

About a paper analysing the rules for withdrawal of CANH from PVS patients by Celia and Jenny Kitinger

I have just read a really good paper by Celia and Jenny Kitinger, titled 'Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: family experiences' - if you Google the title, you should come up with a link to the paper [Kitinger C, Kitinger J. *J Med Ethics* 2016;42:11–17 – the paper is open access].

In one sense, the paper is somewhat obsolete: at its core is an objection to Practice Direction 9E of the Court of Protection, and a recent ruling by Mr Justice Jackson has seemingly got rid of that Practice Direction.

However, the paper is very good on describing what I shall describe as 'the emotional stress' on families, if they need to decide that 'our loved-one should be allowed to die', and it is still worth reading because of that.

The more perceptive – and 'MCA nerdy' - reader, will have noticed that I wrote above about families 'deciding': this was deliberate, and this is where I take issue with part of the paper, and, indeed, with much of the 'medical establishment'. I'll start, with the section of the Kitinger paper I have a dislike of:

Set against these benefits would be the loss of 'therapeutic jurisprudence'. 9 To preserve these benefits, healthcare teams making best interests decisions not to continue ANH-treatment would need to ensure (as they should do currently²²) that family members know that the decision is not theirs to make, that the burden of responsibility lies with the clinical team and that everyone involved recognises the immense gravity of the decision to allow death.

I'll mention that the paper uses ANH for clinically-assisted nutrition and hydration but other people, including recent court rulings, use CANH for the same thing. I'll also quote another section of the Kitinger paper:

One possibility would be to treat ANH-withdrawal from PVS patients just like ANH withdrawal from all other patients. This would mean in accordance with common law and professional guidelines^{5 6 21} that clinicians would be able lawfully to withdraw ANH without recourse to the courts if they determined that ANH was not in the patient's best interests (and if this was not contested).

That includes 3 different 'things':

- 1) the question and determination of whether withdrawal of CANH is in the patient's best interests;
- 2) the lawfulness of the action of removing the equipment involved in supplying the patient with CANH;
- 3) the 'if this was not contested' suggestion.

These things are conceptually intertwined, but I'll start by going back to the other extract from the paper - '*that family members know that the decision is not theirs to make, that the*

burden of responsibility lies with the clinical team' - and I'll explain why, despite my being in a minority, that is a legally-flawed statement.

Anybody who is sufficiently well-informed, can make a defensible best-interests decision that withdrawal of CANH would be in the patient's best interests: we know that normal lay people can satisfactorily make best-interests decisions about the withdrawal of life-sustaining clinical interventions, because [although this is very badly worded – it is not in fact {think about sections 6(6) and 6(7) of the MCA} 'consenting to'] attorneys are usually normal lay people, and we are told by the MCA:

(7) Where a lasting power of attorney authorises the donee (or, if more than one, any of them) to make decisions about P's personal welfare, the authority—

(a) does not extend to making such decisions in circumstances other than those where P lacks, or the donee reasonably believes that P lacks, capacity,

(b) is subject to sections 24 to 26 (advance decisions to refuse treatment), and

(c) extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P.

(8) But subsection (7)(c)—

(a) does not authorise the giving or refusing of consent to the carrying out or continuation of life-sustaining treatment, unless the instrument contains express provision to that effect, and

(b) is subject to any conditions or restrictions in the instrument.

7(c) and 8(b), although clumsily phrased in terms of 'consenting to an offered treatment' instead of what would be correct (making a best-interests decision in the knowledge that a treatment is either already being applied, or has been offered for application), **makes it obvious that non-clinicians can make best-interests decisions.**

So, for my:

1) the question and determination of whether withdrawal of CANH is in the patient's best interests

both relatives, or indeed friends, and clinicians can answer that question – the requirement is 'can the person claim to have understood enough to claim compliance with section 4(9) of the MCA'.

My second question – the lawfulness of the action of removing the CANH equipment – is in essence down to the answer to 1): the CANH can be removed, if there is no sensible reason to doubt that doing so would be in the patients best interests.

Which, leads us to:

3) the 'if this was not contested' suggestion.

That is the point, and the current analyses of these situations by most authors is **almost correct**: where it is incorrect, is in its 'effective assertion' that the clinical team 'makes the best-interests decision', after discussion with family and friends.

What would be a correct description of the wording of the MCA, is that the clinical team and the patient's close family and close friends need to talk together, in some depth, with

an objective that after those discussions **some individuals** would then be sufficiently well-informed about the things described by section 4 of the MCA, as to be able to **individually** claim to have arrived at a best-interests decision which can be 'defended' by compliance with section 4(9).

Those 'sufficiently-well-informed individuals' are not defined by clinical or lay status – they are solely defined by their ability to defensibly claim compliance with section 4(9) of the MCA:

4(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

CONCLUSION

Provided that there is no exclusion of anyone who wants to be involved in the discussions – for an example, provided no close family or close friends who it is suspected might 'form a contrary [but defensible] opinion about best interests' are excluded from the discussions – **then if everyone agrees about the nature of the best-interests decision** (here, for example, that CANH should be withdrawn in the patient's best interests) **that is the best-interests decision which should guide subsequent actions.**

Which is NOT 'the clinicians made the decision'.

And, of course, the larger the number of individuals who can each claim compliance with 4(9), the 'stronger' is the best-interests decision which each of those individuals had arrived at.

See also

<http://www.bmj.com/content/352/bmj.i222/rr-0>