

Research Evidence on mandatory court applications for CANH-withdrawal for PVS/MCS patients

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Research from the Coma and Disorders of Consciousness Research Centre includes literature reviews, use of 'key informants' internationally, in-depth narrative interviews with family members of people in vegetative and minimally conscious states, and ethnographic action-research tracking individual cases through best interests decision-making processes in care homes, hospitals, rehabilitation units and the courts.

Full details about our research and downloadable publications are available on our website: www.cdcc.org.uk.

1. Mandating court applications before CANH can be withdrawn from PVS/MCS patients is out of kilter with international law.

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.¹

2. Mandatory court applications mean that many patients in England and Wales are subjected to long periods of ongoing treatment that it has already been decided is not in their best interests.

Evidence based on applications made to the Court of Protection provides a very limited view of what is happening on the ground and the wider effects of the law. It is estimated that there are between 4,000 and 16,000 PVS patients in England and Wales² but very few applications for withdrawal of clinically assisted nutrition and hydration (CANH) from such patients reach the courts (maybe 100 or so in the two decades plus since Bland). The vast majority of PVS patients continue to receive CANH over years or decades. Since no court in England and Wales has ever found continued administration of CANH 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, often over protracted periods of time. A recent case before the Court of Protection concerned a patient in PVS for over two decades.³

¹ 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* <https://academic.oup.com/medlaw/article/23/4/556/2413124>

² POST note Vegetative and minimally conscious states, Number 489, March 2015 <http://www.parliament.uk/mps-lordsandoffices/offices/bicameral/post/publications/postnotes/>

³ Kitinger J & Kitinger C. 2018. 'Why futile and unwanted treatment continues for some PVS patients (and what to do about it)' (in press). *International Journal of Mental Health and Capacity Law*

- A perception that court applications are mandated acts to deter consideration of whether or not CANH is in the best interests of PVS/MCS patients, because it adds to the already hugely symbolic freight of CANH the additional – often very daunting - obstacle of courtrooms with lawyers, expert witnesses, judges and, potentially, media attention. It can lead to life-prolonging treatment by default, without reference to the best interests of the person.⁴ Even those families who believe that it would be in the patient's best interests to have CANH withdrawn are sometimes opposed to an application to the courts because they feel intimidated or 'accused' ("I'd feel like a criminal").
- The process of making court applications introduces unnecessary and unacceptable delays which is compounded by difficulties experienced by CCGs, Trusts, Health Boards and medico-legal practitioners in understanding and implementing the requirements of the court. In one documented case it took more than a year from the date on which the multidisciplinary team agreed formally to request a court application until a court application was actually made.⁵

3. The perceived special legal conditions relating to CANH for PVS and MCS patients contributes to failure to place patients on the most appropriate pathway and to provide the best palliative care

The fact that CANH-withdrawal (unlike other types of withdrawal/withholding) is seen to necessitate court involvement leads some clinical teams (with the support of families) to try other methods of permitting the patient's death instead (e.g. from lung infections). This often means repeated and distressing near-death events over many years until the patient is eventually able to die of something other than CANH-withdrawal.^{6,7} Note: Deaths of PVS/MCS patients following CANH-withdrawal and proper implementation of the national palliative care guidelines⁸ were, in practice, reported by families we interviewed as 'peaceful' and described as 'better deaths' compared with reports of deaths following infections.⁹

⁴ Kitinger J & Kitinger, C. 2012. 'The "window of opportunity" for death after severe brain injury', *Sociology of Health and Illness* <http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12020/abstract>

⁵ Kitinger, J & Kitinger, C (2016) 'Causes and Consequences of Delays in Treatment-Withdrawal from PVS Patients: A Case Study of Cumbria NHS Clinical Commissioning Group v Miss S and Ors [2016] EW COP 32', *Journal of Medical Ethics* <http://jme.bmj.com/content/43/7/459>

⁶ Kitinger C & Kitinger, J (2015) 'Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: Family experience', *Journal of Medical Ethics* <http://jme.bmj.com/content/42/1/11>

⁷ Kitinger C & Kitinger J. 2015. 'Family perspectives on proper medical treatment' in Fovargue S & Mullock A (eds) *The Legitimacy of Medical Treatment: What Role for the Medical Exception?* Biomedical Law and Ethics Library. London: Taylor & Francis. http://www.tandfebooks.com/userimages/ContentEditor/1448367660965/9781138819634_oachapter6.pdf

⁸ Royal College of Physicians 2013. Prolonged Disorders of Consciousness: National Clinical Guidelines <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>

⁹ Kitinger J & Kitinger C. 2018. 'Deaths after feeding tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience'. *Palliative Medicine* (in press)

4. The inappropriate treatment delivered to PVS patients in part as a result of a perceived mandatory court application requirement displaces alternative NHS services

- 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) was estimated a few years ago as being 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 CANH 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 and/or could be better spent on assuring appropriate services, rehabilitation and best interests decision-making for the full spectrum of patients in disorders of consciousness.¹⁰
- In addition, since the perceived need to go to court acts as a deterrent to CANH-withdrawal from PVS patients, and leads to the indefinite provision of CANH, prolonging the life of some patients indefinitely, it is appropriate to consider the cost of continuing ongoing treatment. The continued cost of treatment is around £90,000 per individual per year and this can extend over decades. 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.⁸

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¹⁰ Formby A, Cookson R. & 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. www.york.ac.uk/media/che/documents/papers/researchpapers/CHERP108_cost_analysis_CANH_PVS_declaratory_relief.pdf