

Family tragedy and institutional delay in best interests decisions about life-prolonging treatment

By Celia Kitzinger and Jenny Kitzinger, 9th April 2024

Published On Open Justice Court of Protection

<https://openjusticecourtofprotection.org/2024/04/09/family-tragedy-and-institutional-delay-in-best-interests-decisions-about-life-prolonging-treatment/>

In July 2020, a woman identified as “OO”, collapsed at home with a cardiac arrest. This was totally unexpected: she was otherwise fit and well (and only in her early 30s). Despite resuscitation from her family and then from the Ambulance service, her heart stopped beating for at least 30 minutes. She sustained severe generalised hypoxic brain damage.

It turns out, from later investigations, that she has “long QT syndrome”. This is an inherited heart problem that affects the heart’s electrical activity and can cause cardiac arrest (there’s an NHS page about the condition [here](#)). She wasn’t aware of this – and the NHS does say that some people with long QT syndrome don’t have any symptoms and don’t know they have this condition until something goes wrong.

OO had been a lively, active, fun-loving person who loved to walk outdoors, travel, and listen to music. At the time of her collapse, she’d been about to start studying for a biomedical degree

More than three years after her cardiac arrest, OO has been assessed as being in a disorder of consciousness in the lowest end of the spectrum of awareness (Minimally Conscious State minus [MCS-]). This means she is able to focus on and track objects or people in her environment. When subject to interventions that might be expected to cause pain (and sometimes spontaneously too) there is also facial grimacing, moaning and profuse sweating – but there is a question mark over whether or not she actually experiences pain. She’s unable to communicate or interact socially with anyone, including family members. She cannot show that she recognises people and is unlikely to be able to discriminate between them. She breathes on her own, but receives clinically assisted nutrition and hydration (CANH) via a tube into her stomach.

According to the independent expert, Professor Derick Wade, Consultant in Neurological Rehabilitation: “*Almost all recovery seen after hypoxic brain injury occurs within 12 weeks, possibly with a few people improving a little over the second 12 weeks*”. The medical consensus more than three years on is that OO’s condition is permanent and there is no prospect of any improvement.

Like most people, unfortunately, OO hadn’t made any formal advance decisions about what she would want in this situation. Nor had she ever discussed what she might want with her family. As her sister said, “*It never crossed anyone’s mind before to even speak about it because she was very healthy*”.

So, it was up to those providing life-sustaining treatment – and now up to the judge – to decide whether or not continuing to provide it is in OO’s best interests.

This blog post is divided into two parts.

The first part (“I. Best interests and delay”) is largely based on the documentation received from the court^[1]. Without it, we’d have very little idea of what was going on. It should provide a useful summary of the case as it stands at present – and since the case will be back in court in late April, it will provide useful background reading for anyone wanting to observe that hearing.

The second part (“II. The hearing”) deals with what actually happened in court on the day. It gives a sense of the challenges faced by observers, and also of the kinds of procedural issues the court has to deal with in addition (and prior) to hearing substantive weighty moral and legal end-of-life issues. For non-lawyers, we hope it conveys a sense of what lawyers spend a lot of time doing – arguing about reporting restrictions, searching for colleagues willing to act pro bono, and arguing for or against adjournments – all the messy business of law-in-action.

I. Best interests and delay

There seems to have been a delay in bringing this application to court – and indeed, a delay in considering whether or not continuing treatment was in OO’s best interests.

As far as we can tell from what happened in court, and from the documents we’ve received, OO was diagnosed as having a “permanent” disorder of consciousness in Spring 2021, following multiple testing and brain scans at the Royal Hospital for Neurodisability (RHN) where she’s an inpatient. However, there was no best interests meeting with relevant professionals and members of OO’s family until March 2023 (so two years after her MCS- became “permanent”). There was no explanation available to the court as to why this best interests meeting was so delayed.

The apparent failure of the Royal Hospital for Neurodisability to hold a timely best interests meeting for OO is especially surprising given the court had extensively criticised the RHN for delay in decision-making about another patient, ‘GU’, in June and July 2021 – so just a few months after OO was admitted to their long-term care ward.

The case of *North West London Clinical Commissioning Group v GU* [2021] EWCOP 59) concerned a 70-year-old man in a prolonged disorder of consciousness (‘GU’) who had been cared for in the RHN for many years. The (then) Vice President, Hayden J commented that the hospital (an acknowledged ‘centre of excellence’) was actually “*a long way behind the curve*” in engaging with up-to-date legal and professional standards. 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 by the RHN to treatment that was not in his best interests for some time. He also criticised the fact that the RHN were not party to the proceedings, commenting 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*”. We blogged about the case here: [Clinically-assisted nutrition and hydration: Decisions that cannot be ignored or delayed](#).

In a supplementary hearing after deciding the substantive matter before the court in GU, the judge made a series of very powerful observations about the obligations imposed upon treating bodies to ensure proper consideration of whether continuing treatment is in a person’s best interests, and to take proper steps to secure timely resolution of any dispute. See our earlier blog post: “[Burdensome and futile” treatment and dignity compromised: Poor practice at a leading UK hospital](#). We would have expected this case to have prompted the Royal Hospital for Neurodisability to ensure best interests decision-making for all patients in their care – including OO.

It was clear that the Official Solicitor had the same expectation. In her position statement for the OO case, the Official Solicitor referred back to the case of *North West London Clinical Commissioning Group v GU* [2021] EWCOP 59 and expressed a concern that “*lessons may not have been learned, and significant delays in bringing cases of this nature to court are still occurring*”. She further submitted that there should be “*an independent review of the evidence disclosed by the ICB and RHND to ascertain whether the protocols and procedures in place to ensure timely best interests decisions are made for patients in PDOC are consistent with the Royal College of Physicians Guidance and are sufficiently robust to ensure that delays in cases of this kind will not be repeated*”.

A documented best interests meeting for OO did not finally take place until nearly two years after her diagnosis of her condition as permanent, in March 2023. At that meeting all present agreed that it was no longer in OO’s best interests to continue with clinically assisted nutrition and hydration (CANH). The treating clinicians were all of this view, and so were the family. Her mother said that OO “*wouldn’t want this life as she was independent and active*” and her friend said “*hand on heart she would want to go*”. The position of the family was confirmed in a letter written by OO’s sister received in early April 2023. Their view at that point was that this was not a quality of life that OO would have found acceptable for herself.

An independent second opinion expert, Professor Derick Wade, also concluded that there was no prospect of improvement in OO’s condition and, after speaking to the family, he also came to the view that it was no longer in her best interests to continue CANH. After review by the RHN Ethics Committee in May 2023, it was agreed that CANH would be discontinued on 14th June 2023.

Then, following a visit from a cousin in early June 2023, both parents changed their position and stated that they now felt that CANH should continue.

In subsequent statements, this cousin stated that OO “*was a fighter who held onto life very tightly*”. Her view is that, whatever the medical evidence says, “*we as her family will always have hope that one day [OO] will eventually heal; time is the best medicine*”. She described looking into OO’s eyes and feeling that OO is saying to her “*I want to live... do not let them take my life away from me.... I can definitely see in her eyes that she would want to continue living and having hope that one day her body, mind and soul will recover from this trauma*”.

The mother says she feels “*guilty*” about the decision made at the previous meeting – which she sees as about “*killing*” her daughter. She wrote: “*[OO] is my daughter and as her mother I cannot bear losing her as she is the reason I am alive. I fight every day for [OO]. I will commit suicide if [OO] dies...*”.

Her father says he believes that “*she is fighting*” and will “*come back to life*”. He wrote: “*Please do not stop her medications as she is our beacon of light... As a father, I want the best for my daughter and she deserves to live*”.

Her mother told the solicitor that they are hoping for a miracle and that she would “*prefer [OO] to give up on her body herself and pass away like that; I don’t agree with withdrawal of CANH*”. She believes “*if she is to let go herself it would be natural and not by the hospital*”.

A friend of OO’s now opposes withdrawal of CANH out of concern that the mother “*may not be able to cope mentally or emotionally with the consequences*”.

Other family members, notably OO's sister (and possibly her other siblings – this wasn't clear) maintain their original position but have chosen no longer to be involved in the process.

Following the parents' change in position in June 2023, a court application could – maybe should – have been made immediately.

Instead, further assessments were completed. They continued to show a low level of responsiveness, and no evidence of significant awareness. There seems to have been an increase in pain behaviours such as crying, grimacing, moaning and frowning. Despite pain medications and an antidepressant, OO often shows apparent distress in response to suctioning and at times when staff are handling her, e.g. washing her, or moving her into a wheelchair, and also sometimes these occur spontaneously. The clinical evidence is that she does not smile or display pleasure.

These pain behaviours are distressing for the nursing care team and to family members – some of whom do not visit because it is so distressing to observe. Between 1 August 2023 and 31 January 2024, OO was visited on 14 out of 184 days – mainly by her mother and sister.

An application to the Court of Protection was eventually made on 2nd February 2024. That's 3 years after OO was diagnosed as having a “permanent” disorder of consciousness, and nearly a year since the original best interests decision was made that continuing treatment was not in her best interests.

The ICB (North Central London Integrated Care Board) is the applicant in this case (this is the ICB that commission OO's care). The application is seeking a determination under the Mental Capacity Act 2005 that OO lacks capacity to conduct proceedings and to make decisions regarding her medical care and treatment, and that it is lawful and would be in OO's best interests for those treating her not to continue to provide CANH and for her to transfer to a palliative care pathway.

The Vice President, Mrs Justice Theis (we think on the papers, i.e. without an actual court hearing) made directions in February to join OO as a party to the proceedings, invited the Official Solicitor to act as OO's litigation friend, and gave directions to file evidence, including evidence from the applicant ICB addressing any delay in bringing the application. She also made a transparency order.

Having considered all the evidence to date, the Official Solicitor “*with great sadness*” and subject to hearing oral evidence from the family and from the medical experts, takes the position that the benefits of continuing CANH are outweighed by the significant burdens – especially the risk that OO may be experiencing pain. The Official Solicitor also raised a concern about “*unacceptable delay*” in bringing the application to court. Furthermore, said the Official Solicitor, “*it remains unclear if the question of whether it is in OO's best interests to continue CANH was considered at all in the period from 15 March 2021, when she was admitted ... for long term care, and 8 March 2023, when the process of making a best interests decision was started*”.

The hearing (COP 14034582) before [Mr Justice Cusworth](#) was listed for two and a half days, from 25th-27th March 2024 – but in the event it was adjourned just after half past two on the first day. It will be back in court on (some or all of) 24th, 25th and 26th April 2024.

II. The hearing

We didn't know what this hearing was about in advance – Celia just happened to choose it as one to observe, and all the information in the previous section emerged later. Celia (after some delay caused

by confusion about the transparency order discussed below) was eventually able to alert Jenny, who then joined from lunchtime onwards.

It was a hybrid hearing, starting at 11am on 25th March 2024. Counsel and the judge were in the physical courtroom, but some people, including one medical expert, were attending remotely via video-link. Hybrid hearings can be challenging for those of us on video-links – in particular it can be hard to hear what’s going on in the court, and we rely on someone to move the camera (or to set up additional cameras) to capture counsel, the judge, and any witnesses.

It was quite a disjointed hearing with several adjournments and with a muddle at the beginning which negatively affected transparency and open justice.

In summary, here’s what happened, under three hearings (1) Transparency issues; (2) Legal representation for the mother; and (3) Considering delay.

1. *Transparency issues* (Celia)

The applicant counsel – be-wigged, and distant to the camera so I had no idea who he was – gave a verbal description of the transparency order already made by Mrs Justice Theis (which observers had not been sent). He explained that the order protects (as usual) P and P’s family. It also protects the identity of the treating clinicians, which is less usual and which – when this restriction is applied – is often lifted at or shortly after the end of a hearing, or after the protected party has died.

Following counsel’s account, the judge said “*during this hearing until the end when the transparency order can be reconsidered, there must be no reporting of what is going on in court*”.

This was a very unusual restriction. We are normally free to blog, or otherwise communicate about hearings, during the course of hearings – and have done so frequently.

Counsel then offered to give an opening summary of the case but the judge said, “*I don’t require any more detailed opening*” – so that left me in the dark as to what the case was about.

This was all extremely frustrating because on joining the hearing, I’d noted that Professor Derick Wade had been named as someone available to give expert evidence – and this alerted me to the possibility that the case would concern someone in a prolonged disorder of consciousness, since that is Professor Wade’s area of expertise. But (a) I didn’t know that for sure since there was no opening summary; and (b) I couldn’t alert anyone else to this hearing since the judge had said I mustn’t report “*what is going on in court*”. I wanted to alert other members of the public that this might be a hearing of interest to people with family and/or professional interests in prolonged disorders of consciousness and end of life decision making (specifically Jenny Kitzinger, and the PhD student we both supervise, Rhiannon Snaith). What the judge had said meant I couldn’t do that, and I wasn’t sure whether or not this accurately reflected the transparency order made by the previous judge (Theis J) and if not, whether the judge had intended to extend the transparency order made by Theis J.

I sent an urgent email to the judge via the RCJ email address:

Attnt: Mr Justice Cusworth

Please could someone send me a copy of the TO for this case. I had understood from what

counsel said that it was in the usual terms except for including treating clinicians, but from your subsequent comment, the restrictions sounded far more draconian. I am concerned from an open justice perspective both not to breach the TO and also to ensure that it is not in fact more restrictive of reporting than it needs to be in the circumstances of the case.

I am also finding this case very hard to follow as there was no opening introduction (as recommended in the former President's guidance). Nor have I been able to request Position Statements since I do not know the name of the male barrister and have had to guess which "Ms Watson" might be the female barrister.

I would appreciate your support with this matter since I know the judiciary does aspire to transparency.

The judge responded to the effect that he had not intended to extend the restrictions beyond those already in place in the order made by Theis J, sent me the Position Statements, and asked whether it would be helpful for him to request a summary. Thank you!

By this time, though, the ICB had asked for a variation in the transparency order along the lines the judge had so fortuitously suggested, asking for "*no blogging today until there's greater clarity about the issues in this case*". As I still didn't really know what the hearing was about (not having yet had time to read the position statements), I wasn't in a strong position to oppose this. I did turn my camera on and raise with the judge the fact that I'd now contacted a couple of people to tell them about the hearing (Jenny Kitzinger and Rhiannon Snaith who have research interests in prolonged disorders of consciousness and end-of-life court decisions respectively). I also said that I'd like to be able to say something about the issues before the court on the Open Justice Court of Protection webpage under "Featured Hearings" (granted!). Given that, at that point, it appeared that the restriction on blogging would last for only a couple of days, and I wasn't actually planning to blog in that time period anyway, I didn't press the point.

Later, when it became apparent that the case wasn't going to be decided in the next couple of days, and that it would be a whole month before it would be back in court, I checked back with the judge and was told I could write a blog – which is how this blog post became possible.

2. Legal representation for the mother

The ICB was represented by [Rhys Hadden](#) and OO was represented via her litigation friend the Official Solicitor by [Claire Watson KC](#) (both of Serjeants' Inn Chambers).

The mother was in court, but unrepresented. She asked to be joined as a party to the proceedings and for the hearing to be adjourned so that she could find a legal team.

She was crying and her words were translated via an interpreter. She said, "*I don't want to lose my daughter like I lost my other daughter, otherwise I will kill myself*". Her other daughter, it transpired, had died by suicide

The judge was sympathetic but firm: "*Is there a solicitor you have approached already – someone you want to instruct?*"

"*Right now there is no one*", she said, "*but we can research and find*".

“How long do you think you will need to find a solicitor and instruct them and then come back to court?” asked the judge

“In shortest time as possible”, said the mother.

The judge expressed concern (*“I don’t want this to be adjourned for a lengthy period”*) and turned to counsel, both of whom opposed the application for an adjournment. Counsel for the ICB acknowledged there *“has already been delay”* and said *“further delay is not in OO’s best interests”*. In particular, the ICB *“would not want instruction of further experts”*. Counsel for OO pointed out that as the mother wasn’t a party, she’d not even seen the papers before the court until a few days ago. However, she said *“the Official Solicitor feels strongly there must be a prompt determination and any further delay would be contrary to those interests. With a heavy heart and great sadness, we do not feel able to support an adjournment on this basis”*.

The judge took a different position. Given, he said, the *“extraordinary delay”* there has been already, he *“can’t help feeling a short further period of delay would not be disproportionate”*.

The judge said he would rise to allow time to find out how quickly it might be possible for the mother to find a legal team and come back with the case; once he had a suggested time-line he would make a decision as to whether that was proportionate. Addressing the mother directly, he said, *“What I’m at the moment NOT minded to direct is that you should instruct your own medical evidence because that would lead to a much longer delay”*.

Counsel returned with the matter still unresolved and the court rose early for an extended lunch break. As counsel for the ICB said, any further delay should be *“purposeful”*. If there is no realistic possibility of legal representation for the mother, then there is no point in delaying further.

Resuming at 2pm, counsel announced that they’d found a colleague, [David Lawson](#), willing to act for the mother pro bono.

3. Considering Delay (Celia and Jenny)

Having adjourned the substantive matter of whether or not continuing CANH is now in OO’s best interests, the judge suggested that the matter of *“delay”* in relation to considering her best interests over the years and months since her original injury could be addressed over the course of the remaining time already allocated to this hearing. Counsel were in court and doing it now would free up time next month.

Counsel for the ICB made the rather surprising submission that it wasn’t in fact necessary to spend any time considering the delay. This was because, he said, both the hospital (which, anyway, wasn’t his client and wasn’t in court) and the applicant (the ICB) accept there has been delay in bringing this case to court.

The Official Solicitor pointed out that *“simply accepting there’s been delay doesn’t address the issue of WHY there has been delay. The Vice President said there should be evidence about why there was delay”*.

The judge clearly shared the view put forward by the Official Solicitor and suggested that if the ICB was not ready to proceed today, then there were still two more days of allocated time for the hearing:

“you could file tomorrow and I could decide on Wednesday”. Counsel asked for a longer deferment, pointing to the “risks of the court making findings against a non-party”. Although the Official Solicitor pointed out that Theis J had asked for an explanation of the delay back in February, so that the answer should have been prepared and set out in writing before the court by now, the judge decided that it would be preferable to have a careful explanation set out in writing and gave the hospital 14 days to produce something to be considered at the next hearing. We will be very interested to learn about this explanation at the next hearing and welcome the focus on this issue.

Delay in making best interests decisions about life-sustaining treatment for PDoC patients is a problem that we’ve been highlighting for almost a decade now^[ii]. Over the course of the last ten years we’ve supported many families in cases reaching court and delays have repeatedly been challenged in hearings e.g. in 2016 Hayden J’s final judgment highlighted the imperative to avoid delays that were not ‘clinically purposive’. Stating that “*respect for a patient’s autonomy, dignity and integrity requires all involved in these difficult cases to keep in focus that these important rights are compromised in consequence of avoidable delay*” (para.13 *Cumbria NHS Clinical Commissioning Group v Miss S and Ors* [2016] EWCOP 32).

Some of the underlining causes of delay have been addressed since then by changes in the way cases are managed in relation to court hearings – a change that resulted from the *Re Y* judgment (*An NHS Trust v Y* UKSC 46). In addition, more timely decision-making has been supported by the production of the [RCP National Clinical Guidelines on Prolonged Disorders of Consciousness following Sudden Onset Brain Injury](#) (2020) and the [British Medical Association Guidance on Clinically Assisted Nutrition and Hydration](#) (2018). These guidelines not only emphasise the importance of timely and regular best interests decision-making but give step-by-step guidance on how to do this.

But it’s still the case that delay in best interests decision-making remains one of the main reasons family members approach us for help. In spite of positive changes it seems that some centres may be struggling with a backlog of cases where no best interests meetings have previously been held, and they may still be finding it difficult to conduct best interests decision-making processes in a timely manner, perhaps especially in the face of family divisions or fluctuating feelings. We also suspect that some centres caring for a great many PDoC patients may still be avoiding making best interests assessments all together – a suspicion in part informed by the fact that, as far as we can see, very few cases – or no cases at all – are reaching court from some centres which we know to have large numbers of PDoC patients. It is unlikely that these centres have no situations where there is disagreement about the person’s best interests, or where the decision is finely balanced. An important questions for us (and for the Official Solicitor?) is what is happening in these centres, who continue to maintain many patients in PDoC without ever triggering court applications about their best interests.

So, this all means that the next hearing for OO is not only significant for OO and her family, but may have wider implications for the care of other patients. Evidence from the RHN regarding how and when best interests decisions were made (or not) in this case, and their account of their own procedures, will be important for the continued fight to ensure timely, patient-centred care. We anticipate the issue of how to combat delays will be the focus of our next blog.

Celia Kitzinger is co-director of the Open Justice Court of Protection Project. She has observed more than 500 hearings since May 2020 and written more than 100 blog posts. She also co-directs (with Professor Jenny Kitzinger) the [Coma and Disorders of Consciousness Research Centre](#). She is on LinkedIn ([here](#)), and tweets @KitzingerCelia. She can be contacted via openjustice@yahoo.com

Jenny Kitinger is Professor of Communications Research at Cardiff School of Journalism, Media and Culture. She also co-directs (with Professor Celia Kitinger) the [Coma and Disorders of Consciousness Research Centre](#) and runs [online training for healthcare professionals](#) about law and ethics. She tweets [@JennyKitinger](#)

Posted by [openjusticecourtofprotection](#) 9th Apr 2024

Tags: [Best Interests](#), [clinically assisted nutrition and hydration](#), [Court of Protection](#), [Cusworth J](#), [Delay](#), [Legal Practice](#), [Mental Capacity](#), [Not Secret Court](#), [Open Justice](#), [Transparency](#)

[i] We've received Position Statements from the applicant, the North Central London Integrated Care Board, (represented by Rhys Hadden of Serjeants' Inn Chambers) and from the Respondent, OO by her litigation friend, the Official Solicitor (represented by Claire Watson KC also of Serjeants' Inn Chambers), plus an "Agreed Case Summary and List of Issues". The mother was joined at a party during this hearing: we have no written statement from her.

[ii] [Kitinger, J. and Kitinger, C. 2018. Why futile and unwanted treatment continues for some PVS patients \(and what to do about it\). International Journal of Mental Health and Capacity Law 23 , pp.84-149](#); [Kitinger, J. and Kitinger, C. 2017. Causes and consequences of delays in treatment-withdrawal from PVS patients: a case study of Cumbria NHS Clinical Commissioning Group v Miss S and Ors \[2016\] EWCOP 32. Journal of Medical Ethics 43 , pp.459-468. \(10.1136/medethics-2016-103853\)](#)