



## Evidence submitted to:

# The Law Commission 2015 Consultation on the Law on Mental Capacity and Deprivation of Liberty

**Professor Jenny Kitzinger, Cardiff University**

Co-director of the Coma and Disorders of Consciousness Research Centre  
(Universities of Cardiff and York)

### A. About me and the research

I am professor of communications research at Cardiff University, specializing in health/risk communication. My research now focuses on decision-making for people with catastrophic brain injuries. I served on the Royal College of Physicians' working party on prolonged disorders of consciousness and the Nuffield Council on Bioethics working party on neurotechnologies. I am responding as co-director (with Celia Kitzinger) of the Coma and Disorders of Consciousness (CDoC) Research Centre – which carries out research on social, ethical and legal issues around coma,

the vegetative and the minimally conscious state. This research, funded largely by the Wellcome Trust and by the Economic and Social Research Council (ESRC), included in-depth interviews conducted by myself and Celia Kitzinger with 65 family members with a severely brain injured relatives (and additional interviews with practitioners working with this patient group). Publications and online resources from this research are available at [www.cdorc.org.uk](http://www.cdorc.org.uk), and the work has won recognition for outstanding impact on policy (from Cardiff University) and in society (from the ESRC) and for patient information on ethical issues (from the British Medical Association).

## B. Focus of this feedback – Advance Decisions

This feedback is in relation to the Law Commission's concern with advance decisions – in particular the issue of whether “*practitioners should be required to discuss the options with patients and service users*” and the Law Commission's wish “*to explore ways in which advance decision-making, in general, could become more central to health and social care*” and request for views on “*whether legal solutions would be appropriate and useful in this context.*” (13.34).

## C. Main points and evidence

Interviews with family members and practitioners highlighted the ethical and legal dilemmas involved in treating patients in vegetative and minimally conscious states where there is no Advance Decision to Refuse Treatment and there is a belief that the patient would not have wanted to be sustained in such a condition. Family members talk about their relatives being ‘kidnapped’ or ‘imprisoned’ and subject to unwanted life-sustaining interventions and both families and healthcare practitioners often believed that Advance Decisions would improve appropriate decision-making for these patient, and reduce the emotional, legal and practical difficulties for those left to make (or inform) decisions about the patient. ADs would be useful to *determine* decisions if they were ‘valid and applicable’ and, to *inform best interests decisions* if they did not fully meet the ‘valid and applicable’ criteria eg. as happened in *Re D [2012] EWHC 885 (COP)* and *Westminster City Council v Manuela Sykes [2014] EWHC B9 (COP)*.

### 1. We agree that “practitioners should be required to discuss the options with patients and service users”.

1.1 Our research underlines the importance of presenting patients with the option of writing Advance Decisions – *especially where loss of capacity to make one's own treatment decisions is an obvious risk of the disease/illness (eg dementia or stroke) or intervention (eg high risk surgery).*

Our research sample included the families of several patients who were being maintained in a vegetative or minimally conscious state against the apparent wishes the individual had expressed *prior* to losing capacity, but *after* recognizing the risk of such an outcome because of a diagnosis/incident or because of imminent high-risk surgery.

In spite of medics, and the patient, being aware of such risks, none of these patients had been given support to clarify or record their wishes in an

Advance Decision. The patient, and their family, had usually been unaware that this was an option (or how to go about producing such a document), and sometimes they were apparently under the misapprehension that next-of-kin could automatically make decisions of behalf of the patient and so thought that discussing wishes within the family was sufficient protection against unwanted future treatment.

In two cases patients/families reflected in advance about the risk of brain injury after high risk surgery – and reported that they – or the patient – were ‘terrified’ of such an outcome – but both the patients ended up in a VS/MCS without an AD. In other cases individuals had been triggered to articulate their wishes to refuse treatment after a first experience of illness/injury eg a stroke (from which they made recovery to full capacity) – only to lose capacity after a subsequent incident but be maintained in VS/MCS in the absence of having recorded their wishes in an AD.

#### **Example 1: One interviewee's sister was in a vegetative state after catastrophic brain injuries resulting from a second major stroke, and, he says, had been clear she wouldn't want be maintained in this sort of condition but:**

‘Because that [her wish] wasn't recorded anywhere, and it was just hearsay, when then it came to dealing with legal people, or the medical profession it was difficult to get them to accept that that's what she wanted. And basically as a family we could say it ten times over but they would only go with what they could do legally to provide her with the care that she needed.’

#### **Example 2: Another interviewee's father suffered a similar fate (VS/MCS) and she talked about how guilty she felt that she was unable to ensure his wishes were respected:**

‘I knew how he was – his views on this kind of thing before were so strong after his stroke. ...He was in and out of hospital for a year [after the first injury] and he was paralysed on his left side. ... But he got about and he was very independent ... And then he said, “...if anything happens to me again and I can't [be independent], then just sort of – yeah, let me go, kind of thing.” ...

And even afterwards his friends were coming up to me in town and saying, “You know what his wishes are. You know he said after the last time... Why are you doing it [keeping him alive]?” ... [But] you're not given that sort of choice. It's not up to you. ... – if I could, I would [let him die]. But I can't.’



In these situations patients may be maintained for many years in conditions they had stated they would find unacceptable and family members often feel extremely guilty that they had not been enabled to ensure their relatives' wishes are respected ('Is this my fault?').

In a few cases where the patient had a confirmed PVS diagnosis, family members we interviewed were involved in court proceedings to consider the option of withdrawal of ANH (but only after many years and at great cost, and also additional layers of guilt). However, in most cases life-sustaining treatments such as ANH were continuing by default. This was also true for patients in minimally conscious states – and in these cases most families (and many practitioners) did not think court proceedings to withdraw ANH were likely to succeed – even where family members were clear that MCS would have been equally – or even *more* – unacceptable to the patient than VS.

It is clear in cases such as those outlined above that a 'window of opportunity' to discuss options with patients, and protect their wishes, has been missed – with huge subsequent emotional cost to families and financial cost to the NHS.

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**1.2. Requiring practitioners to discuss the option of writing an AD only with “patients and service users” should not be the only focus and health care practitioners should not be the only practitioners raising the option of ADs.**

People end up in VS/MCS resulting from 'higher-risk' activities such as skiing, horse-riding, motorcycling and high-risk occupations (eg serving in the armed forces). Some of the families we interviewed reported that their relative had seen friends/colleagues with catastrophic acquired brain injuries – and acknowledged their own risk – and expressed their views about what they would want in such circumstances, but had not known, that simply informing their 'next-of-kin' was insufficient, and had been unaware of the option of writing an AD. We would also note that many of the families we interviewed had relatives in VS/MCS where the injury came completely out of the blue (eg from 'random' car accidents). The option of writing (or at least recording the existence of) an AD should be 'normalised' and discussed with people engaged in 'high risk' activities and more widely with 'the general public' (including in routine ways eg when registering with a GP or for a driver's licence.) It should *not* be limited to 'patients and service users' within the health system known to be 'end-of-life'.

**1.3. General publicity about ADs (and LPAs for health and welfare), and resources to support writing ADs (and LPAs) are needed to support completion.**

Our research found that family members with experience of a relative with catastrophic acquired brain injuries are often very clear that they would wish to refuse life-sustaining interventions for themselves under such circumstances (and were much more likely than the general population to have written an AD). However, even among this highly motivated population many did not have an AD because they did not know about them or were unsure how to go about writing one. This finding underscores the importance of a general advertising campaign to raise public awareness (as well as outreach to specific groups) and the provision of resources to support writing ADs for people who want one. All the suggestions above, would need appropriate training, infrastructure and resources.

**2. We ask the Law Commission to recommend reform of Practice Direction 9e to address the legal anomaly between PD9e and the Mental Capacity Act 2005**

This section mirrors the evidence presented to the Law Commission from ADA, the Advance Decision Assistance charity. The permanent vegetative state (PVS) is one of the iconic conditions which people who write ADs are often concerned to avoid. It is unusual to see an advance decision to refuse treatment that does NOT seek to refuse treatment in the event of a permanent vegetative diagnosis. This concern reflects the origins of advance decisions in

the USA where the widely-reported case of Nancy Cruzan (a 25-year-old woman who was maintained for 7 years in PVS) was directly responsible for the Patient Self Determination Act, which took effect in 1991 and gave statutory support for anticipatory decision-making.

The Mental Capacity Act 2005 in England and Wales seems to give statutory support for advance decisions such that, if an AD is valid and applicable, it is legally binding on health care professionals. The medical treatments refused in the valid AD must be withheld or withdrawn at the point at which it applies to the person's situation. There is a widespread assumption among those responsible for implementing the Mental Capacity Act that withdrawal of artificial nutrition and hydration from a PVS/MCS patient with a valid and applicable advance decision refusing such treatment would not require a court application – a view shared by family members we interviewed who had such a document themselves. However, there is apparently some legal uncertainty about this issue due to s. 5(a) of the Court of Protection Practice Direction 9e which reads:

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 ([www.judiciary.gov.uk/publications/practice-direction-9e-applications-relating-to-serious-medical-treatment-effective-from-1-july-2015/](http://www.judiciary.gov.uk/publications/practice-direction-9e-applications-relating-to-serious-medical-treatment-effective-from-1-july-2015/))

Practice Direction 9e is silent on the question of ADRTs (and also on lasting power of attorney for health and welfare). This leaves it open to a reading that court hearings are required even concerning those PVS patients who have explicitly refused artificial nutrition and hydration in a valid and applicable advance decision in accordance with the Mental Capacity Act 2005. This is the interpretation given to it by some lawyers who say that they would advise CCGs/Health Boards to apply to the courts before withholding/withdrawing artificial nutrition and hydration in such cases. However, another reading of PD9e is that it is irrelevant where there is a valid and applicable ADRT since Practice Directions apply only to decisions the CoP has jurisdiction to take and there is nothing in any relevant provision to suggest that the validity or applicability of all ADRTs has to be determined by the CoP.

Evidence from our research with practitioners suggests that PD9e may be ambiguous, and is causing confusion and delays. Evidence from our interviews with family members of VS/MCS patients – where they have written documents in an attempt to avoid being sustained in a similar condition themselves – supports the view that those writing such ADs would not want to have their ADs come before the court, but want their prior decision as represented in their AD to have effect, in a timely manner and in accordance with the MCA, “as if he had made it [the decision], and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.” (MCA 2005, 26(1))

We ask the Law Commission to recommend reform of s. 5(a) Practice Direction 9e so that it is clearly compliant with the Mental Capacity Act. This could be done along the following lines (taking into account LPAs as well as ADs):

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 (*unless there is a valid and applicable advance decision refusing treatment or unless an attorney with the relevant decision-making powers authorises withdrawal*)

**Jenny Kitzinger**

2nd November 2015

**Contact details:**

Coma and Disorders of Consciousness  
Research Centre  
JOMEC  
Cardiff University  
Bute Building  
King Edward VIIth Av  
Cardiff  
CF10 3NB

**Email:**

[kitzingerj@cardiff.ac.uk](mailto:kitzingerj@cardiff.ac.uk)

**CDoC Research Centre Website:**

[www.cdorc.org.uk](http://www.cdorc.org.uk)