

[“Burdensome and futile” treatment and dignity compromised: Poor practice at a leading UK hospital](#)

By Jenny Kitzinger, 17th November 2021

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Court of Protection judgments can provide valuable insights into everyday care in ways that challenge poor practice and can be used to help improve person-centered care for the future.

This is certainly true of last week’s publication of [North West London Clinical Commissioning Group & GU \[2021\] EWCOP 59](#).

The judgment is essential reading for everyone involved in treating patients with Prolonged Disorders of Consciousness [PDoC] or advising care providers about their legal responsibilities.

The case focuses on GU, a 70-year-old man in PDoC, cared for at the acknowledged ‘centre of excellence’, the [Royal Hospital for Neuro-disability](#) [RHN] in Putney, London.

The RHN is one of the oldest and most respected centres in the world dedicated to looking after people with a range of neurological conditions and injuries. It has highly trained staff and impressive facilities for the initial assessment, rehabilitation and long-term care of a large cohort of severely brain injured individuals. The RHN also provides training for others and runs a series of interesting talks and conferences about PDoC.

In this case, however, the RHN clearly failed to provide high-quality, patient centred care – and part of this Court of Protection judgment is dedicated to exploring why this happened and what lessons might be learned.

At the heart of this case is the fact the GU was given medical treatment to keep him alive for 7 years in PDoC – although he had made it clear to family and friends in advance that this is not what he would want, and from at least four years after his injury, family members had tried to make this fact very clear to the RHN.

The judgment quotes GU’s views, as reported by family members.

He told his sister, “*if I do not have my mental facilities there is no reason for me to be here*” (para. 32)

He said to his brother “*I would never forgive anyone who let me be like mum is now [with severe dementia]*” (para. 30)

His ex-wife gave evidence that GU had spoken at length with her:

“we often had conversations about death, and he would always say that his greatest fear would be in a vegetative state. He would make me promise to ‘pull the switch’...” (para.33)

Having seen these (and similar) statements about GU’s views from family and friends, the judge, Mr Justice Hayden, concluded:

“GU left nobody in any doubt at all that he would not want to continue in the parlous circumstances in which he finds himself. His views have been communicated consistently, volubly and unambiguously...” (para. 29)

“I was left in no doubt at all that he would have recoiled from his present circumstances. I emphasise that nobody, son, brother, friend, sister, wife had any ambivalence about what he would have wanted.” (para 36)

How then did it come about that, in spite of his wishes, GU was kept in this condition for so long?

The judge was clearly very troubled by this question and had held a supplementary hearing precisely to try to understand what had happened (I wrote about that hearing [here](#)).

His conclusion was that the RHN (which had cared for GU since 2014) was guilty of “*extraordinary delay*” (para. 92) in addressing GU’s best interests, with the consequence that it had, for some time, subjected GU to treatment which was:

“...burdensome and futile and entirely contrary to what he would have wanted. His dignity was avoidably compromised. Even the most summary assessment of his best interests would have revealed this many years ago.” (para. 95)

This is an exceptionally long judgment (over 100 paragraphs). It covers both the initial hearing (10th June 2021) at which the judge ruled it was not in GU’s best interests to have Clinically Assisted Nutrition and Hydration continued (I wrote about that hearing [here](#)) and the supplementary hearing (15th July 2021) to allow those who had provided treatment to account for their actions (which I wrote about [here](#)). As well as addressing the specifics of GU’s clinical condition and evidence about his wishes it engages extensively with debates about human dignity in ways that will be useful for future hearings. Here, however, I want to highlight two sections concerning (a) the moral status of CANH; and (b) the “Lessons Learned” for organisations and professionals responsible for looking after patients like GU.

Clinically Assisted Nutrition and Hydration – exploring diverse perspectives

The majority of GU’s family had concluded (long before this case reached court) that clinically-assisted nutrition and hydration was no longer in his best interests. Indeed,

after the [Re Y](#) judgment back in 2018, GU's brother (representing most of the family) had become particularly active in trying to lobby for a proper best interests review of this intervention.

However the patient's eldest son was horrified at the thought of withdrawing CANH. He shares this reaction with many people facing similar situations for their loved ones. Our [research](#) shows that even those who eventually do support this course of action sometimes describe the idea of it as 'barbaric'. (However, it should also be noted that [follow-on research](#) found that families report that, in the event, deaths after CANH withdrawal often seem calm and peaceful.)

The judgment gives careful attention to the feelings expressed by GU's eldest son, and quotes him extensively. According to this son, CANH should continue because: "*When my father's time is up, he will go, but on his own terms, not ours to decide*". For this son, access to food & water is a basic human right, a point vividly underlined when he referred to working in Africa where "*you can see a child there walking for miles to get a glass of water and here, in the UK, we'd deny water to my dad?*" (para. 24).

The judgment also records that the son argued powerfully:

"A vet would put a sick pet down quick and painless. Maybe he [my dad] did say to some people 'If I'm ever like that, shoot me' – but ok shoot him, don't starve him."

Mr Justice Hayden clearly respects this "*human & visceral reaction*" from GU's son and highlights the son's "*deeply rooted & instinctive filial love*". He acknowledges that "*in daily life, the consumption of food and drink frequently involves pleasure and conviviality. Not uncommonly it is an expression of love*". The judge however states that it is:

"a mistake to equate CANH with the consumption of food and drink in the ordinary sense... nutrition & hydration which is 'clinically assisted' is properly identified as 'medical treatment' (see: [Airedale NHS Trust v Bland](#) [1993] AC 789)." (para. 26)

Clinically-assisted nutrition & hydration can relieve symptoms or prolong or improve quality of life but:

"[CANH] may become burdensome or futile and serve only to extend life in its most vestigial sense, failing to achieve anything that might properly be identified as 'quality of life' for a patient in a prolonged disorder of consciousness." (para. 26)

It can then be viewed as "*protracting death*" rather than extending life.

"To impose nutrition & hydration on those who would not wish to receive it...is to risk suborning autonomy and compromising human dignity." (para. 27)

Criticisms of the hospital and lessons learned

During the hearing the judge was at pains to make clear that ‘A’ (the patient’s eldest son) must not feel in any way responsible for the hospital’s failure to address his father’s best interests – that responsibility lay squarely with the hospital and the clinicians caring for his father.

The judge was also perturbed by the hospital’s admission that perhaps their “*ethos*” made it hard to give proper consideration to a patient’s best interests in relation to CANH. During the hearing, it also became clear that some of the problems existed at the very top of the organisation – especially in relation to addressing a patient’s best interests in the context of disagreements within families.

The hospital was, the judge commented, “*a long way behind the curve*” in engaging with up-to-date legal and professional standards in this area.

In the judgment, Mr Justice Hayden was clear that the focus must always be on the patient’s wishes, values, beliefs and feelings (not the feelings of others). He said that family dissent:

“should never stand in the way of an incapacitated patient’s best interests being properly identified...differing views [should be] considered in their totality &, where necessary, by a Judge. To do otherwise is to risk silencing the voice of the vulnerable individual at the centre of the process.” (para.4)

A unit’s ethos must not trump the law and clinical guidance. Distress from staff can be recognised but these factors “*have no place at all in evaluating... best interests. Factoring these matters into the decision process is both poor practice and ethically misconceived.*” (para. 100)

The judgment reiterates key points about timing and responsibility for the best interests decision-making process in relation to Clinically Assisted Nutrition and Hydration – all clearly laid out in the [relevant professional guidance](#).

The judgment highlights the following points:

- A proper assessment about CANH should have been carried out by the person “*with overall responsibility for the patient’s care, as part of their clinical responsibility to ensure that treatment provided is in the patient’s best interests*” (para. 98). This was not done.
- It is the responsibility of clinicians (not of patients’ families) to initiate and pursue best interests discussions about CANH – this should never have been left up to the patient’s brother. The judgment makes clear that leaving family to raise the issue places them in “*a highly invidious position*” of having to press for the discontinuation of life-sustaining treatment for someone they love and this may mean the issue is never addressed at all (“*many in E’s situation might have*

found themselves unable or unwilling to take this course. They should not have to do so” (para. 99).

- The need for clinician-led regular review is underlined (just because CANH was in a patient’s best interests some years or months ago does not mean it still is) and Mr Justice Hayden highlights that best interests “*requires to be kept in constant & unswerving focus*” (para. 105) and not just limited to an annual event.
- Where there is doubt or disagreement about a patient’s best interests and this cannot be resolved, treating teams and commissioners should not simply continue treatment by default because it is the ‘easiest’ option – they must refer the case to court in a timely manner.
- If the treating hospital is, for whatever reason, unable to bring an application to the court itself, it has a duty to “*take timely & effective measures to bring the issue to the attention of the NHS commissioning body with overall responsibility for the patient*” (para. 103).

This judgment includes ample evidence that GU’s physical care was “*first class*”- but also makes it starkly clear this is not the same as ethical, person-centred treatment.

Ways forward

The challenges the RHN faced, such as a family member or member of staff who is horrified by the thought of stopping CANH, will be familiar to anyone working in this field.

It is to be expected that some, or all, family members will at the very least be ambivalent about CANH-withdrawal, even if they are clear that their relative would not want to be kept alive in their current state.

Similarly it is perhaps not surprising that those working in rehabilitation and care settings are often exceptionally committed to keeping hope alive for patients and may believe in the value of life under all circumstances.

The point is that it is the patient’s beliefs and values, not those of family or staff, that should inform the best interests process – but the patient is, of course, unable to speak for themselves so it is easy for other people’s values to sometimes take precedence.

Ways of addressing such routine challenges include:

- strong organisational policies to ensure staff follow professional guidance and act according to the law, and know they will be supported by senior management in doing this
- clear lines of responsibility and communication to ensure well co-ordinated patient care, led by the responsible professionals

- support for families which includes information about different care pathways and support to think through the patient's likely wishes.
- high-level staff training about decision-making, including the opportunity to tease out and reflect on their own biases, and know where to find decision-support tools to turn principles into practice
- an organisational and MDT unswerving focus on the patient's best interests (and willingness to refer to court where necessary).

It is deeply disappointing that failures in best interests decision-making happened at a centre that is recognised internationally as a 'centre of excellence' in the field, and where, I know, there are many well informed and highly skilled staff, committed to the highest standard of care and passionate about delivering on the Mental Capacity Act 2005 and the latest professional guidelines.

I think every centre looking after PDoC patients can learn from the mistakes made in this case. And I look forward to seeing how the Royal Hospital for Neuro-disability uses this opportunity to review and transform its organisational practices so that it can be a true 'centre of excellence' in all aspects of patient care in the future and help roll out best practice across England and Wales.

Additional Resources

- The BMA/RCP has a useful flowchart and proforma for best interests decision making about CANH available here: <https://www.bma.org.uk/advice-and-support/ethics/adults-who-lack-capacity/clinically-assisted-nutrition-and-hydration/the-decision-making-process>.
- A podcast about the role of the family in decision-making is available [here](#).
- The Coma & Disorders of Consciousness Research Centre has developed a short, free, online course about CANH withdrawal. This includes sections exploring the concerns and experiences of staff around end-of-life decision-making and care. See: <https://cdoctraining.org.uk/end-of-life-care/>.
- The section of this course about family experiences can be useful for family members too: <https://cdoctraining.org.uk/module-1/supporting-families/>.

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