Withdrawing Life-Prolonging Treatment from Adults in Vegetative & Minimally Conscious States in England and Wales

Professor Celia Kitzinger + Professor Jenny Kitzinger
Coma and Disorders of Consciousness Research Centre
Universities of York + Cardiff

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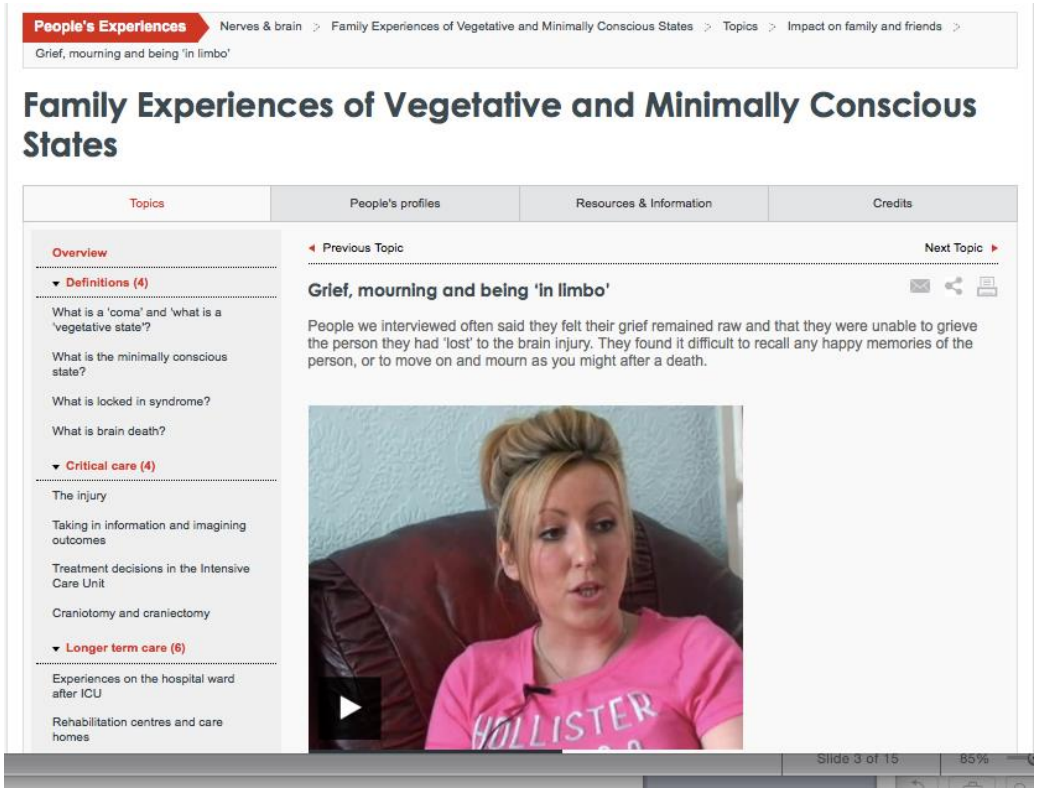
Dedication

- Our work is dedicated to our sister, Polly Kitzinger – catastrophically brain-injured in a car accident in 2009 + kept alive in VS and MCS with medical treatments she would have refused if she could.
- Polly has survived with profound multiple neurological + physical disabilities. We have told part of her story – click here

Coma and Disorders of Consciousness Research Centre - cdoc.org.uk

Open-Access Publications: click here

Online Resource: Family Experiences of Vegetative and Minimally Conscious States – click here



Awarded British Medical Association Prize for Patient Information on Ethical Issues

- Interviews with families + medical professionals
- Wide range of perspectives + experiences
- Used in medical schools + patients referred to it by clinicians

Prolonged Disorders of Consciousness:

- **Coma:** No awareness of self or environment; no sleep/wake cycle. (Rarely prolonged)
- **Vegetative state (VS)**: Sleep/wake cycle – but no awareness of self or environment. Said to be 'prolonged' after 4 weeks and 'permanent' 6 months after anoxic or other non-traumatic injury, 12 months after traumatic injury.
- **Minimally conscious state (MCS)**: Fluctuating intermittent awareness of self + environment. (+/-). Defined as 'permanent' after 5 years.
- **Estimated numbers:** 4,000-16,000 patients in VS, plus 3x as many in MCS i.e. up to 48,000 in MCS (POSTNote 2015 based on extrapolation from numbers in UK nursing homes; click here)

(Definitions condensed from National Clinical Guidelines click here)

Chronology of Life-Prolonging Treatments in PVS/MCS

- Initial brain injury – may include **CPR, craniectomy, artificial ventilation** + other emergency treatments.
- **Clinically assisted nutrition + hydration** (CANH) – shift from nasogastric -> PEG tube
- 3-6 months – **antibiotics** for life-threatening (lung) infections
- Once stabilized – **CANH** is usually only ongoing medical treatment (unless P is also e.g. insulin-dependent diabetic)

Previous research on CANH-withdrawal at EOL

- Many families are dismayed + concerned about reduced nutrition and hydration at EOL
- Lack of clarity about CANH as ‘medical treatment’ (v ‘basic care’)
- Heavy symbolic and emotional freight (even at EOL with dying patients)
- Concern about ’bad death’ from ‘starvation and dehydration’ (‘the sloganism of starvation’)
- No research about death after CANH-withdrawal from PVS/MCS patients

Our research finds....

- A ‘window of opportunity for death’ (e.g. in ICU/ high dependency care) when prognosis is still unclear - closes as the prognosis becomes clearer
- Feeding tubes seen as ‘default’ (‘basic care’) - even when ceilings of treatment are in place (DNACPR, no return to ICU, no intravenous antibiotics etc).
- Rare to find ‘best interests’ discussion about feeding tubes – families often not aware of possibility of withdrawal.
- Repeated infections and ‘near deaths’ – some deaths from untreated pneumonia, gangrene, + other comorbidities

- When **clinicians** raise CANH-withdrawal there is often significant concern from families (“barbaric”, “cruel”, ‘lethal injection preferable’)
- When **families** raise CANH-withdrawal they’ve been told by clinicians ‘we don’t do that here’, it’s ‘against our philosophy of care’ or even ‘that’s murder’.
- Both families and clinicians fear protracted and painful death after CANH-withdrawal

Dying after CANH-withdrawal for PVS/MCS patients

- Kitzinger & Kitzinger (under submission)
- Interviewed 21 people (12 families) – 8 PVS, 2 MCS, 2 either PVS or MCS (uncertain diagnosis) *(approx 10%+of all court-authorised deaths for this patient group in UK since 1993)*
- Arrived at view that CANH-withdrawal = 'least bad option' but retained ethical objections
- Fearful about the dying process e.g. "'I had nightmares and things about her being all shriveled and like a skeleton'

Deaths were all described as peaceful

- “her life just ebbed away”
- “He just lay there and he just made a couple of shrugs and then he just passed away gently”
- “The only difference was her breathing was more shallow, and sort of panting […] No-one could say this was a bad death. It was so peaceful”

But there was a 'burden of witness'…

- For the last three days she looked dead, gaunt, hollow cheeked… her face was skeletal and […] her eyes didn't close completely. […] It wasn't her body anymore, never mind *her* not being there anymore. […] 'That's why I had a closed casket, I didn't want anyone seeing her like that, […] and I told the children not to come at the end. But she wasn't in pain, it was peaceful.'

Reasons for not withdrawing CANH

- Believe CANH is in P's best interests (e.g. P would have wanted life at all costs)
- Family not ready to 'let go', hoping for future recovery or new cure, etc + override P's best interests
- Family/clinicians have ethical objections to CANH-withdrawal + override P's best interests
- **COURT OF PROTECTION:** Acts as **DETERRENT** to CANH-withdrawal from PVS/MCS patients - By singling out withdrawal of CANH as requiring a court application - adds to heavy symbolic freight of feeding tube withdrawal + notion that it's 'basic care'. It's also expensive, frightening/stigmatising + causes delay.

Court of Protection Practice Direction 9E

"Matters which should be brought to the court

5. Cases involving any of the following decisions should be regarded as serious medical treatment for the purpose of the Rules and this practice direction, and should be brought to the court:

(a) 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; "

Airedale NHS Trust v Bland [1993] AC 789

The decision whether or not the continued treatment and care of a P.V.S. patient confers any benefit on him is essentially one for the practitioners in charge of his case. The question is whether any decision that it does not and that the treatment and care should therefore be discontinued should as a matter of routine be brought before the Family Division for endorsement or the reverse. The view taken by the President of the Family Division and the Court of Appeal was that it should, at least for the time being and until a body of experience and practice has been built up which might obviate the need for application in every case. As the Master of the Rolls said, this would be in the interests of the protection of patients, the protection of doctors, the reassurance of the patients' families and the reassurance of the public. I respectfully agree that these considerations render desirable the practice of application.

Unintended consequences of PD9E

- Clinical team may abdicate responsibility for best interests decision-making about feeding tube, believing that this can only be decided by a court.
- Default position is that continuing treatment is ‘appropriate’ pending a court decision
- Clinicians are reluctant to engage with law and uncertain how to navigate legal processes
- View court application as a ‘last resort’ – hope that P will die by other means (many repeated ‘near deaths’)

- Clinicians often wrongly believe that they must wait until PVS/MCS diagnosis is confirmed before initiating court hearing
- Diagnoses are sometimes withheld – or re-diagnosis ('in P's best interests') can mean PD9E is inapplicable (e.g. PVS rediagnosed as 'coma'; MCS as 'emerged')
- CANH-withdrawal is rarely considered for MCS-patients
- Focus is (wrongly) on whether withdrawal of CANH is in P's best interests – it should be whether continuing CANH is in P's best interests.

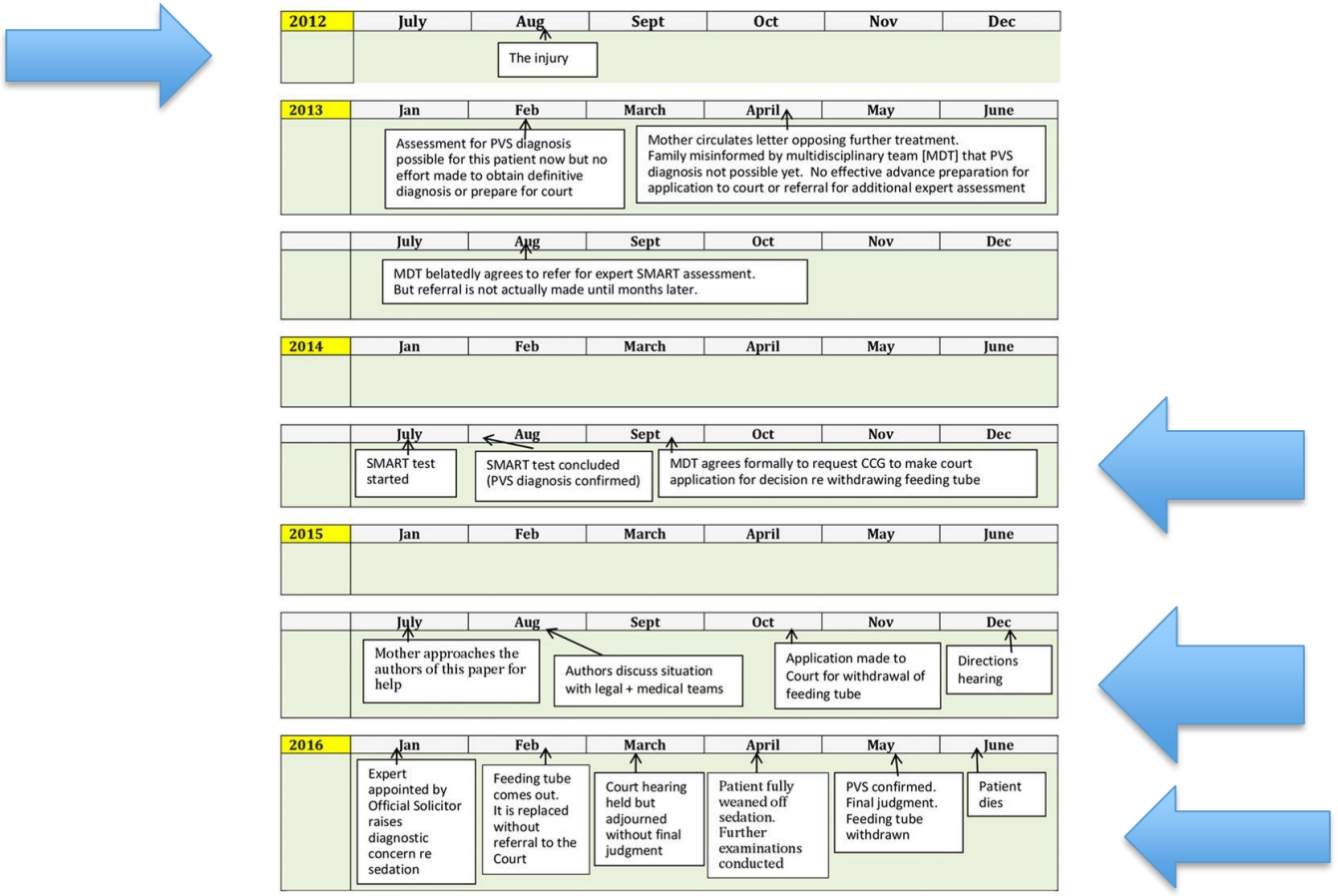
Is PD9E appropriate post-*Aintree*?

[T]he focus is on **whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it.** If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. (*Aintree* [2013] UKSC 67)

Avoidable delays in making applications

- Typically many **years** after family believe CANH to be not in P's best interests before applications made to CoP.
- Lengthy delays between best interests meeting at which clinicians/family agree that CANH is not in P's best interests + application to court
- Further delay between application + hearing

Timeline: summarising key points in background to Cumbria NHS Clinical Commissioning Group (CCG) v Miss S and Ors [2016] EWCOP 32.



KEY

PVS	Permanent Vegetative State
MDT	Multidisciplinary Team
PEG	Percutaneous Endoscopic Gastrostomy ("feeding tube")
CCG	Clinical Commissioning Group (Pays for treatment and is responsible for application to court)
SMART	The Sensory Modality Assessment & Rehabilitation Technique (one of the tests commonly used to diagnose PVS & MCS)

Jenny Kitzinger, and Celia Kitzinger J Med Ethics 2017;43:459-468

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JME

Human Rights implications

- Are patients receiving life-prolonging treatments that they would refuse if they could and/or which are not in their best interests?
- Court has never found feeding tube to be in best interests of PVS patient, but 1000s so maintained.

Real stories – real people healthtalk

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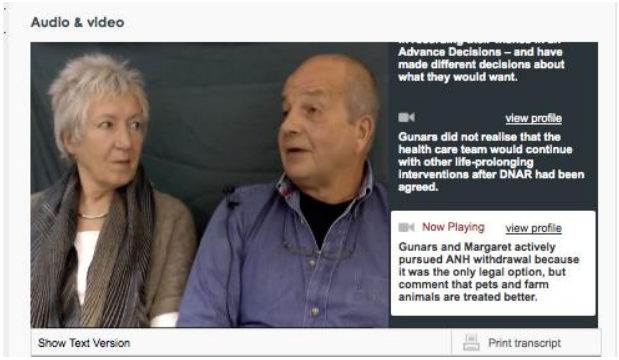
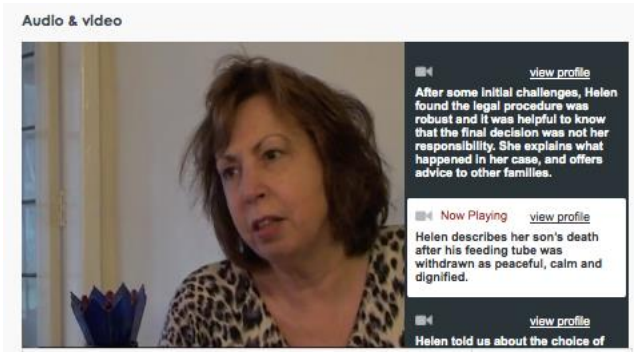


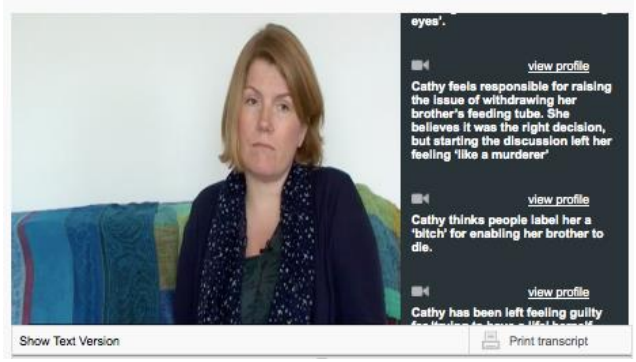
Gunars & Margaret

In 2008 his sister had a brain haemorrhage at the age of 53 and never regained consciousness.
In 2013 the CoP declared it lawful and in his sister's best Interests to have ANH withdrawn.



Helen

In 2008 at the age of 16 Helen's son was severely Injured in a car accident. He was eventually diagnosed as being in a PVS and died in 2010 after the CoP declared itlawful to withdraw his ANH



Cathy

In 1990 Cathy's 16-year old brother was hit by a car while walking home. Her family nursed him at home for 8 years in a PVS until an application to the Court resulted in a declaration that it was lawful to withdraw ANH.