Neutral Citation Number: **[2024] EWCOP 3**

Case No: 14199484

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 25/01/24

Before:

THE HONOURABLE MR JUSTICE HAYDEN

- -

Between:

GUP

Applicant

-and-

(1) EUP
(BY HER LITIGATION FRIEND, THE OFFICIAL SOLICITOR)
(2) UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

Respondents

- -

Mr GUP (as a Litigant in Person) **for the Applicant**
Ms Bridget Dolan KC (instructed by the Official Solicitor) **for the First Respondent**
Mr David Lawson (instructed by Hempsons) **for the Second Respondent**

Hearing dates: 22nd – 25th January 2024

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Approved Judgment

This judgment was delivered in person at 14:45hrs on Thursday 25th January 2024.

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This judgment was delivered in public but a transparency order is in force. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family OR the parties must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

MR JUSTICE HAYDEN:

1. This is an application concerning EUP, a woman in her late eighties. Later in this judgment, I will consider what EUP's views may have been regarding her medical treatment. To try to evaluate this it is necessary for me to consider something of her life and the code by which she has lived it. EUP has plainly experienced a full and interesting life. Like all her generation, she was a child of the Second World War. The partitioning of India led ultimately to her and her husband settling in the United Kingdom. The couple was obviously happy and there were five children. They are a Hindu family and the traditions and customs of that religion and culture percolate, in varying degrees, and to different effect, throughout the entire family, as one would expect. One of EUP's sons has suffered from significant mental health problems and has lived all his life in the family home. He is now, as I understand it, in his sixties. Until latterly, EUP was his primary carer. The application has been brought by GUP, her youngest son. The family have plainly agreed that he should bring the application, which they all support, though with differing degrees of emphasis. EUP's life has not been without sadness or disappointment. In his early 70's, her husband developed dementia. EUP cared for him personally for as long as she could and even at the very end of his life took an active role in managing his condition. That illness and decline had a significant emotional impact on EUP and her son and, I strongly suspect, the whole family. From seeing their father as a strong and independent man, they saw him transform into somebody they did not recognise and who did not recognise them. By the end, he lost his ability to swallow. This is something I will return to because it highlights something of EUP's approach to death and terminal illness.

2. Though EUP declined, physically, with age and loss of mobility, she remained strong, cognitively. GUP told me in his evidence that though she rarely left the house, in recent years, she remained active, engaged and interested in the world. She enjoyed cooking. She managed the housework and had been an active gardener, sometimes taking on tasks which GUP worried were too much for her. He once discovered her moving a number of quite large bricks around the garden. As he told me this, he communicated to me, not only his concern for his mother's welfare, but an underlying delight with her energy and commitment. The recollection struck me as soothing to him. Happily, EUP lived at home with her eldest son and daughter throughout the pandemic.

3. EUP was hopeful for a grandchild. I sensed that with five children, she considered there to be a reasonable prospect of her becoming a grandmother. In her mid-eighties, however, EUP received the news that her daughter gave birth to a son. EUP's delight was unconfined and, despite her present parlous condition, communicates itself, almost palpably, through GUP's evidence. I am told that there is some confusion about EUP's date of birth and that the birth certificate might be inaccurate. Accordingly, I am simply going to refer to her as being in her eighties.

4. EUP has a history of bilateral severe strokes because of bilateral internal carotid artery severe stenoses (narrowing of intracranial vessels). Prior to her first admission to hospital on 21st October 2023, her "premorbid clinical frailty score" was between 5-6, meaning that she was "moderately frail". She has a history of osteoarthritis of her knees

which limited her mobility indoors (she required a frame to mobilise). She has a background of GCA (Giant Cell Arteritis) for which steroid therapy was given.

5. On admission on 21st October 2023, following a left Middle Cerebral Artery (MCA) stroke, EUP had difficulty finding words, dysphagia and right arm weakness. These were investigated and she was discharged home on 27th October 2023. Sadly, EUP was readmitted to the National Hospital for Neurology & Neurosurgery following an unwitnessed fall on 28th October 2023. While admitted, she suffered from recurrent infarcts (ischaemic strokes due to lack of blood supply). She initially received dual antiplatelet therapy (blood thinners) but because of ongoing stroke events she later underwent stenting of the left internal carotid artery (ICA). This was explained to be a procedure that carried significant risk and to be associated with further strokes.

6. There has been poor neurological recovery since the stent was inserted on 17th November 2023. I have not been able to identify a clear or consistent approach to EUP's care since that date. There has been increasing divergence between the growing hope of the family for some meaningful recovery and the view of the clinicians that comfort and dignity ought to be the focus of EUP's care, at what they assess to be the end of her life. Whilst these two perspectives of EUP's medical needs have diverged, I am concerned that the treatment she has received reflects a convergence between the two. In other words, the treatment plan has an air of compromise about it, a negotiation between the family and the medical team. There may, sometimes, be a place for that, but not if the person at the centre of it becomes marginalised. P (the protected party) must always be afforded care, which is identifiably in her own best interests. The family's views are relevant only insofar as they provide a conduit for P's own wishes and feelings. Families, however loving and well-meaning gain no dominion over their dying and incapacitous relatives. The family's role, which is crucial, is to promote and not subvert P's autonomy.

7. From 15th December 2023, it was impossible to deliver nutrition to EUP. She was, however, provided with hydration. It has been difficult to tease out the reasoning behind this approach. Ultimately, I have been unable to identify a cogent rationale. It reflects a compromise between the two different approaches identified above. Moreover, I do not consider it has been in the best interests of EUP. It is important, therefore, that I consider EUP's clinical history. In doing so, I can draw heavily from the statement filed in this application by Dr Robert Simister, a Consultant/Neurologist and Clinical Director for Stroke and Acute Neurology at the National Hospital. It is important that I identify from the outset that I have found Dr Simister to be an extremely impressive witness. He has engaged with all the questions put to him, whether supportive or challenging. He has displayed, in my judgement, both kindness and empathy towards his patient and her family. Where he has, occasionally, advanced views expressed by a collection of other professionals and found those conclusions wanting, he has unhesitatingly withdrawn from them. I have been greatly impressed by his integrity, in circumstances where others perhaps might have been inclined to obfuscate.

Clinical history

8. EUP was admitted to the National Hospital for Neurology & Neurosurgery on 21st October 2023 following a left Middle Cerebral Artery (MCA) stroke. Following her MCA stroke on 21st October 2023, she was treated with high intensity antiplatelet therapy but had recurrent left MCA territory ischemic events. Through her period of admission she had the highest possible protective treatment strategy. This treatment strategy was discussed during several MDTs by multiple consultants. Prior to the stenting procedure the ward team noted that EUP was aphasic (unable to express or comprehend language) and had complete weakness in the right arm with weakness also noted in the left arm and both legs.

9. On 17th November 2023, she underwent a left internal carotid artery stenting and was subsequently admitted to the ICU and was, at this time intubated and ventilated. This was a higher risk intervention which required a complex decision- making process. The family were, by Dr Simister's recollection, informed that the stenting procedure itself carried a risk of stroke. This was estimated at a likelihood of approximately 15% for poor clinical outcome and an additional 3% for mortality. GUP's recognition of these statistics differs slightly but not in any significant way. On the ICU the managing team recognised that EUP was not awakening following the procedure and accordingly, further brain imaging was requested and undertaken. This showed that there had unfortunately been further stroke events in both cerebral hemispheres following the stenting.

10. There was a clinic review on 27th November by the Attending Stroke Consultant, Dr Fiona Humphries. What was observed was a persistent low level of alertness was noted despite withdrawal of sedation. Further meetings between the ICU team and Dr Humphries, resulted in the family agreeing to extubation and transfer to the ward. There was no other option. I am satisfied that it was understood, at least by GUP, that this transfer would not carry with it potential for recovery and carried with it a high risk for intercurrent infection. EUP was discharged from ICU to the stroke ward, on 30th November 2023. When on the ICU, a nasogastric tube (NGT) had been inserted. It remained in place as it had been possible to insert it with direct vision and anaesthetic agents. Earlier attempts at direct insertion were unsuccessful. NG feeding and medication was continued until 15th December 2023 when it was documented that approximately a length of 17cm of tubing was below the level of diaphragm, and there was bending of the tube within the stomach with its tip appearing to at the gastro-oesophageal junction. In the course of treatment, the use of that tube became impossible, hence on 15th December 2023 the NGT was removed because it was displaced and no longer functional.

11. There were daily unsuccessful attempts at NGT insertions between 15th December 2023 and 21st December 2023, it was a distressing time for all concerned. For 7 days, every day, and sometimes twice per day, attempts were made at NGT insertion. There is clear documentation as to the extent to which these attempts were distressing, most particularly, for EUP. Not all, but some of the attempted insertions took place with the family in attendance. That must have been acutely distressing for them also. On 22nd December 2023, Dr Turner, another Attending Stroke Unit Consultant reviewed EUP.

He noted that there had been no change in the level of arousal or general function since the discharge from ICU. He records that the NGT insertions were unsuccessful and causing distress. Dr Turner was clear, as it must be stated, the entire clinical team are now clear, that EUP is in the final phase of life. Consideration of that review, on 22nd December 2023, led to the conclusion that it was in EUP's benefit, to stop the attempts to insert the NGT. It strikes me that no other humane conclusion could have been reached and I do not see, from the way the case has been presented by the family that they would take issue with this point. The focus of the plan became, to maintain EUP's comfort and dignity, predicated on the recognition that there was no neurological improvement. That decision, I am satisfied, was communicated to the family in clear and sensitive terms.

12. On 3rd January 2024, there was a clinical review by Dr Simister. He too identified no change in the level of arousal or function. There was no distress. Discussion on this date was held with the family in the presence of the Charge Nurse and Dr Jonathan Martin, Consultant in Palliative Care. The meeting updated the family on the level of function and then focussed on feeding. It was in this meeting, that the medical team explained, in clear terms, why it would not be possible for surgical treatments to be performed on EUP to introduce feeding via a tube through the abdominal wall or to insert tubes into the large veins. In consequence, focus returned to whether NGT insertion should be tried yet again. I am bound to say, I cannot see how, having regard to the history, this was thought to be in EUP's interests. It strikes me that it was undertaken to console the family. In any event, ENT guided insertion was arranged and performed on 4th January 2024. There has been an enormous range of specialists involved in EUP's care. The ENT specialist, Mr I, struggled but eventually placed the NGT, with direct visualisation of the back of the throat. This was recorded to have been *"a prolonged and distressing procedure",* to which I would add, as it had been on the many times it had been attempted before. Mr I noted that the NGT was persistently expelled from the oesophagus, despite initial correct placement. That presented a challenging clinical scenario and he drew from it, the conclusion, that there was some kind of *"functional obstruction"* that made the procedure very difficult. The NGT remained in position for 24 hours and then was spontaneously expelled into the mouth by EUP. No feeding was possible via this route thereafter.

13. Further meetings were held with the medical team and with the family. Following this failed final NGT insertion procedure, it was explained to the family that NGT insertion had been distressing, and that the NGT would not, in any event, change her prognosis. It was further explained that they could not secure a safe and reliable feeding route. Since that point, EUP has been based on the ward. She has received, what is manifestly, a very high level of nursing care. It is testimony to that care that there has been no ward based significant infections and no skin injury due to immobility. The team and the family are in agreement that there is no obvious distress in day-to-day nursing. Intravenous fluids have continued. These have led to some fluid overload, which has become manifest as swelling and oedema of the arms and legs.

EUP's mental capacity

14. There can be no doubt that EUP lacks capacity. It is recorded that from her admission on to the ward from 30th November 2023 to today, a typical level of arousal is that EUP will have eyes closed and make no sound even with unpleasant stimulation. She has periods of spontaneous eye opening which are recorded by staff as *"short lasting"* and predominantly reported at night. There is no account of any observation that she will direct her gaze to a visual target or away from visual threat. I have listened carefully to her son's evidence, and although he speculates more optimistically as to the potential to fix visual gaze, his description does not support his contention, nor am I satisfied that he believes that his mother can fix her gaze. There has been no observed episode of any directed limb movement. Prior to the stenting procedure, it was agreed that EUP was aphasic. This limited her ability to understand or verbally communicate her wishes on any question relating to her care. The bedside assessment, since the stenting, demonstrates that EUP has little or no interaction with her environment and is unable to non-verbally communicate her wishes.

Second opinions and Reviews from other specialties

15. The Trust has sought, rightly, second opinions from two Consultant Stroke Physicians. The first one was from Dr Maneesh Bhargava of North Middlesex University Hospital. Dr Bhargava is the Clinical Lead of the North Middlesex Stroke Service. A further second opinion was elicited, on 3rd January 2024, from Dr Adam Webber, Clinical Lead of the Barnet General Hospital Stroke Service on 18th January 2024. Dr Bhargava's view was that feeding would be inappropriate and that EUP is in final weeks of life. It was his view that EUP should be kept as comfortable as possible.

16. Dr Webber was also of the view that there is no prospect of EUP making a meaningful neurological recovery. He too, thought it appeared as though she is nearing end of life. Dr Webber expressed the view that there is a high risk of her being in pain, discomfort and suffering. All the surrounding evidence that I have referred to, supports and corroborates that opinion. In view of that, the main motivation of any medical interventions should be directed at symptom support. He was clear that it would not be appropriate, in his opinion, to pursue enteral feeding either PEG, RIG or surgical gastrostomy, nor TPN. This, he was clear, would only serve to generate burdensome side effects without changing her prognosis. It is this that has been the central issue for the family. In line with the emerging philosophy of EUP's care plan, she was reviewed on 17th January 2024 by Dr Mike Young, Consultant in Elderly Care at UCLH. I have been taken by all, to Dr Young's observations. Dr Young's review of EUP took place in the presence of the family and spoke at length with the family following this assessment. However, what is striking about his report is that he was alarmed that the intravenous fluids were beginning to cause potential distress with respect to the limb swelling. He confirmed that feeding was not possible and recommended that care is to be focussed, palliatively, at the final stage of life. In the statement that he provided at short notice, Dr Simister emphasised Dr Young's observations on this occasion. Dr Simister is emphasising that Dr Young, at the very least, was flagging up that the intraveneous fluids were likely to be of *"dubious benefit"*. Expressly, Dr Simister noted that the fluids were actively appearing to cause harm. I find this incredibly troubling.

Dr Simister confronted the question with the integrity I have already found to be characteristic, as to why this was thought to be in EUP's best interests at all. In my survey of this clinical picture, I must, for completeness, incorporate two further views. First from the nutrition team.

17. The Nutrition Team input has been provided on several occasions since January 2nd 2024 and the decision made by the Nutrition Team that surgical insertion of a feeding tube into the stomach or insertion of a tube into the veins would not be appropriate was documented in the notes on 4 January 2024 and this judgement has been further confirmed on the MDT meeting of 23 January 2024.

Review from Dr Cormac Magee

18. There was a further review by Dr Magee, on 19 January 2024, which confirmed this position and also confirmed that further NGT placement would also not be appropriate given the ongoing status of EUP. His report sets out, in some detail, the explanation the unacceptable risks that would be associated with gastrostomy tube insertion. He also explained that parenteral nutrition (known as TPN) would be particularly hazardous generating, as it does, elevated risks for sepsis and vessel clotting. The statistical possibilities of this strike me as irrelevant to the evaluation as to whether this course should even be tried, given that it would not alter EUP's prognosis. In simple terms, there would be burden without benefit and risk of a painful and difficult death. Due to the challenges of placing a central line and because of the expectation that EUP would need to move back to a high dependency environment for daily and sometimes multiple daily blood testing. Dr Magee noted that the typical indications for TPN in patients with limited life expectancy are covered by national guidelines and require either excellent performance status or expected life expectancy greater than 3 months, neither of which is the case for EUP. All feedback from these assessments has been shared on several occasions with the family.

The present position

19. Dr Simister, in his evidence, has told me that there is no clinical potential to restart provision of artificial nutrition in an ethical way. As I have emphasised, intravenous fluids have continued to be provided, whilst these have ensured some degree of hydration and alertness, they have also caused significant limb oedema and swelling. It is accepted that risks of further stroke acquiring infection or irreversible salt/electrolyte imbalance remain unchanged with or without nutritional support. It is anticipated that, inevitably, one of these risks will cause EUP's death in the coming days.

20. In his witness statement, Dr Simister stated as follows:

> *"It is understood that the continuation of the intravenous fluids has helped to prolong life but has caused significant issues with limb swelling secondary to oedema. The care plan set out for EUP has been discussed with and is supported by all members of the Acute Stroke Unit consultant team (Dr Humphries, Dr*

> *Saber, Dr Turner and Dr Sen) and by Dr Benjamin, Dr Perry and Dr Simister who are consultants in the wider stroke team. The Acute Stroke Unit Multidisciplinary Team has supported this care plan on a weekly basis through the admission on David Ferrier, The current plan is supported by consultant experts (Dr Young, Dr Willsmore, Dr Magee) within UCLH and stroke experts based at North Middlesex Hospital (Dr Bhargava) and Barnet General Hospital (Dr Webber).and all clinicians consulted, both internal and external agree with the clinical view".*

21. As I have foreshadowed, the medical team is aware that ongoing intravenous hydration is causing limb swelling, increases the risk of skin break down and makes cannula resiting more difficult and distressing. The intravenous fluids are likely to be prolonging life but will not change final outcome. In his oral evidence, Dr Simister told me that having communicated more widely with his colleagues overnight, the only identifiable 'benefit' of the hydration is to maintain a level of alertness. It has no impact on symptom control, indeed, this can be done more effectively by alternative strategies such as moistening of the mouth and tongue. The swelling has caused stretching of the tissues, as well as tearing. It is difficult to insert the cannula which requires to be replaced regularly. GUP agrees that this is, at best, every two or three days, but sometimes more frequently. Resiting has become difficult and uncomfortable. One of the clinical team has noted crepitations in EUP's chest, bilaterally. This, he suspected, to be caused by a leakage of fluid into the lungs, consequent upon the hydration related oedema. This was causing EUP to struggle and cough. Based on his working hypothesis, the doctor treated this with a diuretic. At risk of stating the obvious, the diuretic was intended to dispel the fluid, that is its job. It was successful. The fluid was expelled. In these circumstances, it is reasonable to conclude that the leakage into the lungs is related to the artificial hydration. In my judgement, GUP, who is an articulate and intelligent man, who has navigated these proceedings and the range of views within his family, regarding his mother's treatment with skill and sensitivity, also recognises the force of this analysis. He told me that if driven to choose between the provision of nutrition or hydration, he would choose nutrition. He reasoned that the concomitant hydration involved in the provision of nutrition might reduce the risk of swelling and oedema. This struck me as an intelligent hypothesis and Dr Simister, when it was put to him, did not discount it. It is perhaps convenient to say at this point, that I have been enormously impressed with GUP's integrity. I think his evidence on this point illustrates it. I heard from his twin sister, HUP. It was clear that she loves her mother greatly but I found her to be oppositional and angry towards the clinical team in a way that is unproductive for all concerned. Anger is a recognised facet of grief and sadly, the onset of grief does not await death itself. I emphasise that I do not condemn or criticise her, but I do strongly encourage her to make what I am satisfied are the last days or weeks of her mother's life as comfortable as possible and free from conflict. I have no doubt that she has the capacity to do so.

22. GUP has struggled to accept the fact that Dr Simister and the Nutrition Team have been clear that there are no options for tube insertion in the stomach (a gastrostomy) because of extreme risks with insertion, risk of skin breakdown at the site, distress incurred during insertion and post insertion monitoring. These risks extend similarly to the provision of total parenteral nutrition (TPN). The Nutrition team and the expert assessors have all been clear that there are no options related to repeated NGT insertion. This is because of the clear evidence that repeated insertion would be unlikely to secure a meaningful feeding route and because of well documented evidence of the distress caused by insertion attempts.

23. EUP has a devastating series of strokes leaving her profoundly disabled with obvious injury to language and limb function, even before further stroke events post stent insertion in November 2023. The November stroke has been described as *"massive"* by Dr Simister, and given his obvious expertise and experience, it is not a phrase that he will use lightly and reflects the real extent of these catastrophic injuries. Whilst GUP and HUP and, I am told, a number of their friends, have seen eye movements which they believe were not observable a few months ago, the extent of the brain damage and the broad neurological clinical picture provides no foundation for any hope that EUP will survive or recover in any meaningful way. I accept what GUP says about the changes in his mother's eye movements. He has questioned himself, properly, as to whether these can bear the significance that he wishes to attribute to them. This, he tells me, is why he has solicited the observations of friends. Dr Simister and the treating clinicians have not observed this change. Inevitably, they do not spend anything like the time that GUP and HUP do with their mother. Both stay with her regularly overnight at the hospital. Indeed, as I understand it, for the last two weeks, they have both stayed there every night. The nursing staff do not appear to have seen these changes either. They, of course, spend far more time with EUP than the Consultants do and so I attribute some significance to the fact that they have not seen these changes. Nonetheless, I am prepared to accept what GUP says but I do so on the basis that EUP's opening of her eyes must be infrequent (otherwise, the nurses would have noticed it). Dr Simister was prepared to take the same approach.

24. The extent of the irreversible damage, over every hemisphere of the brain, comprehensively discounts the possibility of the kind of neurological recovery that the family would wish for. Such "improvements" as may theoretically be possible, at the margins of consciousness, cannot accurately be described as "meaningful" in the sense of engagement with the world. With real candour, GUP tells me that if something like her present condition is all that can be achieved, he does not think his mother would wish to live in this way. He does not accept the poverty of the prognosis and argues that some form of nutrition should be provided to his mother. As Mr Lawson puts it in his written closing submissions:

> *"A difficulty with the applicant's case is that they want nutrition to be given but defer to the medical team on how to do this. The medical advice is clear, unanimous and long-standing: there is no viable way to give nutritional support. Believing that it is for*

> *the clinicians to decide how to do something makes it difficult not to change view when they say that there is no proper way to do it.*
>
> *There were daily attempts to place an NG tube in December and a lengthy attempt on 3 January, which succeeded but only for 24 hours and nutrition was not successfully provided in that time. This led Dr Simister to conclude that "the NG route would not be a reliable feeding route". Placing the tubes caused distress. This overall view seems beyond sensible dispute. Drs Benjamin and Flanagan made the same points on 6 January.*

25. Dr Simister concludes:

> *"In accord with all the provided opinions I judge that the lack of any meaningful change in neurological state in the two months since stent insertion and the last known stroke, further emphasises the likelihood of death within the coming days secondary to intercurrent infection or further stroke. In accord with all the provided opinions all options for repeated NGT insertion have been exhausted. In accord with the recent specialist opinions I recognise that the ongoing intravenous fluid administration may potentially cause problems with skin break down, limb pain due to swelling and painful cannula insertion. In accord with all provided opinion I judge that if there becomes a situation where the team or the family are noted active distress then the management of the cause of this should take precedence. In accord with all provided opinion I judge that EUP is in the last days of life".*

26. It is also important to highlight the conclusions of Dr Adam Webber, Consultant Geriatrician and Stroke Physician at the Royal Free London NHS Foundation Trust:

> *"There is already evidence clinically, of intravenous fluids causing harm, including gross peripheral oedema as well as significant chest crepitations suggesting pulmonary congestion. In view of this, the main motivation of any medical interventions should be directed at symptom support. It would not be appropriate, in my opinion, to pursue enteral feeding either PEG, RIG or surgical gastronomy, nor TPN, which would all cause unacceptable side-effects without altering her prognosis. Whilst it is difficult to predict the exact prognosis in terms of life expectancy, it seems as though she is in the final stage of life and we should therefore concentrate on ensuring comfort and dignity rather than any interventions which would prolong her suffering and the dying phase (which would not prolong life of meaningful quality)."*

27. The law in this sphere is settled and relatively easy to state. The application of it, however, is always intensely difficult involving, as it invariably does, the intersection of ethics, medicine, the law and, not infrequently, religious belief.

28. In *Burke v General Medical Council* [2005] EWCA Civ 1003 [2006] QB 273 the Court of Appeal described the general position as follows:

> *"(i)* ***The doctor, exercising his professional clinical judgment, decides what treatment options are clinically indicated (i e will provide overall clinical benefit) for his patient****. (ii) He then offers those treatment options to the patient in the course of which he explains to him/her the risks, benefits, side effects, etc involved in each of the treatment options. (iii)* ***The patient then decides whether he wishes to accept any of those treatment options and, if so, which one****. In the vast majority of cases he will, of course, decide which treatment option he considers to be in his best interests and, in doing so, he will or may take into account other, non-clinical, factors. However, he can, if he wishes, decide to accept (or refuse) the treatment option on the basis of reasons which are irrational or for no reasons at all. (iv) If he chooses one of the treatment options offered to him, the doctor will then proceed to provide it. (v) If, however, he refuses all of the treatment options offered to him and instead informs the doctor that he wants a form of treatment which the doctor has not offered him, the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (i e he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion." (emphasis added)*

The court's role where a patient lacks capacity to consent to medical treatment

29. Lord Stephens, in *A Local Authority v JB* [2021] UKSC 52 [2022] AC 1322, described the relationship between the MCA and the Court of Protection as follows (at [47]):

> *"The MCA defines the powers of the Court of Protection. In essence the Court of Protection has the power to decide whether a person lacks capacity to make decisions for themselves, and, if they do, to decide what actions to take in the person's best interests."*

30. Baroness Hale, in *Aintree v James* [2013] UKSC 67 [2014] AC 591, described the questions for the court as follows:

> *"18. ...[The court's] role is to decide whether a particular treatment is in the best interests of a patient who is incapable of making the decision for himself.*

> …
>
> *19. … Generally it is the patient's consent which makes invasive medical treatment lawful. It is not lawful to treat a patient who has capacity and refuses that treatment…*
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> …
>
> *22. [T]he focus is on* ***whether it in in the patient's best interests to give the treatment, rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it****…" (emphasis added)*

Presumption in favour of approving life-sustaining treatment powerful but not absolute

31. There is no obligation on a patient with decision-making capacity to accept life-saving treatment, and doctors are neither entitled nor obliged to give it. As set out by Lord Brandon in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1:

> *"a doctor cannot lawfully operate on adult patients of sound mind, or give them any other treatment involving the application of physical force ... without their consent', and if he were to do so, he would commit the tort of trespass to the person"*

32. In *Aintree v James* [2014] AC 591 at §§35 - 6 Baroness Hale stated as follows:

> *"35. The authorities are all agreed that* ***the starting point is a strong presumption that it is in a person's best interests to stay alive****. As Sir Thomas Bingham MR said in the Court of Appeal in Bland, at p 808, "A profound respect for the sanctity of human life is embedded in our law and our moral philosophy".* ***Nevertheless, they are also all agreed that this is not an absolute. There are cases where it will not be in a patient's best interests to receive life-sustaining treatment.***
>
> *36. The courts have been most reluctant to lay down general principles which might guide the decision.* ***Every patient, and every case, is different and must be decided on its own facts.*** *As Hedley J wisely put it at first instance in Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 FLR 21, "The infinite variety of the human condition never ceases to surprise and it is that fact that defeats any attempt to be more precise in a definition of best interests" (para 23). There are cases, such as Bland, where there is no balancing exercise to be conducted. There are cases, where death is in any event imminent, where the factors weighing in the balance will be different from those where life may continue for some time." (emphasis added)*

33. In *North West London Clinical Commissioning Group v GU* (Rev1) *[2021] EWCOP 59*, I made the following observations:

> *[63] Though it is an ambitious objective to seek to draw from the above texts, drafted in differing jurisdictions and in a variety of contexts, unifying principles underpinning the concept of human dignity, there is a striking thematic consistency. The following is a non-exhaustive summary of what emerges:*
>
> *1. human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
>
> *2. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;*
>
> *3. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*
>
> *4. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
>
> *5. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*
>
> *6. compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.*
>
> *[64] Thus, whilst there is and can be no defining characteristic of human dignity, it is clear that respect for personal autonomy is afforded pre-eminence. Each case will be both situational and person specific. In this respect there is a striking resonance both with the framework of the Mental Capacity Act 2005 and the jurisprudence which underpins it. The forensic approach is 'subjective', in the sense that it requires all involved, family members, treating clinicians, the Courts to conduct an intense focus on the individual at the centre of the process. Frequently, it will involve drilling down into the person's life, considering what he or she may have said or written and a more general evaluation of the code and values by which they have lived their life.*

Best interests

34. Where a person is unable to decide for himself, there is an obligation to act in their best interests: s.1(5) MCA 2005.

35. Where a decision relates to life-sustaining treatment, the person making the decision must not be motivated by a desire to bring about death: s.4(5) MCA 2005.

36. When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence their decision if they had capacity, and to the other factors that they would be likely to consider if they were able to do so: s.4(6) MCA 2005.

37. Account must be taken of the views of anyone engaged in caring for the person or interested in their welfare: s.4(7) MCA 2005.

38. Carers, including health professionals, are permitted to carry out acts in connection with personal care, health care, or treatment of a person who lacks capacity to consent: s.5 of MCA 2005. It provides a significant degree of protection from liability, provided that the act is done in the reasonable belief that capacity is lacking and that the act is in the person's best interests.

39. The provisions of ss.15 to 17 MCA 2005 give the court power to make decisions about personal welfare and to make declarations and orders in respect of a person who lacks capacity. Section 15 deals with declarations, including declarations as to the lawfulness or otherwise of any act which has been or is to be done. Section 16 enables the court, by making an order, to make personal welfare decisions for a person without capacity, and, by section 17, the court's power in this regard extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care.

40. Section 16(3) MCA 2005 makes it clear that the court's powers under section 16 are subject to the provisions of MCA 2005 and, in particular, to section 1 and to section 4. What governs the court's decision about any matter concerning personal welfare is therefore the person's best interests.

MCA 2005 Code of Practice

41. The MCA 2005 Code of Practice ('**the Code**') issued under s.42 MCA 2005 came into effect in April 2007. Chapter 5 of the Code titled '*How should someone's best interests be worked out when making decisions about life-sustaining treatment?'* includes the following guidance:

> *"5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold*

> *life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment".*
>
> *"5.33 ... Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests"?*
>
> *"5.38. In setting out the requirements for working out a person's 'best interests', section 4 of MCA 2005 puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account - whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests ..."*
>
> *"5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes)"*

42. I think it is important to this family that I confront the fact that somewhere within the fabric of this case is an instinctive recoil from a treatment regime that deprives their mother of the very basics of life, nutrition and hydration. It is not difficult to see how they might react in that way. She was, for them, a dutiful and devoted mother. She was plainly strong minded. She was uncompromising on her daughter's divorce, which she volubly disapproved of. Her approach, I suspect, was probably wrong, but undoubtedly well-meaning. She provided an upbringing for her family, which manifestly allowed their potential to flourish and find expression in their interesting and varied careers. GUP told me that he was a *"fussy eater"* and his mother would prepare dishes for him which were *"lamb and chicken based",* as he preferred. It is an instinct for mothers to provide their children with food, the first of which comes, for most children, from the maternal breast. Co-operation with a regime which requires the withdrawal from a mother of that with which she has provided for them throughout their lives is intensely painful to contemplate.

43. When EUP's husband was at the very end of his life, unable to swallow, in consequence of his advanced dementia, she was dogged in her determination that he should be provided with artificial nutrition. GUP, though himself traumatised, took another view. Insofar as this casts light on what EUP would have wanted, in her present predicament, it points to her being prepared to go to any length to hold on to life. However, GUP has also told me that if her present circumstances were all that was open to her, or something very like them, he did not think that his mother would want such a situation. GUP identified nothing in anything his mother had said to support this. I have more than a suspicion that it reflects his objective view of her circumstances and is not, strictly speaking, a reflection of his mother's views. I recognise the strain he faces. Ultimately, the evidence does not provide any clear indication of what EUP would have wanted other than every opportunity to see more of her children and grandchild. However, the providing of nutrition is not a medically ethical option nor, in my judgement of the available evidence, has it been for some time. It cannot be achieved without further burden and there is no prospect of it changing the prognosis. In any event, even if I were unpersuaded by the medical evidence, I certainly could not compel the doctors to undertake treatment contrary to their own medical ethics: ***R (Burke) v GMC*** [2005] EWCA Civ 1003, [2006] QB 273.

44. In relation to the question of hydration, Ms Dolan KC, on behalf of the Official Solicitor, makes the following submission:

> *"Given the above position the continued provision of hydration is, in the Official Solicitor's view, now prolonging a process of dying that is already well in train. The provision of IV fluid is of itself apparently causing harm by oedema. When asked for the rationale for its continued provision Dr Simister relied on the effect of it hydrating the mouth and avoiding that particular discomfort. However the evidence is that moistening of the mouth is achievable through other care. The Official Solicitor's position is that in [EUP] case giving IV fluid/glucose in the absence of providing nutrition can be properly construed as prolonging her death rather than preserving life. There are no other discernible benefits of IV fluid that cannot be achieved by other external means. To preserve her life in the hope of neurological recovery is unrealistic. The Official Solicitor's view is therefore of the view that continuation of IV fluid is not in EUP's best interests.*
>
> *Similarly given how likely it is that EUP in her present state would succumb to an infection even were antibiotics provided, the position of the Official Solicitor is that antibiotics should not be offered to her.*
>
> *There is, correctly, no dispute regarding the provision of CPR. The Official Solicitor accepts the evidence that it would serve no*

> *purpose and likely cause indignity and distress to EUP given the event precipitating a cardio-pulmonary arrest would be irreversible in her case".*

45. For the reasons succinctly set out in this submission and following my evaluation of the evidence above, I have come to the clear conclusion that neither provision of nutrition nor hydration is in EUP's best interests. In his evidence, Dr Simister was at pains to draw a distinction between artificial provision of nutrition and consuming food by eating. He told me that patients sometimes get to a stage when the desire for nutrition goes altogether. It is not experienced any longer as pain or starvation. He considers this likely to be EUP's situation and does not think that this will cause her pain. Furthermore, he points to the availability of an experienced palliative care team who will be able to ensure her comfort.

46. At this point, and I emphasise only at this point, I note that the evidence of each of the specialists instructed and those consulted in relation to the question of hydration is unanimous. Both the Trust and the Official Solicitor on behalf of EUP invite me to make declarations reflecting this analysis of EUP's best interests. I do so. I have appended the declarations to this judgment.

47. I know that this lengthy ex-tempore judgment is painful for the family to hear. Though I do not wish to protract it unnecessarily, it is important that I say something relating to the issues concerning the procedure that has been pursued in this case. The Official Solicitor expressly deprecates the fact that GUP was required to bring this application before the court himself. The consequence has been some procedural confusion which has generated delay and led to this case being listed in the urgent applications list. Inevitably, as a litigant in person, GUP had not identified in advance or in clear terms the relief he sought. The Trust had also failed to give sufficient thought to their obligations to their patient in relation to the hydration that she was receiving and which had been identified as delivering burden without benefit. The hearing, therefore, has been to some degree dynamic, however, as is clear from the above, GUP has advanced his case clearly and cogently and made it perfectly plain what he would wish to happen. I have found many of his questions to be insightful and well-constructed, as I have commented upon during the evidence.

48. In this case, the hospital had put in place a regime focused on palliative care. As I have identified above, this is undoubtedly in EUP's best interests, at least at the stage at which I am hearing the case. However, it was also clear that GUP and his family were never fully on board with that plan. It is certainly the case that there was a broadly co-operative relationship with GUP but I think it was equally clear that he had not accepted the medical consensus. The same applies to his sister, HUP. Who has expressed strenuous resistance to the hospital's plans at this hearing. GUP has told me that the hospital had indicated to him that they were to make an application to court to seek endorsement of their approach. I do not think this is in dispute. However, on 16th January 2024, the Trust confirmed to the family that they had been advised by their lawyers that it was not necessary for them to issue an application. The likely reasoning

behind this is that the Trust considered that there was no ethical route to provide nutrition to EUP. The family disagreed and saw this as passivity, with profound consequences. They perceived an important decision having been taken, even though the decision was to take no action. They considered that the Court ought to be able to review that decision making process and identify its own evaluation of where EUP's best interests lay. I agree with the family. A decision not to provide nutrition is every bit as serious as a decision to withdraw nutrition. Where there is conflict, these cases must be resolved by the court.

49. The preceding day, 15th January 2024 (Monday), GUP had made attempt to contact the out of hours duty High Court Judge. I am not clear what occurred on that occasion but I note that by the 18th January 2024, GUP had prepared a full application which was emailed to the court. On the Friday evening, 19th January 2024, GUP made a further out of hours application to Theis J who asked the Official Solicitor to speak to him. A representative of the Official Solicitor's office also provided him with details of solicitors specialising in this area of law. On 22nd January 2024, in the afternoon, GUP appeared before me in the urgent applications list. I ensured that the documents were sent to the Trust and listed the case for the following day. On the 23rd January 2024, as the application was plainly urgent, I began to hear it.

50. Ms Dolan submits that the practice guidance, which I issued in January 2020, then as Vice President of the Court of Protection, indicates that the Trust, in circumstances such as these, should bring the case to court promptly. Whilst that document is expressly stated to be by way of guidance only, it is rarely departed from in cases of this gravity. Had the Trust followed it, and at an earlier stage, it would have greatly alleviated the stress to the family. Ms Dolan goes further in her written submissions but I do not. Neither can I imagine that the lawyers advising this Trust were unfamiliar with the guidance. It has been widely promulgated, see also [2020] EWCOP 2. Where there is conflict in these serious medical treatment cases, it is in everybody's best interests, but most importantly P's, to bring an application to court. That will be most efficiently achieved where it is driven by the Trust's application. There are many and obvious reasons why it is also to the Trust's advantage to have their treatment plans, in cases such as this, scrutinised by the court.

IN THE COURT OF PROTECTION **COP 14199484**

IN THE MATTER OF THE MENTAL CAPACITY ACT 2005

AND IN THE MATTER OF EUP

BETWEEN:

GUP

APPLICANT

- AND -

(1) EUP

(by her litigation friend, THE OFFICIAL SOLICITOR)

(2) UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

RESPONDENTS

ORDER

THESE PROCEEDINGS ARE IN PUBLIC BUT SUBJECT TO A TRANSPARENCY ORDER. PUBLICATION OF ANY INFORMATION CONTRARY TO THE

TRANSPARENCY ORDER IN RELATION TO THESE PROCEEDINGS MAY BE IN CONTEMPT OF COURT. ANY PERSON FOUND IN CONTEMPT MAY BE FINED OR SENT TO PRISON.

IF YOU RECEIVE THIS ORDER YOU SHOULD OBTAIN A COPY OF THE TRANSPARENCY ORDER. READ IT EXTREMELY CAREFULLY. YOU HAVE THE RIGHT TO ASK THE COURT TO VARY OR DISCHARGE THE TRANSPARENCY ORDER.

BEFORE: Mr Justice Hayden sitting as a tier 3 Judge of the Court of Protection at the Royal Courts of Justice on 23, 24 and 25 January 2024

UPON hearing the applicant in person, leading counsel, Ms Bridget Dolan KC, for the first respondent (instructed by the Official Solicitor) and counsel, Mr David Lawson, for the second respondent

AND UPON reading the application, the witness statements of Mr GUP, Ms N, and Dr Simister and the exhibits to that statement, the position statement of the second respondent and written closing submissions.

AND UPON hearing from FUP and Dr Simister in person, and HUP by telephone.

AND UPON the Court having made a transparency order on 23 January 2024

IT IS DECLARED PURSUANT TO SECTION 15 OF THE MENTAL CAPACITY ACT 2005 THAT:

1. EUP lacks capacity to conduct these proceedings.

2. EUP lacks capacity to make decisions as to her medical care.

3. It is not in the best interests of EUP, and therefore not lawful, for her to:

a) be given life sustaining medical treatment (including clinically assisted nutrition and hydration provided by any means);
b) receive antibiotics; or
c) be subject to cardiopulmonary resuscitation in the event of cardiac arrest,

and any such treatment currently being provided may be lawfully discontinued.

4. It is in Mrs EUP's best interests to be given, and the responsible medical practitioners, nurses and health care staff may lawfully provide, such palliative treatment and medical and nursing care under medical supervision as may be appropriate.

IT IS ORDERED PURSUANT TO SECTION 16 OF THE MENTAL CAPACITY ACT 2005

5. The Court consents on Mrs EUP's behalf to the delivery of palliative and end of life care.

6. The end of life care of Mrs EUP shall be provided in such a way as to ensure that, as far as practicable, she retains the greatest dignity and suffers the least discomfort until such time as her life comes to an end.

IT IS ORDERED THAT:

7. There is permission to bring this application.

8. A copy of this order may placed on EUP's medical records and it may be disclosed to any person who is caring or may prospectively care for EUP.

9. This order shall take effect immediately notwithstanding it does not bear the seal of the court.

10. The second respondent shall pay 50% of the reasonable costs of the Official Solicitor of these proceedings, to be subject to assessment if not agreed, and there shall be no further order as to costs.

DATED 25 JANUARY 2024