Clinically-assisted nutrition and hydration: Decisions that cannot be ignored or delayed

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Hearings in the Court of Protection often bring crucial issues into sharp relief in a vivid, poignant and intellectually rigorous way. This was certainly so in the hearing I observed last week**:** Case No. 1375980T on 10 June 2021. It concerned GU, a 70-year-old man who sustained a severe anoxic brain injury in April 2014 following electrocution, a cardiac arrest and possible drowning. He has been unconscious ever since and there is no prospect of recovery. His wife, siblings and adult children all agree he would not want to live like this. All but one family member – the patient's eldest son – believe that clinically-assisted nutrition and hydration (CANH) should be stopped.

The application to address whether or not continuing CANH was in GU's best interests was brought by the Clinical Commissioning Group that commissions GU's care (represented in court by barrister Mungo Wenban-Smith of 39 Essex Chambers). Two of GU's family members (his brother and his eldest son) were also in court as litigants in person. GU himself was represented by the Official Solicitor (the barrister was Debra Powell QC of Serjeants' Inn). Unusually, the hospital where GU has been treated since September 2014 was not in court and was not the applicant in this case.

Originally, the hearing on the 10th June was scheduled as a one-hour directions hearing. However, Mr Justice Hayden, noted that even a cursory glance at the paperwork had led him to consider that the case was "*ready to be heard and had been for some time*". Because "*delay can be inimical to the welfare and best interests of a protected party*" he wanted to move to a full hearing immediately. The priority given to this, and the flexibility of the Court of Protection and everyone involved, was illustrated by the rapid move to clear diaries and rearrange plans.

Once the full hearing was convened, the court heard evidence from an independent clinical expert, Professor Wade, a neuro-rehabilitation consultant. He informed the court that GU was almost certainly completely unaware of himself and his environment and had been for seven years. GU was being treated at a recognised centre of excellence and had received first class physical care. There were no reversible causes of his lack of consciousness. None of those who saw him regularly as part of their work on the ward had ever noticed any interaction or any response to suggest awareness. GU had been thoroughly tested using standardised tools such as the "WHIM" (Wessex Head Injury Matrix) and the "CRS-R" (the Coma Recovery Scale – Revised). His life expectancy now might be another 10 years, but there would be no change in his condition.

We then heard from GU's brother and his son (both of whom also had the opportunity to ask questions of Professor Wade). Between them, these two men conjured up a vivid picture of GU as a talented airline pilot, gregarious and sociable, and someone who had had "*a great appetite for life*". Both men were clear in court that, given everything they knew about him, they did not believe GU would want to live in his current state. This view was also supported by written statements from other family members and friends.

The point of divergence between the patient's brother and son concerned the appropriateness of clinically-assisted nutrition and hydration. The brother stated that he (and the rest of GU's family and friends) were clear that it was wrong to continue with this. The son, by contrast, said that it would be wrong to stop it. His father had expected, he said, to "*go with a bang*" at 36,000 feet while flying a plane – a fate almost the polar opposite, as the judge observed, to his current situation. If there was the option of a fatal injection the son said he would be prepared to give it to his dad himself, but he could not contemplate having any part "*in taking away my Dad's God-given right to food and water*". He is not alone in this: interviews with families of PDoC patients show that many feel the same way.

Mr Justice Hayden's skill in hearing these sorts of cases was amply illustrated in the way he handled this situation. He kept the focus on the patient while also showing a great deal of care to the family members present. He said to the son: "*I entirely understand and respect both the views you express and the clarity and sincerity with which they are articulated"*. When the son declared that it is "*my duty to look after my dad*", the judge said it was his responsibility as a judge to think about what GU wanted for himself "*not what his son would want to do for him*". He was also careful to ensure that the son, as litigant in person and as the individual now isolated within the family as a whole, was able to express his point of view in detail and have it fully considered in court.

Discussion of the morality of discontinuing CANH occupied a large part of the hearing. The son's arguments were given extensive attention. This included discussion about any potential for pain (and the palliative care measures put in place to try to avoid any such possibility) and how long it might take for a person to die following withdrawal of a feeding tube. Broader ethical considerations were also addressed, including engaging with the son's experiences of working in Africa (where he'd seen how a child might walk for miles to find water) and reflections on his appeal to the Universal Declaration of Human Rights (enshrining a person's right to access adequate food).

The judge probed the independent expert to ensure that he addressed the son's concerns about clinical issues, such as the potential for pain and the likely length of the dying process (estimated to be somewhere between one to three weeks), but acknowledged that the more fundamental concerns were intractable. He commented that the son's written testimony submitted to the court presented a "*brutally intellectually honest opinion*", put forward with "*uncompromising integrity*", "*legitimately philosophically and morally argued*", presented through a "*stark and intelligent articulated perspective*".

Mr Justice Hayden offered to visit GU himself first thing the following morning and to reconvene the court after that. The hearing restarted at noon the next day and, before revealing his decision, the judge took great care to describe his visit to GU to the family – painting a vivid picture of the patient being well cared for by "*heroic*" and devoted nurses, in a room with a view over a rose garden ("*in full and resplendent bloom*"). Only then did he deliver his judgment with his conclusion that it was not in GU's best interests to continue with CANH.

Having heard both the clinical evidence and evidence about the type of man GU had been, Mr Justice Hayden concluded that the current course of treatment was "*protracting his death not prolonging his life*". He added:

> "*None of the options available are attractive. He can stay as a husk of the man he once was for a decade (not an attractive way to die). The only other option is what his son would characterise as 'starvation' – but its benefit is that it can be palliatively protected and even if it is 21 days, it is not a decade"*

In the oral judgment he said:

> *"What we are truly contemplating is not the prolongation of his life but how he should be permitted to conclude his life at the end of his days. It's not a 'right to die'. It is a facet of how he should live at the end, and for how long"*

He stated that CANH should be discontinued as soon as possible, and he hoped the rift in the family would heal and that they could remember GU as he had been before his injury.

Reflections on delays in assessing GU's best interests about CANH

Throughout the hearing, and in his oral judgment (a written one is not yet available), the behaviour of the hospital treating GU was repeatedly an issue. There were questions about their behaviour that the hospital was not there to answer. Although he wanted to make sure that the hospital would have the opportunity to make representation in the future, and underlined that the Court of Protection was "*non-adversaria*l" , Mr Justice Hayden clearly wanted to make sense of what had gone wrong.

Reviewing the evidence presented in the independent report, and hearing from the family, Mr Justice Hayden considered it "*highly likely*" that GU had been subject to treatment that was not in his best interests for some time and that *"what we are doing now should have been undertaken a long time ago".*

In discussion with the Official Solicitor, the judge explored the possibility that this unjustified treatment may have been going on since at least 2017 or 2018. The reason for choosing 2017 as a significant marker since when treatment has been unjustified seemed to be because this was when a series of ceilings of treatment were put in place in discussion with family members – but this discussion may have failed to address the question of the feeding tube. The reason 2018 is significant is because this is when the brother, with the support of the rest of the family, most overtly challenged the hospital's use of CANH. The year 2018 is also significant because this is when the British Medical Association and Royal College of Physicians produced detailed guidelines on decision-making about "Clinically assisted nutrition and hydration for adults who lack the capacity to consent". These guidelines include clear advice about annual reviews and the importance of consulting families to unpack what the patient themselves might have wanted.

In was also in 2018 that a landmark decision was handed down by the UK Supreme Court *An NHS Trust v Y* UKSC 46 (*'Re Y'*). The Supreme Court ruled that it is not mandatory to seek judicial approval for decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in vegetative or minimally conscious states. Instead, a decision to withdraw can be taken by the responsible clinicians so long as robust procedures are followed in accordance with the national guidance on and there is no disagreement about the patient's best interests. It also made clear that the courts are still available where the patient's best interests are in dispute, or where the decision is 'finely balanced'. A family dispute, such as the one evident in this case, would be one clear reason for going to court if the clinicians responsible were unable to resolve this to make a best interests decisions.

The judge underlined that "*It is a principle of medicine never to do harm*". The fact that a family member had moral reservations about withdrawing CANH "*does not absolve the hospital from bringing this case quickly. Doctors are not allowed to continue in a way that compromises a person's dignity*." Mr Justice Hayden also went out of his way to try to be clear about where responsibility lay declaring: "*I do not attribute avoidable delay to [eldest son]. His point [concern*

about CANH-withdrawal] was properly made, nor would it have ever been reasonable to expect him to change his mind."

It is the responsibility of clinicians to ensure they any treatment they give is in the best interests of their patients. In expressing his displeasure at the fact that the hospital was not a party to the case, the judge noted "*the hospital has deliberately avoided the litigation*" and stressed that "*The hospital can't be allowed to hide away from responsibility by not confronting decisions that need to be taken and then not joining legal proceedings*". Avoidance of an issue such as whether or not CANH is in a patient's best interests "*can never be reconcilable with medical ethics*". He said of the hospital, which seemed to have continued CANH by default: "*To act in a way that has only one outcome is as ethically compromised as taking the wrong decision: perhaps it's time to confront that.*"

At one point during the hearing Mr Justice Hayden commented:

> "*This is one of the greatest hospitals in the world. If they can't comply with or choose not to follow the guidelines – if the reality is that they do harm – then we have to find some way of addressing this. What can I do as Vice President of the Court of Protection?'*

He concluded however: "*I draw back from making any further comment because I wish to investigate this further. I do not wish my investigation to be conflated with the individual at the centre of the process."*

Here I, too, will draw back from adding any further comment on the delays – partly because it is important to await the outcome of further investigation and partly because, from 2020, I was myself involved in supporting this family in trying to support the best-interests decision-making processes in this case. What I plan to do in a second blog however, is to contextualise the questions Mr Justice Hayden raised about delays by reflecting on my wider experience of being asked to help in such situations, I will illustrate both some of the good and not so good practice that is happening in units across England and Wales and discuss how this has changed (or not) over the last decade, as case law and professional guidance has evolved.

In the meantime, the message from this hearing is clear. Family concerns about the morality of CANH-withdrawal should be taken very seriously indeed. This does not mean that it is necessarily in the best interests of a patient to continue to provide CANH and it certainly does not mean that clinicians can simply 'avoid' making a decision or 'wait' in the hope of an emerging family consensus.

When considering whether to continue or discontinue a treatment, 'no decision' is not an option. All institutions and clinicians working in this area need to be fully familiar with the law and professional guidelines. They need to be sure they are consulting appropriately with the patient's family and friends and acting in patients' best interests, taking into account the best available clinical evidence and – crucially – information about the individual's approach to life, and their values, wishes, feelings and beliefs.

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