 of the National PDOC guidelines.[6]
[c]Mode of death as recorded on Part 1a of the Medical Certificate of Cause of Death (MCCD). CANH = Clinically assisted nutrition and hydration; PDOC = Prolonged disorder of consciousness.

Table 2. Breakdown of the mode of death within each of the guideline categories

Guidelines category[b]		Category descriptor[a]		Mode of death[b]	
CANH not withdrawn in RHRU (n=41)					
1	41 (100%)	Imminently dying from another condition	41	Bronchopneumonia	30 (73%)
				Organ failure, various[c]	8 (20%)
				Sepsis	2 (5%)
				Venous sinus thrombosis	1 (2%)
CANH withdrawn (n=39)					
1	22 (56%)	CANH not possible	16	Organ failure, various***	10 (45%)
		Abdominal pathology/vomiting	12	Bronchopneumonia	8 (36%)
		No feeding route	4	Acute cardiac event/ pulmonary embolus	3 (14%)
		Imminently dying (from another condition)	6	Sepsis	1 (5%)
2	7 (18%)	Comorbidity/frailty	7	Multi-organ failure (plus other pathology)	6 (86%)
		Hydrocephalus	1		
		Frailty/Multiple pathology	6	Acute hydrocephalus	1 (14%)
3	8 (21%)	Elective CANH withdrawal (High certainty about prognosis for recovery)	8	Multi-organ failure	6 (75%)
				Bronchopneumonia	2 (25%)
4	1 (3%)	Elective CANH withdrawal (Lesser certainty about prognosis for recovery)	1	Multi-organ failure	100%
5	1 (3%)	Elective CANH withdrawal following a Court decision	1	Multi-organ failure	100%

[a]Category for proportionate external scrutiny - see page Table 4.2 of the National PDOC guidelines.[6]
[b]Mode of death as recorded on Part 1a of the Medical Certificate of Cause of Death (MCCD).
[c]Cardiac, respiratory or multi-organ failure. CANH = clinically assisted nutrition and hydration.

required higher doses of analgesia/sedation. Although the majority of patients were well-managed with just Stage 1 of the RCP protocol, a fifth required Stages 2 or 3. This emphasises the importance of palliative care planning to ensure that provision is in place to progress to the higher stages, should this be necessary.

Fourteen patients have undergone elective withdrawal of CANH since the mandatory requirement for Court approval was lifted in July 2018. All of these had complete documentation using the recommended proforma, and met the standards set out in the national guidelines for documented best interests decision-making and appropriate independent external scrutiny.

The delivery of end-of-life care following elective withdrawal of CANH is a challenging area of healthcare that has rarely been written about. A number of learning points have arisen from our multi-disciplinary team reflections in this context that we believe may be of interest to share.

- However sensitively managed, BI discussions regarding elective CANH withdrawal can be very difficult for families, and they require support in their own right. Nevertheless, the feedback from families has been very positive with many expressions of gratitude to the team for supporting a dignified and peaceful death.
- BI decision-making is also challenging for the clinical staff. Communication and involvement of team members, together with staff support at all levels, is essential to ensure that any concerns are heard and taken into account. Procedures are in place on the unit to support this.[10] With these measures in place, in 8 years only very rarely has a staff member expressed a conscientious objection and asked not to be involved. Given the rarity of this event, we have been able to support their preferences without impacting on patient care.
- Many people express concern that the patient would experience symptoms such as hunger and thirst over what can be quite a prolonged dying phase. In practice, with meticulous mouth care and proactive palliation using the RCP protocol to establish 'calm coma' from an early stage, symptom control was good in all cases of elective CANH withdrawal. In fact, learning from our reflections on the quality of symptom control, our experience has been that dying in this situation has often been more peaceful than dying a respiratory death.
- Proactive prescribing is critical. Patients are reviewed by the consultant at least three times a day. Initially, the medical team was hesitant about titrating up the dose of palliative medication for fear of this being interpreted as 'hastening death'. The use of IV continuous infusion means not only that medication is quickly absorbed, but bolus doses can be given simply at the press of a button (rather than by separate injection). In our experience, this enables close and timely titration of smaller boluses according to patient need, with less risk of overdose. Importantly, there was no evidence that higher doses of analgesia/sedation were associated with earlier death.
- The guidelines[6] recommend escalating morphine and midazolam to 100 mg/24 hours each before transition to Stage 2 (levomepromazine or low-dose phenobarbitone). However, because high doses of morphine can sometimes increase agitation, in our more recent experience over the last 18 months, on the

Table 3. Symptom control for the patients (n=65) managed on the PDOC guideline palliative care protocol

Protocol features		Good symptom control	Difficult symptom control	All
		N=50	N=15	N=65
Protocol stage* N (%)	1	47 (94%)	7 (47%)	54 (83%)
	2	2 (4%)	6 (40%)	8 (12%)
	3	1 (2%)	2 (13%)	3 (5%)
PDOC diagnosis at death	Coma	2 (4%)	-	2 (3%)
	VS	23 (46%)	8 (53%)	31 (48%)
	MCS	20 (40%)	7 (47%)	27 (42%)
	Emerged	5 (10%)	-	5 (8%)
CANH withdrawn N (%)	Yes	29 (58%)	8 (53%)	37 (57%)
	No	21 (42%)	7 (46%)	28 (43%)
Max dose morphine mg/24 hrs	Mean (95% CI)	33 (27, 41)	90 (61, 120)	46 (36, 58)
	Range	0–100	10–240	0–240
Max dose midazolam mg/24 hrs	Mean (95% CI)	35 (28, 42)	76 (58, 91)	44 (36, 52)
	Range	0–100	10–100	0–100
Other medications N (%)	Levomepromazine	1 (2%)	5 (33%)	6 (9%)
	Phenobarbitone	2 (4%)	3 (20%)	5 (8%)
	Anti-emetics	9 (16%)	6 (40%)	15 (23%)
	Drying agents	2 (4%)	4 (27%)	6 (9%)
	Other	2 (4%)		2 (3%)
Mode of death	Bronchopneumonia	26 (52%)	8 (53%)	34 (52%)
	Multi-organ failure	18 (36%)	5 (33%)	23 (35%)
	Respiratory failure	2 (4%)	2 (13%)	4 (6%)
	Cardiac event/failure	2 (4%)		2 (3%)
	Other	2 (4%)		2 (3%)

For full description of palliative care protocol stages see Tables 5.2b and 5.2c of the national PDOC guidelines.[6] CANH = clinically assisted nutrition and hydration; PDOC = prolonged disorder of consciousness.

advice of our local senior palliative care consultants, we have aimed to cap the morphine at around 60 mg/24 hours and introduced Stage 2 earlier if needed, thus avoiding periods when high doses of opiate were given with diminishing effect while waiting for transition to Stage 2). Anecdotally, this has proved to be both safe and effective and, on the basis of this experience, we would recommend that this approach should be considered for adoption in the next iteration of the guidelines.

Strengths and weaknesses

The most obvious limitation of this analysis is that it comes from a single centre. On the other hand, this is the first published series in this area within the world literature, and it comes from the unit with the largest and longest experience of implementing the UK PDOC guidelines for EoL care.

Conclusion

Elective withdrawal of CANH is still comparatively rare – it is much more commonly withdrawn in patients who are already dying of the complications of their brain injury. Our findings demonstrate that decisions can be made responsibly without an application to the court, and the Guidelines protocol provides safe and largely effective EoL care. We hope that this review will encourage others to examine and share their own experience.

Key points

- Current national guidelines provide practical advice for responsible decision-making and also protocols end-of-life (EoL) care if a decision is made to withdraw treatment.
- The recommended EoL protocol provides good symptom control for the majority of patients to support a peaceful and dignified death.
- About a quarter of patients had symptoms that were difficult to control, requiring higher doses of medication, but there was no evidence that this hastened death.
- Elective withdrawal of CANH is still comparatively rare, but clinicians can make these decisions responsibly without the need for an application to the court.
- Clinicians should be aware that it is a legal requirement to ensure that continued life-sustaining treatment is in line with the patient's own likely wishes, and that it is the giving, not the withdrawing, of treatment that needs to be justified. ■

Table 4. Elective withdrawal of CANH (n=14) since August 2018

Age	**Years**	**Mean 54 (range 35–79)**
Gender	Male:Female %	71:29 %
Aetiology	Traumatic	5 (36 %)
	Hypoxic	7 (50 %)
	Metabolic	1 (7 %)
	Vascular	1 (7 %)
Level of consciousness	Vegetative state	6 (43 %)
	Minimally conscious state	8 (57 %)
Time since onset of BI (months)	Mean (range)	13 (3–112)
Guidance category	2: Frailty/comorbidity	6 (43 %)
	3: Previously healthy – high certainty	7 (50 %)
	4: Previously healthy – less certain	1 (7 %)
Second opinion	RHRU (Referring unit first opinion)	4 (28 %)
	Internal (palliative care consultant)	5 (36 %)
	External PDOC expert physician	5 (36 %)
CANH documentation	Paperwork fully complete	14 (100 %)
	Days from submission to approval	7 (range 0–34[a])
Days from withdrawal to death	Mean (range)	9 (2–26)
Protocol stage	1	12 (86 %)
	2	1 (7 %)
	3	1 (7 %)
Routine of administration	IV	13 (93 %)
	IV and SC	1 (7 %)
Symptom control	Good	14 (100 %)
Mode of death	Multi-organ failure	12 (86 %)
	Bronchopneumonia	2 (14 %)

[a]One outlier of 34 days as the Trust requested a further external opinion. Otherwise, the range was 1–16 days.
IV=intravenous; SC = subcutaneous; PDOC = prolonged disorder of consciousness; RHRU = Regional Hyperacute Rehabilitation Unit.

Supplementary material

Additional supplementary material may be found in the online version of this article at www.rcpjournals.org/clinmedicine.
S1. Key points from the National Clinical Guidelines.

Conflicts of interest

Professor Turner-Stokes is the lead author for the National Clinical Guidelines for Prolonged Disorders of Consciousness (2013, 2020) and was also lead clinician on Guidelines Development Group for the BMA/RCP guidelines on Clinically Assisted Nutrition and Hydration in Patients who lack capacity to consent (2018). None of the authors has any financial or other conflicts of interests.

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