Coma and Disorders of Consciousness
research centre

Serious Medical Treatment and the Law Concerning Patients in a Permanent Vegetative State

EXECUTIVE SUMMARY

Purpose of this document

To summarise key research findings relating to Court of Protection Practice Direction 9e which requires court approval before a feeding tube can lawfully be withdrawn or withheld from a patient in a permanent vegetative (or minimally conscious) state.

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Background

People who suffer profound brain injuries – e.g. through accidents, assaults, strokes, falls and infection – are sometimes left in a permanent vegetative state (PVS): they have a functioning brain stem and can usually breathe on their own but they have no awareness of themselves or their environment. And the longer they remain unconscious the less likely it is that they will ever become conscious again.

After the acute period in emergency and intensive care, treatments for severely brain-injured patients are not particularly high-tech. Keeping them alive requires good basic care (such as turning and changing position to manage skin integrity), a feeding tube, intermittent antibiotics for infections and perhaps some ongoing mechanical ventilation support (such as oxygen at night). In the UK it is estimated that there are between 4,000 and 16,000 PVS patients and it has become routine to deliver life-prolonging treatments indefinitely.

Although clinicians and families often agree on "ceilings of intervention" – for example, that the patient will not be resuscitated if they have a cardiac arrest – many PVS patients are medically stable. The vast majority continue to be kept alive via hydration and nutrition delivered through a feeding tube. Tube feeding is often referred to as either 'artificial nutrition and hydration' (ANH) or 'clinically assisted nutrition and hydration' (CANH) (these terms are used interchangeably): we use ANH (which is still the more common term) in this summary.

It is widely recognized that feeding tubes may not always be in a patient's best interests and treatment is commonly withheld or withdrawn in these circumstances. However, the law singles out patients in PVS (along with those in a minimally conscious state) and treats them differently from other patients in requiring court approval before ANH can lawfully be withdrawn. Originally proposed in Bland as an interim measure until a sufficient body of expertise had been acquired, and then part of common law, this requirement is now laid out in s 5(a) Court of Protection Practice Direction 9e.

Research findings produced by the Coma and Disorders of Consciousness Research Centre (cdoc.org.uk) highlight concerns about Practice Direction 9e. In particular, there is evidence that the best interests of patients are not being served by the current system which requires a full hearing (involving both written and oral evidence) before the President of the Court of Protection, or High Court judges nominated by him. Our findings suggest the need for better ways of making decisions about ANH in relation to patients found to be in a PVS - most especially in straightforward cases where both family and clinicians agree that continued treatment is not in the PVS patient's best interests.

Findings

1. **The requirement for judicial approval before certain treatments can be withdrawn from patients in a permanent vegetative state is a legal anomaly in domestic law [References A and B].**

   - ANH is legally defined as 'medical treatment' and The Mental Capacity Act 2005 specifies that medical treatments can be administered to people who are unable to give or to withhold consent only if those treatments are in the best interests of the patient (and P has not refused them in a valid and applicable advance decision). It is widely recognized that ANH may not always be in a patient's best interests and such treatment is commonly withheld or withdrawn in these circumstances.

   - However, for patients in disorders of consciousness (the permanent vegetative state [PVS] and minimally conscious state [MCS]) – and only for this group of patients - withdrawal of ANH requires an application to the Court of Protection.

   - Following Aintree the focus of the court should be not on whether it is in the patient's best interests to withhold treatment but rather on whether it is in their best interests to give or to continue treatment. The requirement of Practice Direction 9E (para. 5) to seek declaratory relief specifically in relation to 'withholding or withdrawal' of ANH from PVS and MCS patients, and not for providing or continuing to provide this medical treatment, appears contradictory.

   - Other life-sustaining treatments (e.g. CPR, antibiotics) can be – and often are – withheld or withdrawn from PVS patients without recourse to the courts. It seems that ANH withdrawal has been singled out as the only treatment decision for patients in PVS requiring court approval. There is no apparent legal rationale for this special treatment.

2. **English law is out of kilter with international law [Reference A].**

Internationally, the norm is to permit withdrawal of feeding tubes from patients in permanent vegetative states without recourse to courts where families and health care teams agree that it is appropriate to do. For example, no court decision is required in Australia, Belgium, Denmark, Finland, France, Germany, Japan, the Netherlands, New Zealand, Norway, Portugal, South Africa, Sweden or the USA. English law seems to inhabit a small pool of exceptions.

3. **Practice Direction 9e leads to (long-term and invasive) treatment that is not in P's best interests (References B and C).**

There are between 4,000 and 16,000 PVS patients in England and Wales but very few applications for ANH-withdrawal from such patients reach the courts (maybe 100 in the two decades plus since Bland). Most PVS patients continue to receive ANH over years or decades. Since no court in England and Wales has ever found continued administration of ANH to be in a PVS patient's best interests, this means that many PVS patients are receiving treatment that is not in their best interests over protracted periods of time.

- Our research found that PD9e acts to deter ANH withdrawal from PVS patients, because it adds to the already hugely symbolic freight of ANH-withdrawal the additional – often intimidating - obstacle of courtrooms with lawyers, expert witnesses, judges and, potentially, media attention. It leads to life-prolonging treatment by default, without reference to the best interests of the person.

- Even those families who believe that it would be in the patient's best interests to have ANH withdrawn are sometimes opposed to an application to the courts ("I'd feel like a criminal"). Other methods of permitting the patient's death are tried instead and this often means repeated and distressing near-death experiences (e.g. from lung infections) over many years until the patient is eventually able to die of something other than ANH-withdrawal.

- Despite the Mental Capacity Act 2005 which requires treatment to be given only if it is in P's best interests, the practice of delivering ANH to PVS patients (often with no best interests meetings being held) is pervasive and routine across England and Wales. Equality of treatment under the law would recognize the right of PVS patients to equal protection from futile or potentially burdensome treatment that is not in their best interests.

4. **The inappropriate treatment delivered to PVS patients in part as a result of PD9e displaces alternative NHS services [Reference D].**

- The cost to the NHS of requiring a court hearing before a feeding tube can be withdrawn (or withheld) from a PVS patient (in 'straightforward' cases where family and clinicians agree this is in the best interests of the patient) is on average about £122,000 per patient. (This figure includes court costs and the costs of the, on average, 9-month delay between a best interests decision between clinicians and families that ANH is not in the best interests of the patient, and the declaration by the court that this would be lawful.) This displaces alternative NHS services and causes a loss of nine quality adjusted life years from other NHS patients.

- In addition, since PD9e acts as a deterrent to ANH-withdrawal from PVS patients, and leads to the indefinite provision of ANH, prolonging the life of some patients indefinitely, it is appropriate to consider the cost of this. The continued cost of treatment is around £90,000 per individual per year. For each year that each PVS patient is so treated, this results in a loss of seven quality-adjusted life years from other NHS patients.

References

Research Publications from the Coma and Disorders of Consciousness Research Centre

All available to download from: http://cdoc.org.uk/publications/academic-articles/

A. Halliday, S, Formby, A and Cookson, R (2015) 'An assessment of the court's role in the withdrawal of clinically assisted nutrition and hydration from patients in the permanent vegetative state', Medical Law Review

B. Kitzinger,CandKitzinger,J(2015) 'Family perspectives on proper medical treatment' in Fovargue, S and Mullock, A (eds) The Legitimacy of Medical Treatment: What Role for the Medical Exception? Biomedical Law and Ethics Library. London:Taylor & Francis.

C. Kitzinger, C and Kitzinger, J (2015) 'Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: Family experience', Journal of Medical Ethics

D. Formby, A., Cookson, R. and Halliday, S. (2015) 'Cost analysis of the legal declaratory relief requirement for withdrawing clinically assisted nutrition and hydration (CANH) from patients in the permanent vegetative state (PVS) in England and Wales', University of York Centre for Health Economics Research Paper 108.

Additional Resources - (also available via links on cdoc.org.uk)

1. POST note Vegetative and minimally conscious states, Number 489, March 2015
   http://www.parliament.uk/mps-lordsandoffices/offices/bicameral/post/publications/postnotes/

   The Parliamentary Office of Science and Technology (POST) provides balanced and accessible overviews of research from across the biological, physical and social sciences, placing research findings in a policy context for Parliamentary use. This POST note on Vegetative and minimally conscious states provides an objective overview and up-to-date summary of what is known about these conditions.

2. healthtalk.org module: Family experiences of vegetative and minimally conscious states
   http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative- and-minimally-conscious-states/topics
   Based on in-depth research on family experiences of vegetative and minimally conscious states, Professor Celia Kitzinger (University of York) and Professor Jenny Kitzinger (Cardiff University) worked with the Health Experience Research Group, Oxford University (HERG) and the DIPEx charity (which runs the healthtalk.org website) to create a high-quality, multi-media online resource to provide support for families and training for professionals.
   This resource won the Outstanding Impact Award 2015 from the Economic and Social Research Council.

3. Practice Direction 9e (This practice direction supplements Part 9 of the Court of Protection Rules 2007):
   http://webarchive.nationalarchives.gov.uk/20110218200720/http:/www.hmcourts-service.gov.uk/cms/files/09E_-_Serious_Medical_Treatment_PD.pdf
   One of the "matters which should be brought to the court" according to this Practice Direction is "decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state" (s 5(a))

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