Life-sustaining treatment contrary to his best interests: Lessons from a supplementary hearing

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By Jenny Kitzinger, 30 July 2021

The hearing I attended at the Court of Protection on 15th July 2021 (Case No. 1375980T before Mr Justice Hayden) was unusual in that it was described by the judge as a "*supplementary hearing"*. I'd not come across this type of hearing before, so was interested in the format and process as well as its substantive content.

Supplementary hearings are uncommon and it was hard to find out much about how they operate. Although not formally defined (e.g. in a Practice Direction), a lawyer I approached for advice when writing this blog told me about a few other cases where a supplementary hearing had been held. The aim in each case was to pick up on the issues that were identified as important, but which didn't need to be resolved to actually answer the question before the judge in the original hearing.

Judgments from previous supplementary hearings address, for example:

- the correct steps that should be taken to bring serious medical cases to court in a timely fashion (The Royal Bournemouth and Christchurch Hospital NHS Foundation Trust and Dorset Healthcare University NHS Foundation Trust v SE [2018] EWCOP 45).
- guidance on how applications should be made where a treating Trust is concerned that a pregnant woman lacks, or may lack, the capacity to take decisions about her antenatal, perinatal and postnatal care (NHS Trust & Ors v FG [2014] EWCOP 30).

These cases are summarised by 39 Essex Chambers here and here.

The supplementary hearing that I observed was prompted by what happened to GU – a severely brain-injured patient who had been sustained in an unconscious state for several years, despite assertions from family members (including wife, sister, brothers and several adult children) that this was not what he would have wanted – and despite his treating team apparently also not believing ongoing treatment to be in his best interests. The only area of

dispute was that one family member, the patient's eldest son, had profound moral objections to withdrawing clinically assisted nutrition and hydration (CANH).

The judge's decision about this patient's best interests was made back in June 2021. Mr Justice Hayden decided that CANH was not in GU's best interests. After judgment, all life-sustaining treatment stopped and GU was allowed to die. (My blog about that case is here).

The point of the supplementary hearing held in July 2021 was to examine why this patient had been treated contrary to his best interests for so long – and to look at how other patients might be protected from this happening to them. This seemed like an invaluable opportunity for the Court of Protection to address some of the underlying problems in this area.

I was particularly interested to observe this supplementary hearing because this is a family I had supported to help them in getting this case to court. This is one of many families that we (my colleague and sister, Professor Celia Kitzinger, and I) have been involved with as part of our work with the Coma and Disorders of Consciousness Research Centre. We also often support families in best interests decision-making about CANH that often never get as far as court: see my blog here.

I was also keen to watch the supplementary hearing because I've often felt frustrated watching cases that do get to court where it's apparent that there's been lots of delay (Kitzinger and Kitzinger, 2017), but judges invariably focus narrowly on the best interests of the individual patient going forward. This usually means that exploration of any past problems or 'lessons learned' have a relatively low profile.

Who contributed to the supplementary hearing?

The barristers in court were Debra Powell for GU via the Official Solicitor, and Mungo Wenban-Smith for the Clinical Commissioning Group (the applicant in the case). Both had been at the original hearing.

They were joined at this supplementary hearing by Amelia Walker, counsel for the Hospital (It is possible that the judge will give permission for the Hospital to be named, but I have not yet had this confirmed, so I anonymise it here).

The Hospital had not been a party to the original hearing and it was unclear (at least to me) whether or not the Hospital was now joined as a party for this supplementary hearing.

The only witness sworn in during the hearing was the CEO of the Hospital.

The patient's eldest son and his brother were also present: both remained as parties to the case on the paperwork and both spoke briefly during the hearing.

"An ethos at odds with best interests decision-making"

The hearing opened with the barrister representing the patient via the Official Solicitor highlighting the need for further investigation:

"*In the assessment of the Official Solicitor, there was a complete abrogation* [on the part of the Hospital*] from considering properly, or at all, if it was in GU's best interests, and therefore lawful, to continue to give him an invasive medical treatment…. That is a failure to put P at the heart of decision-making and a failure to accord P his rights."*(Debra Powell)

The atypical nature of this hearing and the role of those involved was signalled as this barrister went on to say:

"*Our position is unusual. Since GU sadly died, peacefully, on 26th June, our involvement in protecting his best interests has come to an end. But the Official Solicitor's position is that where there is disagreement about P's best interests then, by some means or another, that dispute must be resolved in a timely way – to do otherwise compromises the best interests and dignity of a patient. It risks a situation, as here, where GU has been treated for hundreds of days – nearly 3 years – when this is not in his best interests."* (Debra Powell)

A concern that these failures in care were linked to the Hospital's "*ethos*" took centre stage from the start.

The judge quoted from an email sent to a family member by the Head of Continuing Care at the hospital. It stated: "*we are not at [the Hospital] about to prevent any resident from having their basic rights of food and hydration."* The judge said this statement suggested there might be "*a philosophical driver rather than a protracted procedural issue behind this delay*" in considering GU's best interests. This was a possibility that, the judge said, needed to be confronted "*with courage and uncompromisingly*".

Further evidence provided by the hospital seems to have added to the judge's concern rather than reassured him.

Taking a few minutes to read the hospital's position statement during the course of the hearing (it had only just been submitted), the judge described it as *"A realistic acknowledgement of the delay as well as an ambitious plea of mitigation for it*."

He then turned to another document the hospital had submitted some days earlier which he found problematic. He explained to counsel for the Hospital:

"*There is a philosophical disconnect between that document [*original information from the hospital*] and your very carefully crafted submission* [the position statement*] – but the two come cheek by jowl and I think that requires explanation."*

Mr Justice Hayden proceeded to read out and criticise various statements from the material provided by the hospital.

- The hospital had written: "*We understand there has been a suggestion of some delay in decision-making regarding GU*". Hayden J commented: "*Where it says 'some delay' it requires to be identified that this was a minimum delay of 3-4 years. It rather minimises the magnitude of the issue here*".
- The hospital document stated *"we would not lightly initiate proceedings in circumstances where there is a disagreement*". Hayden J commented that this is "*a reversal*" of the legal situation. He seemed completely taken aback by this statement – not least because his own guidance makes clear that it is precisely when there is disagreement that court proceedings should be initiated.
- The notion that disagreement might inhibit clinicians from referring the case to court and ensuring the patient had the benefit of legal representation was robustly rebutted by the judge. Disagreement among family members about a particular course of action, he emphasised, "*doesn't make a jot of difference if the hospital identifies it as being in P's best interests."*

Mr Justice Hayden gave short shrift to the suggestion from the Hospital barrister that perhaps guidance about when to bring a case to court was unclear. Commenting: "*I didn't have a sense that anyone had read my guidance. I don't see how I could have expressed myself more unambiguously'.*

He singled out the Hospital's own description of a potential conflict between its ethos and best interests decision-making about CANH for particular scrutiny. The judge read out a passage from the Hospital's submitted documentation where it described its ethos (as a centre for rehabilitation and long-term care) as one where:

"*… often we can expect our patients to live out long lives, during which they will be comfortable and if possible happy. Withdrawing life-sustaining treatment is not immediately aligned to that ethos and though staff are aware that there are circumstances when the withdrawal of CANH is an appropriate course of action, that is not something which many staff are comfortable facing, unless they have to."*

Mr Justice Hayden described this as *"a very troubling passage … not least because it was written knowing this case was being heard."* He underlined that:

*"There is one person who counts and that is P. When you allow it [*staff feelings and values*] to filter in, you risk, as here, doing harm. And that is what I want to stop….*

The fact that staff may have ethical problems withdrawing CANH can never be allowed to eclipse P's right to have it determined by a court, represented by the Official Solicitor …. It is, with respect aligned with the ethos of care for patients. It is not disjunctive from it, as the author of this document suggests."

By the time the Hospital's CEO was sworn in to give evidence, it was clear that a certain amount of repair work was needed. The CEO was quick to acknowledge the unacceptable delay in referring GU's case to court and to assure the judge "*we will completely adjust our policy and our operational policies accordingly".*

The CEO indicated that steps had already been taken to improve the hospital's approach to best interests decision-making about CANH and he expressed the Hospital's future commitment to following Mr Justice Hayden's (2020) guidance about when to apply to court.

The CEO also indicated there were plans to produce leaflets for families and to undertake staff training.

Having been part of teams that have worked on such material for years, I can only hope the CEO for this Hospital looks at the existing information and training made available by the British Medical Association [BMA] and Royal College of Physicians [RCP]. There is no need to reinvent the wheel. For example the RCP working party report on Prolonged Disorders of Consciousness includes a detailed chapter on "*Practical decision-making regarding starting or continuing life-sustaining treatments*". The BMA and RCP have also created a series of user-friendly additions to national guidance about CANH including, for example,

- a flow chart and proforma for decision-making about CANH when the patient cannot consent
- a booklet for families and a podcast about the role of family and friends in decision-making
- useful case studies of what clinicians should do when there is disagreement and how to proceed to a court application

The CEO went on to make various attempts at mitigation – including explaining that the offending email quoted by the judge was sent by "a middle manager": it did not, he claimed, reflect the official hospital position. He also suggested that mistakes made in 2018 (in failing to deal with family concerns about ongoing CANH) were perhaps related to the fact that this was very soon after certain legal changes. He referred in particular to the "Re Y" judgment in the Supreme Court (the judgment which made clear that there was no need to go to court before withdrawing CANH if robust procedures had been followed and there was no doubt or dispute that continuing it was not in the patient's best interests). This led to the following exchange (which, like other quotations in this blog post is captured as accurately as possible through note taking, since recording is not allowed):

> **CEO**: *In 2018, when we were digesting the ruling of the Supreme Court we certainly did err on the side of caution – and I guess with hindsight too much on the side of caution.*
>
> **Judge**: *What do you mean?*

CEO: *A number of relatives expressed concern about whether there would be a rush to withdraw CANH against their wishes. It died down quite quickly, but at the time our nervousness would not have been about keeping someone alive unlawfully but ending their lives unlawfully, so there were a lot of checks and balances*

Judge: *Mr X, this isn't the situation at all – there was never any obstacle to going to court if treatment was against the best interests of the patient and compromising their dignity.*

Reminding the Hospital's CEO that the "*Re Y*" judgement did nothing to change the duty of clinicians to act in the best interests of patients, Mr Justice Hayden went on to say that "*this can't come as a surprise to you – that would require amnesia of a decade within the profession*".

When the CEO indicated that he was taking on board and digesting what the judge had said, Hayden J responded: "*you may be absorbing it, but this is something the hospital should have absorbed a decade ago*". He concluded: "*I've formed the view that on these issues [the Hospital], for all its excellence in rehabilitation, was a long way behind the curve".*

Litigants in Person – the need for full involvement

My only disappointment in this hearing relates to the problems experienced by one of the family members – a litigant in person – who wanted to contribute.

The patient's eldest son (who had opposed the withdrawal of CANH) was able to attend the entire hearing and was offered the opportunity to ask questions of the Hospital CEO. He emphasised his support for the Hospital and admiration for the care they'd provided: "*I for one will carry on donating to the hospital because of what they've done for my dad, and how they've treated me, and how they've been when I visited my dad."*

The problem was experienced by the patient's brother, EU, who'd represented the rest of the family in trying to get CANH withdrawn. Like his nephew, he is full of praise for the physical care given to GU, but he is very critical of the Hospital's approach to best interests. It was he who was particularly keen to contribute to the investigation of the causes underlying delays in reviewing his brother's treatment.

EU had been told at the end of the original hearing that there'd be a supplementary hearing and Mr Justice Hayden emphasised that he'd be welcome to attend this. However, EU was excluded from further correspondence about the case thereafter and when he emailed in an attempt to find out when the hearing might happen or how he might be involved, he did not receive a reply.

He only learned about the date of the supplementary hearing about 48hrs before it was scheduled to be heard and it was only later that he discovered that he still counted as a 'respondent' and could have submitted evidence – but the deadline for this had passed. The hearing also unfortunately clashed with a medical appointment which he had no chance to rearrange due to the short notice. This meant that he had to leave the court before the hospital CEO gave evidence and was unable to ask him any questions.

The Court of Protection often has to work at great intensity and speed, but it seems the parties with barristers in this case had access to information that the Litigants in Person did not. This was potentially a detriment to the court process. In particular it would have been useful if all the parties had received the draft order after the original June hearing, which included information that would have been invaluable to the family in preparing for the July hearing.

Talking to the patient's brother after the supplementary hearing it was clear that this was very frustrating for him. He had intimate knowledge of the challenges from the family perspective as he'd been fighting to have GU's best interests addressed about CANH over several years. He could have provided additional information from correspondence with, and meetings at, the Hospital – some records of which appear to have been mislaid by the hospital or at least were not included in information provided to the court.

At one point, just before having to leave the hearing, EU asked for permission to address the court: as usual, Mr Justice Hayden accommodated this, always being keen to ensure families are heard. It was then that EU took a few moments to highlight the existence of paperwork from a meeting he'd attended in August 2018. At this meeting, a doctor recorded the information that the majority of the family believed CANH should not continue and she also made recommendations about how colleagues at the Hospital should initiate a best interests review: these plans were never followed through. EU believes there was active obstruction.

Although pleased he was able to make this intervention, EU did not have the chance to make other points he'd wanted to raise. These included:

- the fact that senior management staff had been copied into a crucial email thread – part of which Mr Justice Hayden had read out in court – so the 'excuse' that the offending email represented an isolated 'middle management' view was unconvincing.
- that the "*evasion*" he felt he'd encountered in the Hospital and the lack of accurate documentation when he tried to address questions of best interests was a major obstacle ("*in contrast to the reams and reams of detailed documentation of every other aspect of my brother's care*")
- and, that, in his experience, not only did none of the clinical team take responsibility for best interests decision-making about CANH, but the whole atmosphere made even considering CANH as a best interests decision "*almost unthinkable*". For many staff, he said: "*it's not within their psyche, they don't even think that way*."

He remains concerned about other families in the hospital who might never have been asked about their relative's wishes (or who are perhaps left with the burden of the decision, rather than clinicians taking responsibility).

He is also critical of what he suspects may be a potential "conflict of interests" given the large amounts of money going to the hospital from CCGs for every patient. He would have liked to ask the CEO about the funding model on which the Hospital might depend.

I do not think the evidence and questions EU would have introduced would have made any substantive difference to the judgment in this case. However, perhaps there are lessons here about how Litigants in Person can be briefed on court processes and included in correspondence leading up to hearings.

Reflections

The supplementary hearing (which lasted around 2.5 hours) was a thorough and detailed engagement with what the Hospital had done to GU, giving insight into some of the wider issues that affect patient care in many hospitals, rehabilitation centres, and care homes around the UK.

The judgment may help to address a widespread failure to provide clinical leadership in best interests decision-making about CANH. It could be used to challenge the medical passivity around CANH decision-making in some units where, unless families push for it, the question of whether it is in P's best interests to continue CANH is often never revisited or reviewed.

The supplementary judgment may also help to galvanize clinicians who have become frozen in the face of family conflict and sometimes see the court as an option to be avoided at all costs. It may help them to see that not only do they have a duty to refer intractable cases of dispute, but that in fact (as many of the blogs published by the Open Justice Court of Protection Project demonstrate), the court can be an excellent forum for achieving a just resolution that keeps P's interests at the heart of the decision.

EU is hugely grateful to the Official Solicitor and to the Judge for the way they addressed his brother's immediate needs for justice in the original hearing and also how, in the July supplementary hearing, they unpacked crucial areas where change was needed. He hopes one outcome might be to create a "legacy" for his brother – prompting improved best interests decision-making for other patients. He believes the judgment may help to ensure that what was done to GU, and to GU's whole family, is prevented from happening to anyone else.

I hope he is right.

**** Postscript ****

Previous judgments in the Court of Protection have also drawn attention to the problem of the "ethos" of units delivering care – in particular to the way this "ethos" can sometimes conflict both with the law, and with respect for P's prior values and beliefs.

As in this case, it is a problematic "ethos" that is sometimes implicated in long delays in referring disputes to court.

This is illustrated very clearly in this reported case: A Clinical Commissioning Group v P (Withdrawal of CANH) [2019] EWCOP 18.

In that case, all of P's family consistently stated that she'd want to refuse ongoing life-sustaining treatment but:

"... staff felt that any decision to discontinue CANH in relation to P could apply equally to all patients at the Unit. More generally, Ms PL (Clinical Lead at the Unit) [stated that] she and her staff would not want CANH withdrawn, ... not particularly because they felt it was against the best interests, but because "... they are all 'pro-life' in general..' [para 26}

It took several years before this case reached court. The judge, MacDonald, J, concluded that "*Whilst the 'pro-life' approach (as they themselves describe it) ... is a valid point of view ... I am satisfied that it is contrary to the clearly expressed view of P before she lost capacity*" (para. 69)

As with GU it turned out that the P in this case had been treated contrary to her best interests for a very long time.

Perhaps a 'supplementary hearing' after that case (in Spring 2019) might have helped to prevent what subsequently happened to GU.

I wonder, too, whether the Hospital that treated GU could benefit from learning what the nursing home in this earlier case has done since the hearing to address the shortcomings in the care provided to P – and to ensure that, since the judgment, other residents have been treated in compliance with the law.

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