



Appropriate use of CHC funds - CCGs should not pay for unwanted or futile treatments:

Ensuring best interests decisions for patients in prolonged disorders of consciousness

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About us: The Coma and Disorders of Consciousness Research Centre (cdoc.org.uk) was founded in 2010 at the Universities of York and Cardiff by Professor Celia Kitinger and Professor Jenny Kitinger. We are a multi-disciplinary group of researchers exploring the cultural, ethical, legal and social dimensions of coma, the vegetative state and the minimally conscious state.

Executive Summary

- Some CCGs are using Continuing Health Care funding to pay for futile and unwanted treatment that is not in the best interests of some patients.
- Evidence shows this to be the case particularly for some patients in prolonged disorders of consciousness.
- Unwanted treatment violates patients' rights and causes distress to families.
- We recommend a national register of patients in prolonged disorders of consciousness to enable proper tracking and management of these patients (including access to expert reassessment as appropriate) and to ensure timely best interests meetings concerning life-sustaining treatments

Our submission

1. Continuing Health Care costs are rising and place significant pressure on Clinical Commissioning Groups' (CCGs') spending. It is important that money is spent appropriately to support much needed care and that it is not misused by paying for treatments that may be futile, burdensome or unwanted.

2. Research evidence shows that some CCGs are using Continuing Health Care funding to pay for futile and unwanted treatment that is not in the best interests of some patients in prolonged disorders of consciousness (vegetative and minimally conscious states) and where families believe the patient would not have wanted such treatment [1].

3. There are an estimated 4,000 – 16,000 patients in the UK in a vegetative state and about three times that many in a minimally conscious state [2].

4. Patients can be diagnosed as in a *Permanent* Vegetative State (PVS) as early as 6 months to a year after injury (although it often takes much longer than this to secure a reliable diagnosis due to confounding medical factors) [3]. Patients can be diagnosed as in a chronic Minimally Conscious State around 3 to 5 years after injury (i.e. unlikely ever to regain full consciousness) [3]. People report diverse views on what life-sustaining treatments they would or would not want after devastating brain injuries – and how it relates to these diagnoses – but many (most) people say they would not want to continue to receive life-sustaining treatments if they were in PVS or MCS [4].

5. Over 100 cases have reached courts (in England and Wales) concerning continuing life-sustaining treatment for patient in a Permanent Vegetative State and judges have never found continuing life-sustaining treatment to be in the best interests of these patients. As the National Clinical Guidelines [3] point out, reflecting the legal situation since the ‘Tony Bland’ case:

Once it is known that a patient is in **permanent VS**, the Court accepts that further treatment is futile. It is not only appropriate but necessary to consider withdrawal of all life-sustaining treatments, including CANH. Indeed, to continue to deliver treatment that prolongs their life in that condition *in the absence of a reasonable belief that treatment is in the patient’s best interests* may be regarded as an assault (*Bland* [1993] AC 789 per Lord Browne-Wilkinson at 883) [Our emphasis]

6. Life-sustaining treatment may also not be in the best interests of some patients in minimally conscious states, as several recent court cases have found – where it has been clear that the patient themselves would have refused such treatment [5].

7. These cases often reach court only after lengthy lobbying from families who believe ongoing treatment is not in their relative’s best interests. They are also delayed because patients may not have had access to appropriate rehabilitation placements or recent expert assessments. Doubt about their diagnosis (e.g. whether they are VS or MCS) may make appropriate decision-making difficult. It would be appropriate use of Continuing Health Care Funding to ensure that patients have access to timely rehabilitation placements and expert assessments to ensure that recovery is maximized as much as possible in accordance with patient wishes. Ensuring good care, placements and assessments is an essential underpinning to good best interests decision-making.

8. Research based on interviews with families (who should be consulted as part of properly-conducted best interests decision-making) strongly suggests that health professionals are not initiating best interests decision-making in relation to some life-sustaining treatments for patients in prolonged disorders of consciousness - most especially clinically assisted nutrition and hydration [1]. Patients sometimes receive this treatment, without any consideration as to whether or not it is in their best interests, and without review or reassessment, for years or even decades. Both this treatment, and the associated ongoing care costs, are usually borne in whole or in part by Continuing Health Care Funding.

9. There is no central register of patients in prolonged disorders of consciousness, so the number of patients and the cost of funding their treatment can only be estimated. In response to a Freedom of Information request submitted by the BBC last year, only 62 of the 238 health authorities approached could provide any information on how many patients in prolonged disorders of consciousness were their responsibility [6]. Of those able to provide

information, Lambeth CCG and Southwark CCG reported each spending more than £1m on caring for these patients in the 2015/16 financial year. These costs took up 7.5 and 9% of their continuing care budgets respectively [6].

10. Recent judgments from the Court of Protection concerning withdrawal of treatment from PVS/MCS patients show that these patients have often been maintained for years beyond the time at which it was possible to make best interests decisions based on their diagnosis, their prognosis, and what they would have wanted (drawing on their wishes, feelings, values and beliefs, the way they lived their lives and the other considerations they would take into account if they were able, Mental Capacity Act 2005). We know of several cases where it took over 8 years, and one case where it took over 20 years, before best interest discussion about life-sustaining treatments have been convened (and often such discussions have had to be initiated by the *family* because clinicians and/or commissioners failed to do so). Had such best interests discussions about clinically assisted nutrition and hydration been initiated sooner in such cases, the decision could have been made to withdraw treatment much earlier, with support from families (and without leaving them with the burden of having raised the issue). This would obviously have avoided unwanted treatment for the patient, additional distress for the family, and saved the CCG a considerable amount of money: a very conservative estimate from 2015 suggests that maintaining a PVS patient costs around £90k per year (MCS patients would cost more). This means that for each year that any PVS patient is subject to unwanted treatment, this results in a loss of seven quality-adjusted life years from other NHS patients. [7]

11. The widespread practice of delivering long-term treatment to patients in prolonged disorders of consciousness that the person would not have wanted is an abuse of their human rights. Our concern extends beyond the issue of financial costs to include the right of these patients to protection from futile, unwanted and potentially burdensome treatment that is not in their best interests. Continuing to fund and hence implicitly to endorse treatment that is not in these patients' best interests causes harm to patients and enormous distress to their families [8].

12. Given the context of recent developments in legal practice and medical guidelines, we recommend (reflecting the advice of a senior neuro-rehabilitation expert [9]) that CCGs should create a national register of patients in prolonged disorders of consciousness to enable proper tracking and management of these patients (including access to expert reassessment as appropriate) and to ensure timely best interests meetings concerning life-sustaining treatments (including expert case management to support this if the team are inexperienced and feel they need additional input). Annual CHC funding review might usefully include an audit to ensure appropriate efforts have been made to consult with family/friends of the patient to ensure their wishes, values and beliefs have been incorporated into decisions about treatment. Withdrawal of unwanted treatments that are not in patients' best interests will mean better compliance with law and national guidelines and respect for patients' human rights in accordance with the law.

CASE STUDY

In early July 2008 AW, a woman in her 50s who ran a catering business, was a keen sportswoman and enjoyed music and dance, suffered a severe intra-cerebral haemorrhage. She was diagnosed as being in a 'vegetative state' two months later. Although a Permanent Vegetative State diagnosis can usually be confirmed 6 months to a year after a brain injury of this kind, AW's diagnosis was not confirmed for more than three years (on 18 October 2011). A best interests meeting to discuss treatment withdrawal did not take place until nearly a year later (21 September 2012). At that meeting her family formally asked for withdrawal of treatment, and it was finally withdrawn in January 2013. The delay in treatment withdrawal meant that she received unwanted and futile treatment for many years, and this caused huge distress to her family. The legal judgment is here:

<http://www.bailii.org/ew/cases/EWHC/COP/2013/78.html> Short video-clips of her family talking about the experience are available on our online multi-media resource for families here: <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/gunars-and-margaret>

References

- [1] Kitzinger, J & Kitzinger, 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] EWCOP 32, *Journal of Medical Ethics*; Kitzinger, C and Kitzinger, J (2016) 'Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: Family experience', *Journal of Medical Ethics*.
- [2] Parliamentary Office of Science and Technology POSTnote 489 (26 March 2015)
<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-489#fullreport>
- [3] 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>
- [4] Demertzi, Athena, Didier Ledoux, Marie-Aurèlie Bruno, Audrey Vanhauzenhuyse, Olivia Gosseries, Andrea Soddu, Caroline Schnakers, Gustave Moonen, and Steven Laureys. 2011. Attitudes towards end-of-life issues in disorders of consciousness: A European survey. *Journal of Neurology* 258(6): 1058–1065. doi:10.1007/s00415-010-5882-z.
- [5] Butler-Cole, Victoria. 2017. How Court of Protection judges decide best interests in end of life case. https://medium.com/@tor_65185/how-court-of-protection-judges-decide-best-interests-in-end-of-life-cases-b1e03c563282; Kitzinger, J, Kitzinger, C & Cowley, J (2017) When 'Sanctity of Life' and 'Self-Determination' Clash: Briggs v The Walton Centre NHS Trust & Ors [2016] EWCOP 53, *Journal of Medical Ethics*
- [6] Berg, S. & Greenwood G How many minimally conscious patients are there? BBC News. <http://www.bbc.co.uk/news/health-38383338>
- [7] 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.
- [8] Kitzinger, C and Kitzinger J (2014) 'Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising', Editorial. *Clinical Rehabilitation*; Kitzinger C. 2017 Life-and-death decisions: Knowing when to let go. *Neuro-Rehab Times* 4: 30-33.
- [9] Wade, D. Using best interests meetings for people in a prolonged disorder of consciousness to improve clinical and ethical management, *Journal of Medical Ethics*.
<http://jme.bmj.com/content/early/2017/09/14/medethics-2017-104244>