

# Refusing to eat and declining a feeding tube: Capacity at issue

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**By Celia Kitinger**, 21st April 2022

The hearing concerned an application from an NHS Trust (represented by [David Lawson](#)) to insert a [PEG-J](#) tube under general anaesthetic and then to

deliver clinically assisted nutrition and hydration (CANH) to a young woman (P) who was admitted to hospital having fractured her femur and is now refusing to eat.

She's saying she doesn't want CANH – but both parents (who are also parties and litigants in person) support the Trust's application.

The case (COP 13913343) was heard (remotely) across three days (5<sup>th</sup>, 7<sup>th</sup> and 8<sup>th</sup> April 2022) before Mr Justice Williams sitting in the Royal Courts of Justice.

I didn't observe on the first of these dates but did watch on 7<sup>th</sup> and 8<sup>th</sup> April 2022. I had asked to observe on 7<sup>th</sup> April not knowing that the case was “part heard” (this is usually indicated on the listings), and so was surprised to be joining a hearing that had already started two days earlier, and for which (as a result) there were no opening statements from the parties. This meant that it was initially difficult to orient to what the case was about and what was happening<sup>[1]</sup>.

As there was no opening summary (the judge did not permit one due to time constraints), I'm not sure what took place at the initial “*urgent*” hearing on 5<sup>th</sup> April 2022, but I think it must have become clear that there was a problem with making even an interim declaration about P's capacity to make her own decision about CANH, and that the judge must have declared that an independent expert could be appointed. I base this deduction on the fact that (proposed) counsel for P via the Official Solicitor ([Emma Sutton](#), on the first day of the hearing) expressed concern about the evidence on capacity because it was based on:

- evidence from the treating consultant psychiatrist (Dr K) that P lacked capacity to make decisions about nutrition and hydration due to a delirium arising from a urinary tract infection; that infection was resolving, following which he thought she may regain capacity; and
- evidence from a consultant liaison psychiatrist (Dr B) that P does not have any significant psychiatric illness, although she's depressed and has an “*adjustment disorder*” following the breakdown of her marriage, but that her current refusal to eat does not relate to this disorder.

Emma Sutton also queried the need for an “*urgent*” decision, given that P’s weight seems relatively stable at present, and she is willingly receiving IV fluids and vitamins, and has mostly “normal” levels<sup>[2]</sup>.

It appears that an independent expert consultant psychiatrist ([Dr Ty Glover](#)) was appointed following the hearing on Tuesday 5<sup>th</sup> April and that he was asked to assess P’s capacity and best interests.

He visited P in hospital the following day (Wednesday 6<sup>th</sup> April) and the court received his report in time for the hearing on Thursday 7<sup>th</sup> April (the first day I observed).

In his view P does not have capacity to make her own decision about CANH, and it’s in her best interests to receive it.

By this point, the court had also received a new capacity report from Dr B (and I think from Dr K too) saying that P had regained capacity to make decisions about CANH due to improvement in her physical health, the urinary tract infection having been treated. In Dr B’s view, there is no suggestion that P’s capacity was compromised except when she was delirious from infections.

From Thursday morning onwards, then, everything hinged on which way the judge – confronted with contradictory capacity assessments – would decide about P’s capacity to make her own decision about CANH.

If P can understand, retain, weigh and communicate information relevant to the decision, then – in accordance with the Mental Capacity Act 2005 – she has capacity to make that decision. The choice as to whether or not to consent to a PEG-J tube is hers, and hers alone. It cannot be forced upon her, even if (as her doctors say) she may die as a result of her refusal. If she has capacity to make her own decision, the court has no jurisdiction.

If, however, there is evidence that P cannot understand, retain, weigh and communicate information relevant to the decision, then it is the responsibility of the judge to make a decision in her best interests. That decision, it was pretty clear from the outset, would mean court-authorized CANH, likely with restraint, and subsequent psychiatric and psychological support to mitigate her distress at being treated against her will.

P objects to anyone else making the decision for her. She was in court throughout the two days of the hearing that I observed, appearing on screen from her hospital bed. She said clearly in court on Thursday: “*I feel that I am able to make decisions about my health*”, adding that she would accept support and “*guidance*” with decision-making.

Her family (a sister and both parents were in court) had informed the judge that – although they want her to have treatment – they know that P is an independent person and she would be “*fuming*” or “*seething*” if the decision were taken out of her hands.

## **Some background**

The Official Solicitor's two position statements gave some useful background about P and her life.

She's in her early thirties and was born with cerebral palsy, is a wheelchair user, and only has the use of her left hand. There's no clear psychiatric history. She's been treated for depression and anxiety, and a possible brief psychotic state in response to infertility treatment. For a long time, she's also had a "*dysmotility of her oesophagus and stomach*" (which will not improve). This means that treatment (i.e., delivering formula feed via the tube) would likely be long-term.

There is general agreement that she's now depressed, having recently suffered some significant negative life events. She'd been hoping to become pregnant via IVF and it became clear last year that has failed. Also in 2021, she separated from her husband and moved out of the marital home to live with her mother. And then she fractured her femur when she fell as a hoist slipped while her mother was transferring her.

She's lost a lot of weight during the three months she's been in hospital. That's because she's mostly declining to eat – not entirely, but enough to cause dramatic weight loss, and (possible) malnutrition and electrolyte imbalance. On admission on 4<sup>th</sup> January 2022, she weighed 59kg (just over 9 stone). By 22<sup>nd</sup> March 2022 she weighed 39.5kg (just over 6 stone). As the judge, Mr Justice Williams, said several times, that means that she's lost a third of her body weight over a three-month period.

I don't know why she's refusing to eat: she wasn't asked in court, and there is no explanation in the position statements I've seen. The expert psychiatrist in court said he'd found no evidence of fear of weight gain or body image concerns, nor is she actively suicidal or seeking to die (though he reported that she'd

answered affirmatively when he asked her if she sometimes felt it would be better if she just didn't wake up). There was mention at one point of P "*not communicating when she's asked why she's not eating*".

She does not see a problem with her weight and does not believe that her health (still less her life) is at risk from not eating. She has what she calls "*good days*" and "*bad days*" – and as it turned out, the first day of the hearing was "*a good day*" (said the barrister for the Trust) when "*she managed a lot of food*".

In the past, P seems to have been treated as having capacity in relation to CANH. A gastroenterologist who's been involved in P's treatment since 2015 provided written evidence to the court, which was referred to in oral argument. Back in 2015, P seems to have consented to insertion of a PEG-J tube. The following year, she refused reinsertion of a PEG-J after the initial one was accidentally dislodged, and she managed adequate nutrition over the following years, despite being intermittently troubled with various degrees of difficulty of swallowing, nausea, sickness and constipation, which were managed by the gastroenterologist and his team every four to six months.

This gastroenterologist's view was that P has always previously been accepting of treatment when it was really needed – such that now she either does not understand how unwell she is from a nutritional perspective, or she doesn't want to get better. Both of these, he says, are out of character for P.

**Thursday 7<sup>th</sup> April 2022**

**First Witness: expert consultant psychiatrist – P lacks capacity and forced treatment would not cause lasting harm**

The expert consultant psychiatrist, Dr Ty Glover, appointed by the Official Solicitor, gave evidence on the morning of 7<sup>th</sup> April 2022. He'd been appointed at very short notice, had been sent P's medical records but been unable to read them because "*the password didn't work*", and had squeezed in a visit to P on his way back home from a long drive to see another patient the Official Solicitor had instructed him to visit hundreds of miles away.

On arrival at the hospital, he'd found that Dr B, one of P's treating psychiatrists, was with her conducting *his* assessment, so he'd had to wait outside for his turn, and he'd talked with P's father while waiting.

In court, Dr Glover said that P has a "*genetic predisposition*" to suffering from a "*depressive disorder*", inherited from her maternal grandmother. The combination of some "*fairly tough*" life events and "*being vulnerable to anxiety and depression anyway*" makes it "*not surprising*" that (in his view) she's developed what he calls (referring to the [International Classification of Diseases \(ICD\) F33.3](#)) "*Recurrent depressive disorder, current episode severe with psychotic symptoms*".

He found P to have feelings of "*worthlessness*", "*lethargy*" and "*a lack of self-worth*". There is "*a lack of worth P gives to her life, the lack of future she sees*". He described one symptom of her depression as "*psychomotor retardation*": "*You ask her a question, like 'how are you feeling today' and there's an abnormally long pause before you get a response, and because I'm impatient I fill the gap and ask another question like 'has it been a good day?'. I asked her father, 'is that normal for her?' and he said, 'no, she usually chatters away'.*"<sup>[3]</sup>

He attributed her not eating to her depression: *“when you’re depressed you tend to go off food. I always think if I became depressed, that wouldn’t happen, because I quite like food – but she’s always had gastroesophageal problems, and she’s had difficulties in that domain before, in 2016”*.

Although he said she had psychotic symptoms associated with depression, when asked by counsel for P via the Official Solicitor (Pravin Fernando): *“Did you observe any psychotic features in P yourself?”*, Dr Glover said he had not. He seems to have been relying on what P’s father had told him in a conversation outside P’s door, while he was waiting to go in to examine her: *“Her father was fairly certain she suffered from hallucinations – seeing and hearing things that aren’t there. [Her father’s] evidence was so clear and compelling that I knew the diagnosis before I went in to see P”*. He believes that the *“almost certain presence of psychotic symptoms also undermines P’s capacity.... It’s very difficult to retain capacity in a psychotic world”*.

Dr Glover said he thought it likely that if P were treated against her will (with CANH and anti-depressants) she would likely regain capacity to make her own decisions about eating and drinking in about 8-10 weeks.

Until she regains capacity to make her own decisions, the proposed treatment plan involves restraint, the use of mittens to prevent her dislodging tubes, and a period of one-to-one nursing. Dr Glover did not think that forced treatment would have any significant or long-lasting impact on P. He thought the anaesthetic plan was *“very sensible”* (*“the use of anaesthetic drugs will really mitigate some of the acute emotional upset that would go with any operative procedure”*). He also emphasised the importance of family and nursing staff *“rallying around and helping”* which *“will minimise any significant psychological harm”* associated with having her wishes overruled. *“And then*



*you just have to hope that the nutrition is established and as her capacity comes back, she agrees with the feeding. The treatment panorama in 6, 8, 10 weeks' time might be completely different.”*

The judge summarised the situation by saying that *“everyone is agreeing that if she were her normal self, she'd be agreeing to the treatment plan, so I think when she gets better, she'd realise why it was done against her wishes. But is there any risk of her losing faith in her family?”*

*“If she goes back to who she was two-plus years ago,”* said Dr Glover, *“I think she would understand the roles people played in this and that people were trying to look after her – including her family”*.

The judge reflected that he was *“very conscious of P listening to this and how she will be conscious of decisions being made about her, rather than by her, and how that's going to affect her, going forward.”*

### **A significant intervention from P – “I am able to make decisions about my health”**

I got the impression that the judge was ready to make a decision at this point, based on Dr Glover's evidence.

But of course the consultant psychiatrist for the Trust disagreed Dr Glover on the matter of whether or not P has capacity to make her own decision about CANH – and the judge said to counsel for the Trust, David Lawson, that *“if you're relying on his evidence, I'll have to resolve the dispute between the two psychiatrists”*.

Counsel for the Trust said that the Trust was now “*minded to accept the evidence from Dr Glover*” (i.e. that P lacks capacity to make a decision about CANH), thereby clearing the way for the judge to go ahead and make a decision.

The judge checked that the Trust no longer wished to rely on Dr B’s evidence, and indicated (quite strongly) that this would enable a timely decision from the court.

*“In an ideal world, one would want to drill down into all of these issues in terms of evidence, but I was asked to list it for a one-day hearing as soon as possible. Mr Lawson, it’s your application, and it’s up to you how you put your case. If you’re now saying that you accept the evidence from Dr Glover, the court would not need to hear from Dr B. I found Dr Glover’s evidence reasonably convincing and I would see no particular reason to disagree with it unless there’s alternative expert evidence.”*

The judge pointed out that time constraints meant that if he was required to hear additional evidence on capacity he was “*not sure you’ll even get a decision on capacity from me today*”. It would be sensible (he said) to “*focus on what can be achieved today*” and if the Trust wants “*a decision that she should undergo this procedure as soon as possible, then something has to give*” – but it was up to the Trust to decide whether or not to call the doctors whose evidence was that P in fact has capacity to make her own decision: “*the ball is in your court*”.

I expected counsel for the Trust to decide not to call Dr B, and then a judgment.

At this point a family member (I think it was P’s mother) switched on her mike and announced, “*P would like to say something*”. (The judge had previously

made clear at the beginning of the hearing that P was free to address him at any time.)

P's invention was straightforward – and devastating for the course of action the court now seemed about to embark upon.

*“Just to make it clear,” she said, “Dr Glover saw me for literally half an hour, if that. To me, I don’t think that’s fair. Because how can someone’s opinion in half an hour be right?”*

The judge recognised the force of her interjection immediately: *“So you’d like me to hear from Dr B, would you? Because he’s got a different opinion. Dr Glover’s new on the scene, so if you want me hear from Dr B, I’ll do that”.*

The exchange between the judge and P (supported at times by P's sister who was with her at the bedside) went on for a few more minutes – and it was evident from the interaction what Dr Glover had meant by *“psychomotor retardation”*. There were long gaps in P's speech and she seemed to be struggling to find the right words, to the extent that the judge suggested (appropriately, I thought) that she might find it easier to tell her sister who could write it down and report back to him.

But rather than accept that suggestion, P asked *“So just run it by me what Dr Glover’s decision was?”*. The judge explained:

**Judge:** Dr Glover was saying you’ve been through a lot of life events with your marriage and IVF and being admitted to hospital, and that’s exacerbated your anxiety and depression, so you’re not who you usually are, and so you’re not able to make a properly informed decision about a PEG-J. And he thinks with the PEG-J being put in, you’ll get back to your normal self, but without the PEG-

J and nutrition, you'll find it difficult to get back to being your usual bubbly normal self. So, he thinks I should make the decision for you, and have the feeding tube put in. Does that make sense?

**P:** Can uhm (pause) can uhm (pause) can it be (pause). I feel (pause). I feel like uhm (deep sigh)

**Sister:** How do you feel? Go on.

(silence)

**P:** I feel that I am able to make decisions about my health – and day to day things – but I need guidance to do with my health.

**Judge:** Okay. I think Dr B thinks you can make decisions, but at the moment the big decision is about having the feeding tube put in, and I think what I'm being told is that sometimes you say it would be a good thing, and on other occasions you say no, and that's why it's being put into a court to decide whether you can make your own decisions. [...] Everything I've read supports the idea you need this feeding tube to get more nutrition put in and get you physically better. The question really is, should I take the decision or are you able to take the decision for yourself.

**P:** I don't feel like.... (pause). To me, uhm.... (pause). I do have good days and bad days. Some days I can eat and other days that's (pause)

**Judge:** That's part of the problem I think – getting the nutrition in you consistently to keep you well. A feeding tube would make sure you'd get the feed every day, instead of it being erratic.

**P:** To me, it feels I'm not underweight or overweight. I'm at a steady weight.

**Judge:** I've been told you've lost twenty kilos since you went into hospital, which is a lot of weight.

**P:** (speaks quietly to sister)

**Sister:** She wants to know how much that is in stone.

**Judge:** There are 2.2 lbs per kilogram so you've lost (pause) 44 lbs, which is 3 stone. So you've gone from 9 stone to 6 stone. Which is a LOT!

(Silence)

**Sister:** You understand you've gone down from 9 stone to 6 stone?

**P:** What's 6 stone?

**Sister:** What you weigh now.

**Judge:** Ask [Sister] what she weighs – or perhaps you shouldn't! Sisters shouldn't subvert each other like that.

**P:** (says something quietly while looking down at her body)

**Judge:** Did she say 'where's it gone?'

**Sister:** She's just looking at herself and said "oh!"

The judge then asked if it would be okay to talk to the lawyers again and P agreed, but asked him to return to engage with her again after that.

On resuming his address to the lawyers, the judge said, "*Well, that answers the question for us. I think Dr B ought to give evidence as P has raised a question about Dr Glover's knowledge of her*".

It was good to see that P's intervention could influence the course of the hearing in this way. The judge's response to her concern was an excellent illustration of putting P at the centre of decision-making about her.

### **Second witness: Dr B, treating consultant psychiatrist – P has capacity and forced treatment would be 'difficult'**

Dr B gave evidence based on having met P over the course of the last three months at least (he said) 6 and 7 times. He'd seen her several times in the week after her admission to hospital, because he'd been asked to decide whether she had capacity to make a decision about treatment for her hip fracture (he'd decided she did). Then he'd seen her a few weeks later to see if she'd benefit from anti-depressants, as she'd not been eating or sleeping well, and had found it difficult to be in hospital. He'd also discussed her case in multi-disciplinary team meetings and at the Ethics Committee, and had spoken with her mother.

At some point (the chronology wasn't entirely clear) he'd been asked to assess P's capacity to make decisions about a PEG-J and had initially concluded that she lacked capacity due to delirium associated with a urinary tract infection – but anticipated that she would regain capacity when she recovered.

He was then away from the hospital for a period ("*I myself fell ill with COVID*") and didn't see her until his return

In his most recent report, he describes her as "*brighter*" and concludes that she does have the capacity to make her own decision about the PEG-J.

He agrees with Dr Glover that P is depressed "*but I don't think it's severe, and I don't think psychosis is part of her depression... there have been other reasons for her to have psychotic symptoms which have been more transient*" (i.e., the

infertility treatment medication – bromocriptine, of which psychotic symptoms are a possible occasional side-effect – and, recently, the urinary tract infection which led to delirium that in turn led to psychotic symptoms). He also pointed out that some of the symptoms of depression are equally associated with being physically unwell – for example “*lethargy is very common in physical illness and so usually we call these biological symptoms and they are not counted as symptoms of depression*”.

The matter of diagnosis (“depression/adjustment disorder” vs. “severe depression with psychotic symptoms”) occupied quite a bit of court time. This was presumably because of what is often called the ‘diagnostic’ component of the capacity test: does the person have an impairment of, or a disturbance in, the functioning of, the mind or brain (whether permanent or temporary) ([s. 2\(1\)](#), [\(2\)](#) Mental Capacity Act 2005). But as Pravin Fernando said in his closing summary (see below), there is no requirement in the Act for the impairment of, or disturbance in, the functioning of the mind or brain to be tied to a specific diagnosis.

The judge addressed a crucial question – the extent to which P understands that her low weight is threatening her health and (perhaps) her life. This is information necessary to decision-making about the PEG-J. If she doesn’t understand the risks to her health of further nutritional deficits, then (irrespective of which diagnosis is correct, and insofar as either diagnosis constitutes an impairment or disturbance that causes her lack of understanding), she must be found to lack capacity for decision-making.

### ***Capacity unravelled***

This was the point at which the adequacy of Dr B's capacity assessment began to unravel for me.

P's capacity (or lack of it) is at the heart of this case. If she has capacity then the court has no jurisdiction. But it's impossible to know whether or not she has capacity to understand, retain and weigh information relevant to the decision that needs to be made if – as Dr B says – she hasn't actually been given that information.

**Judge:** One of the most striking things in your second witness statement is that P said she thought her weight is appropriate. Does that indicate a lack of understanding?

**Dr B:** Yes, it does.

**Judge:** We saw that earlier perhaps. (*i.e. when P spoke to the court*)

**Dr B:** She has not been weighed that often, or given information about her weight.

**Judge:** But a third of her body weight – 20k for a 60k person is pretty significant, and loss of any more weight may prove to be fatal.

**Dr B:** Yes.

**Judge:** (*reading from Dr B's report*) "She did not think her weight was problematic" – so again, she's not understanding the situation, because her weight is certainly problematic.

**Dr B:** Weight is certainly a problem. We have discussed nutritional quality. We didn't particularly focus on her weight.



**Judge:** If she doesn't understand that losing 33% of her body weight puts her life at risk, she needs to be disabused of any misapprehension about this pretty quickly. (*Reading from Dr B's report*) "If she goes down further she will have difficulties" – that doesn't suggest an appreciation of the risk to her life.

**Dr B:** Correct. One of the things we've noticed is she needs to take things slowly and gradually. At the point in time I saw her – I saw her in two chunks, morning and afternoon – I would personally have explored that a little bit more. But Dr Glover came in. I had a real rapport with P, but I had to curtail my conversation with her. She is not able to eat adequately, and she did say she is feeling the effect of not having enough nutrition. We didn't discuss the full impact, but the discussion was in that direction.

Counsel for P via the Official Solicitor, Pravin Fernando, picked up on this line of questioning in his cross-examination.

**OS:** One of the features of this case is that we understand P doesn't want to die. She says that consistently to professionals who ask her that question – but she also, in the same breath, says she considers that she's not underweight, or has no issues with her weight. How do you marry up these conflicting positions? Because on any objective view, her life is at risk because of the drop in her body weight.

**Dr B:** I think that has been our challenge here. I think that she does not want to die. What she wants to happen is to go back to her loving family. With regards to weight, I don't think she has been given the information about how much weight she has lost and what the impact is going to be.

**OS:** Well, isn't that fairly fundamental to your determination on capacity. Because in determining whether or not she has capacity to make a

decision about a PEG-J, you would need to know whether she understands what the impact is of the weight she has lost.

**Dr B:** (*Reiterates a variant of what he said previously about having discussed nutrition with P, rather than weight*).

**OS:** I don't mean to be flippant when I say this, but how are you able to put forward any positive statement about P's capacity when you're unsure about her understanding about her weight?

**Dr B:** Well, a PEG-J is a fairly technical thing. I have not given her all the necessary information – all the pros and cons of the operation – but broadly speaking I have explained to her why she needs it.

**OS:** You say, 'it was clear that she could consider that if she did not eat enough then she is likely to deteriorate' – you didn't explore that with P?

**Judge:** I think he said he didn't have the opportunity, because Dr Glover then came in, and he'd have spent more time with her if he'd been able to. You saw how P was today (*in conversation with the judge*). Was she similar with you?

**Dr B:** No, she was much more comfortable, much more eloquent. I think she's under pressure at this point. It's not unusual for her to get tongue tied, but this is distinctly different from when I saw her yesterday.

**Judge:** The reaction we saw was surprise- potentially one of surprise – when told she'd lost 3 stone in weight. Was that similar to her reaction to you?

**Dr B:** I didn't exactly put it to her how much weight she'd lost, but I have put it to her how different it is between now and where she was when she was well and happy.

Asked about the psychological impact of being forced to have treatment she doesn't want, Dr B said *"it is clear she would not want anything done against her wishes – anything at all. She did not like the naso-gastric tube. But if we can work with her, she will agree to it"*. He gave as an example the fact that she'd agreed to an x-ray after it had been explained to her and doctors gained her confidence.

And if she doesn't agree? *"That becomes extremely difficult. The tube needs to be there, and she needs to participate cooperatively in terms of nutritional input through the tube. If she did not have capacity and had to be treated against her wish, you have possibly heard about mittens, and that is the situation we would get into, and that is not a pleasant situation"*.

Pravin Fernando (for P via the Official Solicitor) asked, *"Do you think that your opinion [about P's capacity] is at present inconclusive, without having a further discussion with P about the impact of not going along with the PEG-J?"*.

David Lawson (for the Trust) asked: *"If you don't understand that you're critically underweight, you can't make decisions about nutrition and a PEG-J can you? That must be right, mustn't it?"*

Dr B had no satisfactory answer to either question (though he referred to P's right to *"take an unreasonable view"* on the matter).

The judge suggested that Dr B and the gastroenterologist who is recommending the PEG-J should *"talk it through, with the space and time to allow both of you to explore with her the options that she faces and then make a fully informed decision if she's able to."* The court needs evidence, he said, *"that there's been a very specific discussion with P that she understands the options – and if she*

*still doesn't want the PEG-J and everyone else thinks she should have it, then I will have to grapple with whether it's due to a lack of capacity."*

It was agreed that this discussion could happen the following morning, with the hearing to be continued in the afternoon, although – depending on the evidence needing to be heard – the judge could not guarantee a decision in that case before Easter.

The Official Solicitor was not very happy with this course of action and tried to short-circuit the process:

**OS:** There are two avenues – one is the course suggested, that the matter of capacity is revisited with Dr C [the gastroenterologist] and Dr B having this discussion with her – but we do have the evidence from Dr Glover that fundamentally she's unable to make these decisions.

**Judge:** If Dr Glover's evidence is accepted.

**OS:** We were about to proceed on the basis of Dr Glover's evidence

**Judge:** Well that's the danger of hearing further evidence, isn't it. It has an effect.

The case, said Pravin Fernando, had been brought on an urgent basis and *"we really do need to resolve this matter. We have grave concerns about it going any further than tomorrow"*. The judge responded that he would not be able to sit past 4.30pm the following day, and Pravin Fernando subsided: *"I don't think there's anything else I can say"*.

## **A closing interaction with P and her family**

Before closing for the day, the judge returned to P.

**Judge:** P, are you still with us.

**P:** Yes.

**Judge:** P, it's been quite a long day. The plan is for Dr B and Dr C to come and see you tomorrow morning.

**P:** Why?

**Judge:** To make sure that you understand what the plans are and what the consequences are if you have treatment and if you don't.

**P:** Who is Dr C?

**Judge:** The doctor who specialises in stomach problems and nutrition.

**P:** Which one is he?

**Judge:** I think he's here now. Dr C, perhaps you can turn your camera on.

*[Dr C appears on screen]*

**Dr C:** Hello. *(Holds up face-covering)* You'll see me with a mask on tomorrow.

Both parents (they are separated and were participating in the hearing from different locations) were also invited by the judge to speak if they wished to and both expressed scepticism that one more day of trying to explain things to P would make a difference.

P's father said *"Regarding them coming to see P in the morning, it won't make much difference... we've all been explaining it to her all the time.... Twelve*

*months we've been going through this".*

Her mother – crying, and clearly desperately concerned for her daughter – tried to explain a more complex situation than appeared to have been presented to the court: *“P’s problems began before all this... she doesn’t eat three meals a day anyway, prior to all this happening. I can’t get her to eat and drink at home. Before going into hospital, she went from a size 16 to a size 12 and she must be a size 6 now. Initially when she went in, she didn’t have any help at all with food – she has [medication] to help with stomach cramps and these weren’t given to P and when they were given, only intermittently.”*

The judge said (sympathetically) that he hoped to reach an “*end point*” tomorrow. Some arrangements were made for recording tomorrow’s capacity assessment. And since P’s sister couldn’t be with her tomorrow, her father agreed to be there with her.

The court would reconvene at 2pm the next day.

## **Friday 8<sup>th</sup> April 2022**

I missed the first 10 minutes of this hearing because (when I enquired) I was wrongly told by court staff to use the same link I’d been given the previous day, when in fact a new link had been issued. I realised there might be a problem when nobody admitted me to the hearing from the virtual waiting room and I emailed counsel directly asking for the link. Observers should not need to have to do this if the Court is serious about open justice.

## **Agreement on capacity and ways forward**

When I joined the hearing, I learnt that there was now a common position that P lacks capacity to make her own decision about CANH.

As her parents had predicted, the explanations offered by Dr B and Dr C that morning had been unsuccessful. P was unable to understand that she'd had rapid and significant weight loss, and so unable to understand the risks to her health.

Matters discussed included:

1. How psychiatric and psychological support would be provided to P to support her through the process of having treatment against her will (apparently there is no psychology service based within the hospital)
2. Evidence from Dr C about why a PEG-J was the best way of providing nutritional support for P (as opposed to a naso-gastric tube or PEG or jejunostomy)
3. Scheduling of the surgery – likely now to be after the weekend.

## **Final submissions**

### **For the Trust**

In his final submission, David Lawson said that the Trust's position now is that P lacks capacity to make her own decisions about CANH because of her depression and other factors identified by Dr Glover. She doesn't understand that she's lost so much weight, or the risks of that (including the risk of death).

The judge engaged counsel in some attempts to disentangle the two different diagnoses, and David Lawson said that whether P has 'depression' or 'adjustment disorder', either is an impairment of mind or brain and has

“*explanatory power for why she can’t understand, or retain or weigh*” the relevant information.

There was also a discussion about ‘fluctuating’ capacity and its relevance for P. Counsel

was particularly concerned that there should be no interruption of treatment during the three weeks of ‘refeeding’ – as would occur if P were said by Dr B to have regained capacity within a day, or week, of the PEG-J being inserted (in which case, of course, if she asked for the treatment to be removed, he would have to comply). Dr Glover’s estimate that it would take 8-10 weeks for P to regain capacity to make decisions about the PEG-J was mentioned several times.

According to the judge “*P has sadly been sustaining a diminishing lack of capacity over some period of time, and is now in general, usually, well below the capacity line, but it’s conceivable if the operation takes place and she starts to improve that there might be a day, or an hour, when Dr B might say ‘well she appears to have capacity now’ but if you were to go two hours later, she’d have lost capacity again. And I don’t want that to create a difficulty, but I’m reluctant to put a time scale on it. Overall, I think given that the diminution of capacity has happened steadily over some period of time, I think it likely that the regaining of capacity is likely to take some time as well and it’s certainly unlikely that she’ll regain consist capacity before we resume after Easter*”.

Counsel drew on the case of [Royal Borough of Greenwich v CDM \(Rev 1\) \[2019\] EWCOP 32](#) to make a distinction between ‘micro’ and ‘macro’ decision making capacity in relation to fluctuating capacity. In that case Mr Justice Newton considered how a person’s individual decisions about what to eat, and whether



or not to take insulin, had to be assessed in the context of their broader understanding of the management of diabetes. By parallel, it's impossible for P to make a capacious decisions about individual meals ('micro' decisions) if she doesn't understand her that her weight is too low and she's at risk of death (the 'macro' context). This was summed up by the judge as: *"You're saying that she doesn't have capacity in general for anything that falls within the perimeter of nutrition-related decisions"*.

In terms of best interests, P should be fitted with a PEG-J because *"she's a young woman with decades of life in front of her who is severely ill"*. He referred to her [Article 2](#) right to life and said *"there's so much to gain here from a clear management plan for restored nutrition"*. He acknowledged that this decision is contrary to P's wishes but hopes that *"as and when and if she returns to capacity she will come to regard this intervention more favourably"*.

The expectation is that the case will be back in court after the Easter break *"so details of the discharge plan and amount of support can be discussed"* (as the judge put it).

### **For P via the Official Solicitor**

Pravin Fernando began his closing submission by addressing what he called *"some confusion about the necessity for specific diagnoses"* in relation to the Mental Capacity Act 2005. The Act refers simply to *"an impairment of, or a disturbance in the functioning of, the mind or brain"* (2(1)). He added that the [COP 3 form](#) uses the same language and admits the possibility of this "impairment or disturbance" not arising out of a specific diagnosis, when it instructs the person completing it: *"Where this impairment or disturbance*

*arises out of a specific diagnosis, please set out the diagnosis or diagnoses here”.*

The judge intervened to comment that it’s *“always described as a diagnostic limb and a functional limb but perhaps that leads to an undue focus on the specific diagnosis rather than meeting the test of the section”*.

Pravin Fernando replied: *“There’s no requirement, My Lord, for there to be a DSM or ICD-10 specification. I think we can often focus on these things unduly. The point is when one steps back and looks at it from this viewpoint, it’s clear that P (in the view of the Official Solicitor) has an impairment of or disturbance of her mind, affecting her ability to make decision. I should say, for the avoidance of any doubt, that the Official Solicitor does accept the evidence of Dr Glover that P suffers from ‘severe depression with psychotic symptoms’. She is unable to make decisions about the PEG-J and nutrition as a consequence of that impairment. It’s as simple as that, My Lord, when you look at an individual who’s lost a third of her body weight, and barely recognises that, and clearly does not understand how to look after herself and keep herself well.”*

In terms of best interests, Dr C is clear (said counsel) that the treatment is urgent, and that any further weight loss would *“take us into disastrous territory”*. But in addition, *“day by day malnutrition makes the likelihood of the success of the intervention less and less”*. Counsel wanted the operation to fit the PEG-J to take place as soon as possible to prevent *“irreparable damage”* to P.

P’s psychological reaction to being treated against her will was also a concern.

**Counsel:** The concern is this. I'm trying to phrase this diplomatically. Dr B's evidence on capacity was, we say, somewhat wanting. His plan for psychological support is somewhat lacking. We don't want to delay this decision, but we want a plan that properly engages with contingencies, should P have an adverse psychological reaction to the PEG-J being put in. Obviously, we hope that's not going to happen, but it must be catered for.

**Judge:** What do you say is the appropriate mechanism for dealing with that? Obviously it's not going to be done at twenty past three on a Friday afternoon just before the Easter holidays.

**Counsel:** I hope Dr B, who I believe is still on the call, can give the court some assurance that he and his team, once the decision is made will properly engage with the task in hand. My Lord will be able to review that at some point in future should this matter come back.

**Judge:** Are you suggesting a review next week to check that all is being done that needs to be done – if the operation takes place on Monday as Dr C suggests is the more likely option. To see the fleshed out psychiatric and psychological care plan? Or is the Official Solicitor content with a recital that confirms that Dr B will work on this and put it in place.

**Counsel:** No, My Lord. We simply just want them to do it.

**Judge:** I got the impression that Dr B is committed to P and will do his very best to put a package together. Whether it's entirely within his gift, resource-wise, to put in place everything he'd like, is another question.

The judge was obviously concerned about the “*adverse consequences of going against a strong-willed person's expressed decision*” but hoped that when she

recovers she would “*reconcile herself to it as having been necessary*”.

Although he accepted that (based on evidence about P’s decisions in the past) that she would probably consent to treatment if she had the capacity to do so, he pointed that this observation: “*doesn’t answer the question of how you’ll respond to it being done against your will when you don’t have capacity; she can still be very cross, offended, feel violated by me taking a decision and things being done when she said she didn’t want them done, But as I understand it the family’s position, and everybody’s position, is that even if her reaction were at the worst end of the scale, still the benefits of her continuing to live outweigh the Insult to her autonomy of going ahead against her will*”.

## **Judgment**

A brief *ex tempore* judgment dealt with what the judge called “*the headline points*” (helpfully delivered at dictation speed).

I have given some detail here because the judge said explicitly that he did not intend to publish the judgment.

The judge summarised the facts of the case. He said that P has “*lived fully*” and “*made the most of life*”, despite trouble throughout her life with difficulties in eating and drinking, due to her physical impairments, mostly managed without need for a feeding tube. Last year the combination of failed IVF and the breakdown of her marriage (which would be difficult for anyone to deal with) led to deterioration in her physical and psychological health, and she then suffered a fracture of her femur which required her admission to hospital in January 2022, where she has been ever since. Although she was considered to have capacity to make decisions in relation to treatment of her femur during her

stay in hospital, she was not able to eat or drink sufficiently to maintain her weight, and declined medication, investigations and treatments. On 29<sup>th</sup> March 2022 Dr C, a consultant gastroenterologist saw her, was alarmed by her loss of body weight (of around a third), and thought it essential that an urgent application was made to the Court of Protection to insert a PEG-J to enable her to receive sufficient nutrition.

The issues that emerged over the course of the proceedings – said the judge – were (a) the question of P’s capacity to make her own decision and then (if she lacks capacity) (b) on the psychological aspects of the best interests decision to insert a PEG-J (the clinical need for a PEG-J being uncontroversial).

### **(a) On capacity**

The evidence from the psychiatrists on capacity finally led to an agreed position (“*but a position*” said the judge – “*I think I would have reached in any event, even if it had not been agreed*”) which is that P lacks capacity under the criteria set out in [s.3](#) of the Mental Capacity Act 2005.

*“The precise formulation of the condition that P is currently experiencing I don’t think is critical, but it’s agreed that P is suffering from depression. Whether one needs to say that meets any particular diagnostic criteria in DSM or ICD I’m not sure matters very much, but she clearly does suffer from depression. Whether that is properly described (as Dr Glover says) as “Recurrent depressive disorder, current episode severe with psychotic symptoms” or whether it is “depressive syndrome/adjustment disorder” doesn’t really matter. For my purposes, the combination of depression and hallucinatory features – whether they arise from the depression or from the impact on the functioning of her mind of infections or electrolyte imbalances*

*or nutritional deprivation [...] mean that for the purposes of the statutory test it is quite clear that she isn't able to make a decision for herself because she has an impairment in or disturbance of the functioning of the mind or brain. It's clear that she's unable to make the decision because there are deficiencies in her ability to understand some aspects relevant to the decision. I accept the evidence from her family, Dr C, and by extension the evidence from the nursing team, that there have been regular attempts to help her understand the extent of her weight loss and the implications of her weight loss and the implications of her refusal to accept nutrition for her health. While she seems to appreciate there is some consequence of this, she does not appear to appreciate that her life genuinely is at risk. And with only a couple of further steps down this road, her condition will become life-threatening, if it isn't already. And so, I'm satisfied that efforts have been made to give the information to her and that she's not been able to understand it. I'm also satisfied she's unable to use or weigh information relevant to the decision. I wonder at times having seen P on a couple of occasions whether she is in a position genuinely to communicate a decision – though I don't think that's the key here. So, in relation to whether P has capacity to decide about the PEG-J and the care and treatment plan thereafter, I'm quite satisfied that she does not. Looking at it from the other end of the telescope, an aspect that reinforces the correctness of that conclusion, is that Dr M – who's had long involvement with P – says that over the course of dealing with P, she's been able to recognise when she's needed surgical intervention, and he can't conceive of her declining to have the treatment necessary to sustain her life save by not understanding the information or being so depressed she's unable to make that decision. The unanimous view of family is they "want their P back" and this isn't their usual P. She's someone who likes to engage in life, has aspirations for the future – and the P they say they see now is very different to the P*

*they've known and lived with and loved for 30 odd years, until the course of these traumatic events in 2020 and 2021 took their toll on her psychologically.” (Williams J)*

### **(b) On best interests**

The judge reported the parents' view that “*if P had capacity, she would have seen the need for this procedure and would have agreed to it. They think that if it's undertaken against her will that she will come around to the idea that it was necessary*”. Nonetheless, he said:

*“Doing this against her own wishes is likely to add a further layer of psychological insult to her. However, in terms of the overall best interests decision, it's clear from Dr C's evidence, and from the family's to be fair, that P desperately needs this procedure to be undertaken; it's the only realistic route back to physical health and also the best opportunity for restoring her psychiatric and psychological health as well. [...] My concern (and that of others) is what impact would this have on P to do it against her will and how could the consequences be ameliorated? The benefit of Dr B's input is in ensuring that a psychological and psychiatric plan for managing this – albeit in in embryonic form at the moment – has addressed that. [...] So, overall, in terms of the holistic best interests decision, I'm quite satisfied that for medical reasons P should undergo the PEG-J procedures and the implementation of the care and treatment plan. And thereafter, although there will be some impact on her psychologically, it's clear that the benefits in terms of prolonging her life and restoring her psychological and physical well-being outweigh the psychological risks of this being imposed against her will. She will remain in hospital and will remain supported psychologically and psychiatrically... It seems reasonably clear that P's capacity has been diminishing for some*

*months in terms of what's been described as the 'macro' decision in relation to procedure and the nutritional plan, and that is going to endure for some weeks. There would need to be a significant improvement in her physiological wellbeing but also in her depressive condition for her to regain capacity on the macro-decision and that is likely to take some time [...]. The bare minimum Dr Glover thought was 3 weeks and more likely 8 weeks for the medication to have an impact on her functioning. In respect of her lack of capacity, this is likely to endure until there is a really significant improvement in her psychiatric functioning.”*

Working on the basis that P would not regain capacity before the next hearing in this case (after the Easter break), the judge made the declarations and orders sought by the NHS Trust – that she lacks capacity to make her own decisions about her medical treatment, that it's lawful to insert the PEG-J and to administer the care and treatment, and that any consequent deprivation or restriction of her liberty is lawful.

The PEG-J is likely be inserted on Monday, after the weekend.

## **Reflections**

One very important aspect of this hearing (for me) is that it implicitly confirms the fundamental right of people who do have capacity to make their own decision to refuse to eat and drink and to refuse clinically assisted nutrition and hydration. This was never explicitly stated in the hearing (or by the judge) but it's the basis for the whole application, in that if P had been found to have the requisite capacity, her refusal would have been respected.



The whole point of assessing whether or not P had capacity to make the decision for herself was to determine whether or not compelling her to have the PEG-J tube against her wishes was lawful. If she'd had capacity, she could not have been so compelled. Recent judgments have made explicit capacitous people's right to refuse to eat and drink and to refuse a feeding tube (e.g. Re PH [[2022](#)] [EWCOP 16](#)).

The right (capacitously) to refuse to eat and drink and to refuse CANH is so basic that it shouldn't really need to be affirmed – except that I've seen people wrongly sectioned for voluntarily stopping eating and drinking (with the stated intention of hastening death) with no evidence of mental illness and no reason to believe loss of capacity. And I've been told by health care professionals that permitting such refusals, and providing palliative care for people dying as a result, is akin to “assisting a suicide”.

Voluntary stopping eating and drinking (VSED) is sometimes chosen by people who want to control their own dying (e.g. because they are terminally ill and want to advance the time of their death) and unless there is reason to doubt their capacity to make this decision for themselves, their right to make these refusals must be respected. There is more information about VSED on several websites (e.g. [here](#)).

Second, this judgment affirms that when a person stops eating and refuses a feeding tube, it can be appropriate to consider whether they understand that they will lose weight, suffer malnutrition and eventually die as a result – because if they do not understand that, and do not actually wish to die, then – assuming they also have some impairment in the functioning of their mind or brain that ‘causes’ them not to understand this – they clearly do not have capacity to make that decision for themselves. In this case, P did not wish to

die. She did not understand that she had lost a third of her body weight, and did not believe her life was at risk. This is very different from the people I've known who chose VSED because (in their 80s) they had degenerative illnesses and actively wished to speed up the dying process and avoid what, for them, was a humiliating and protracted death. Respecting the right to refuse treatment (as Dr B was clearly concerned to do) must be modified when the person who wishes to refuse it lacks the mental capacity to understand the consequences of her refusal.

Third, it was useful to hear Pravin Fernando's clear and succinct account for why the so-called 'diagnostic' component of the capacity assessment (the requirement for P to have an "*an impairment of, or a disturbance in the functioning of, the mind or brain*" (s. 2(1) Mental Capacity Act) that "*causes*" her inability to understand, retain, weigh or communicate information relevant to the decision to be made) does not actually require a definite or fixed diagnosis. I have listened to a fair number of judges trying to determine which of the different diagnoses presented to them by different witnesses in court is the 'correct' one – and most have felt it incumbent upon them to decide this, despite the fact that any of the possible diagnoses would constitute "*an impairment of, or a disturbance in the functioning of, the mind or brain*" for the purposes of determining capacity. It doesn't seem to me that judges are necessarily best placed to make a determination between contested psychiatric/psychological diagnoses, or that it is actually required that they should do so. In this case, Williams J did not decide between diagnoses but simply accepted that either of them fulfilled the requirements of the Act. (Incidentally, it's very unusual – in my experience – for 'depression' to be the key diagnosis in a finding of incapacity and this case stands out for that reason too.)

Finally, I welcome the judge's recognition that being forced to have treatment you wish to refuse is likely to cause distress – even if, in the long run, you might come to see it as the right thing for your doctors to have done. Personally, I am horrified by the idea of being given medical treatment against my wishes, no matter how good the intentions of those delivering it, and no matter what I might think about the value of the treatment in the future. For me it would be a violation of my autonomy and bodily integrity. I would (literally) rather die. And so, I have written an Advance Decision to Refuse Treatment (an ADRT, in accordance with [ss. 24-26 Mental Capacity Act 2005](#)) which makes it unlawful for doctors to give me a medical treatment to which I do not or cannot consent. If, like P, I became depressed, refused to eat and drink, and refused a feeding tube then (supposing I were found to lack capacity to make my own decision), my ADRT would determine the outcome for me: no feeding tube could lawfully be provided. From what I have learnt about P, I don't think she would have wanted to make an ADRT like mine – but it's not that unusual to meet people who do. (For more information about refusing medical treatments in advance of losing capacity to do so, check out the charity [Compassion in Dying website](#).)

Many other people tell me they are concerned to ensure that they do receive medical treatment at a possible future point when they may have lost capacity and be refusing it. This is particularly so for people with recurrent mental health issues and fluctuating capacity – people who refuse, while sick, the very treatments they welcome when well. They don't want their incapacitous refusals to carry weight with doctors, as P's refusals did with Dr B. It certainly seemed as though P's parents were dismayed that P's refusals – which, for them, were clearly an outcome of her mental illness – were accepted as capacitous by Dr B. For anyone who envisages maybe being in such a

situation, who wishes to maximise the likelihood of receiving the treatment they are refusing, the Advance Statement (provided for in [s.4\(6\)\(a\)](#) Mental Capacity Act 2005) is a good strategy to adopt.

Suppose that P had written, in advance of losing capacity, something like: *“I have difficulties with eating and drinking due to my physical impairments and prefer not to have a feeding tube, but to eat and drink as much as I am able. That is a decision it’s important for me to make when I have capacity to do so. I recognise, however, that there might be a future time when I become depressed or anxious and unable to eat, without recognising the risk to my health and even to my life. If my life is at risk, please give me a feeding tube, even if at the time I am refusing one.”* This *“written statement made by [P] when [she] had capacity”* (s.4(6)(a) Mental Capacity Act) would go quite a long way towards supporting the doctors and the court with the difficult decision to give treatment contrary to P’s (current) wishes. This might be something P would wish to do in future. It’s something anyone who has an ongoing health issue might want to consider.

I have written before about [“advance requests for restraint and compulsory treatment”](#) in relation to a young man with psychological diagnoses involving hallucinations and suicidal ideation. When well, he wants to live and accepts kidney dialysis for his end-stage kidney failure. But when he relapses psychologically, he refuses dialysis and says he wants to die. In court, Mr Justice Hayden asked him whether, if he refuses dialysis in future when he is *“overwhelmed”* by his mental illness, he wants to be restrained and compelled to have it? He didn’t hesitate to say *“yes”*. And that’s what the judge ordered should happen. (See also [“Psychiatric survivors’ views on advance consent and](#)

[‘forced’ treatment](#)” for a legal analysis of how the law could better advance self-determination for people in this sort of situation).

I hope to observe the next hearing in this case when it returns to the court.

**Celia Kitzinger** is co-director (with Gill Loomes-Quinn) of the [Open Justice Court of Protection Project](#). She has observed more than 300 remote hearings in the Court of Protection since 1st May 2020.

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[1] Thank you to Pravin Fernando for sharing the Official Solicitor’s two position statements (prepared for the hearings on 5<sup>th</sup> April 2022 and 7<sup>th</sup> April 2022 respectively) on request and in a timely fashion. I requested but did not receive the position statements from the applicant Trust. As an observer, I was also disadvantaged by the judge’s decision that there should NOT be an opening summary to this case – a decision made on the basis of time constraints. This judicial decision made it much harder for me to follow the case as it unfolded during the hearing. In my view, if the Court of Protection is committed to open justice, judges do need to ensure that there’s an opening summary/orientation to the case. If an observer is willing voluntarily to devote (as I did) many hours to observing this case and writing a report of it, it would seem compatible with the court’s stated commitment to open justice to make a small contribution in the form of a 3-minute introduction for those of us who otherwise struggle to understand a case without any advance knowledge about it. This is especially important when a judge does not intend (as Williams J informed the barristers) to publish his judgment on BAILII. (I’ve also not been sent a transparency order for this hearing – although the existence of one, and the fact that the names of treating clinicians are covered by it, was mentioned during

the course of the hearing – so I have simply made an informed guess as to what it might require of me.)

[2] I think there must also have been a declaration that P lacks capacity to litigate these proceedings, since Pravin Fernando appears as litigation friend via the Official Solicitor, without the qualification “proposed” as attached to Emma Sutton at the first hearing.

[3] All quotations are as accurate as I can make them, given that we are not allowed to record court hearings: they are based on contemporaneous touch-typed notes but are unlikely to be verbatim.

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