Neutral Citation Number: [2021] EWCOP 59

Case No: 1375980T

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 11/11/2021

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

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Between :

NORTH WEST LONDON CLINICAL COMMISSIONING GROUP	**Applicant**
- and -	
GU	**Respondent**
(By his Litigation Friend, the Official Solicitor)	

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Mr Mungo Wenban-Smith (instructed by **Capsticks Solicitor**) for the **Applicant**
Ms Debra Powell QC (instructed by **the Official Solicitor**) for the **Respondent**
Ms Amelia Walker (instructed by **RPC Solicitors**) for the **Royal Hospital for Neuro-disability**

Hearing dates: 15th July 2021

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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THE HONOURABLE MR JUSTICE HAYDEN, VICE PRESIDENT OF THE COURT OF PROTECTION

This judgment was delivered following a remote hearing conducted on a video conferencing platform and was attended by members of the public and the press. 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 must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Hayden :

1. In April 2014 GU was enjoying his retirement in Thailand with his wife. He had been a very respected airline pilot and had achieved considerable distinction in his profession. He was 63 years old. On 14th April 2014 he decided to clean his pond. In the course of that task he began to examine the pump. Tragically, he had forgotten to switch off the electricity and he suffered an electrocution accident, possibly complicated by drowning. He sustained a cardiorespiratory arrest with a significant delay before cardiopulmonary resuscitation was started. He was admitted to a local hospital where a CT brain scan was undertaken which revealed no other intracranial lesion. GU was placed on a ventilator and remained there until 12th May 2014 until he had been gradually weaned off his ventilator. On that date he was transferred to a hospital in Bangkok, effectively as a staging post, to enable him to be transferred to the United Kingdom and eventually to the Royal Hospital for Neuro- disability (RHND). The transfer took place on 1st September 2014. It is important to emphasise that for the whole of this period GU had been unconscious with no behavioural signs indicating any awareness either of himself or his environment.

2. On admission to the RHND, GU was initially suffering with respiratory and chest problems, related to a long-standing history of chronic obstructive pulmonary disease, in consequence of heavy smoking. For the last five years GU has been medically stable. He was assessed by use of conventional standardised assessments. GU has been consistently observed and monitored by a highly specialist team of nurses and therapists. There was no evidence of awareness. All responses were either automatic or reflexive. There was no perceptible change.

3. In August 2018 a request was made, by GU's brother E, for a Best Interest decision concerning his Clinically Assisted Nutrition and Hydration (CANH). A meeting was held with the family on 16th March 2017, following which GU was referred, on the same day, to the palliative care team. The records reveal that there was discussion concerning *"ceilings of care"* and a *"possible end of life plan".* A care plan drafted in 2021 contains the following account:

> "*16th of August [year not stated but presumed to be 2018] regarding end-of-life care with the participation of brother [E], palliative care team and locum GP. The brother expressed that under new laws for palliative care, the life should not be sustained and all hydration, nutrition and medications should be stopped. The rest of the family does not agree with this new decision and therefore [GU] will continue to be cared by nursing staff. An advance care planning form was requested by the brother according to the plan in medical notes from palliative consultant."*

4. This note is not consistent with the evidence I have heard, nor the statements I have read. There is, in fact, only one family member, GU's son (A), who did not agree with the plan and for very particular reasons, which I will return to in detail. In any event, the apparent assumption that in the face of family disagreement *"therefore [GU] will continue to be cared for by nursing staff"* is a troubling non sequitur. Family dissent to a medical consensus should never stand in the way of an incapacitated patient's best interests being properly identified. A difference of view between the doctors and a

family member should not be permitted to subjugate this best interest investigation. The differing views are facets of a broad canvas which requires to be considered in their totality and, where necessary, by a Judge. To do otherwise is to risk silencing the voice of the vulnerable individual at the centre of the process. There can be no mediation of these issues where the needs of the protected person (P) are neither properly identified nor given the priority they require. Autonomy does not evaporate with loss of capacity. It may become harder to identify and evaluate but that is a challenge to be confronted not avoided. All this has concerned me and the Official Solicitor who represents GU by counsel, Ms Debra Powell QC. I requested that it be further investigated. What does seem to be clear is that GU's treating clinicians had come to the clear conclusion by August 2018, that GU was in a prolonged disorder of consciousness for which there had been no change or any prospect of future change. Treatment was both futile and, at least potentially, burdensome.

5. No formal best interest decision has ever taken place. On 14th December 2020 Professor Derek Wade, a consultant in neurological rehabilitation, was approached to provide an opinion to see whether he agreed with RHND that it would not be in GU's best interest to continue with CANH. Professor Wade understood that there was some dispute within the family and that litigation seemed to be likely. Unfortunately, the assessment was derailed by the Covid-19 pandemic. Whether the ensuant delay was unnecessarily protracted is properly queried by the Official Solicitor.

6. It was not until 19th March 2021, that it was possible for Professor Wade to visit. Professor Wade reviewed the notes, assessed GU thoroughly, and was also careful to speak to staff members who have treated GU for a number of years. Various family members also prepared statements and Professor Wade read them. In his report, dated 3rd May 2021, he expressed agreement with the opinions of the treating clinicians and set out his conclusions in unambiguous terms:

> *"I have concluded that he has been unaware of himself or his environment from the outset, and that there is no prospect of any recovery. He may live in this state for up to 10 years. I have reviewed the evidence from family members, which show convincingly that his past wishes would have been that he should not continue with life-sustaining medical treatment.* ***I have reviewed the statement from the dissenting eldest son, and this shows that he has a moral objection, personally, to the withdrawal of food and fluid from his father. He is not disputing any of the factual evidence.*** *(my emphasis)*
>
> *On this basis I have concluded that it is not in the best interests of [GU] to continue with clinically assisted nutrition and hydration. I am satisfied that the local team has the necessary expertise to provide all appropriate palliative end-of-life care."*

7. GU's medical history since his cardiac arrest has been carefully reviewed. There have been a number of infections, including hospital acquired pneumonia. His body has shown resilience. Paradoxically, the fact that he can no longer smoke led to a mild improvement in his lungs. On one occasion morphine was required for respiratory distress. It is not necessary for me further to extend this judgment with any greater detail concerning GU's general health. It is important, however, that I record the observations

as to GU's level of awareness. Professor Wade confirms the view of the hospital that from the outset i.e. following the accident, GU has never been reported as showing any kind of behaviour which could be construed as an indication of possible awareness.

8. There was a formal review undertaken on 29th October 2017. Preceding this, GU had been assessed applying the well-recognised criteria within the Wessex Head Injury Matrix. Additionally, he was assessed clinically during sessions in a sensory art group. Clinical observations were made during therapy sessions. The highest score on the Wessex head injury matrix was four i.e. attention held momentarily by dominant stimulus. The remainder of his responses were entirely automatic or reflex. He showed a low level of arousal, and usually required multiple prompts even to remain awake with his eyes open.

9. Formal assessment of GU's ability to communicate is stated as follows in the medical records:

> *"[GU] demonstrated a profound disorder of communication and did not show evidence of communicative intent verbally or nonverbally. [GU] was unable to comprehend, express himself by any means, and remains fully dependent on others to anticipate his needs and act in his best interests."*

10. It was summarised thus:

> *"[GU] demonstrated overall low responses to sensory stimuli. He demonstrated mainly reflexive responses to auditory stimuli, such as opening eyes and shoulder elevation when sound presented on both sides. He has demonstrated no response to visual stimuli on three out of four occasions and reflexive on one occasion. He demonstrated reflexive responses to tactile stimuli on two occasions. Also, he demonstrated a withdrawal response on one occasion. [GU] demonstrated no functional communication or functional use of his arms within the art group sessions.*"

11. Between 1stApril and 10th May 2019, GU underwent a further period of review. He was assessed five times, again deploying the Wessex Head Injury Matrix, and the highest recorded score was 22. However, this only occurred on one occasion, otherwise his score was never higher than four. A score of 22, I am told, equates to *"tracks a source of sound"*. This described as "*he was observed to move pupils towards the left in response to music being played on this side. This was difficult to interpret due to resting spontaneous movements of the pupils. He did not appear to localise to the right side or in response to other sounds.*"

12. A yet further period of assessment was undertaken between 26th October and 4th December 2020. This included four assessments, once again deploying the Wessex

Head Injury Matrix and again GU's highest score was four. His arousal levels were "low". The overall summary was that he "*demonstrated mainly reflexive, non-meaningful responses to auditory, tactile and visual stimuli in keeping with his presentation in a low-level Prolonged Disorder of Consciousness*."

13. The original score summary sheet for the observations made on the Wessex Head Injury Matrix, record a total of 13 assessments between 30th August 2017 and 19th November 2020, by a variety of different staff members, with individual assessments lasting between 20 minutes and one hour. On one occasion seven behaviours were noted, but otherwise no more than four behaviours and on all occasions bar one, the highest score was four.

14. All the staff on the ward see GU on a regular basis and in many different circumstances, none has ever noticed any suggestion of awareness. To this I would add that at least two of the nurses, one of whom is senior, have cared for GU for between 3 – 5 years. They have also been caring for him during the course of a pandemic where family members have not been able to enter the hospital. GU's family are scattered across the world and face the additional challenges of international travel in difficult times. When I visited, at the conclusion of the evidence, the two nurses caring for him described themselves as having been GU's family in his isolation. The nursing staff observations have to be placed in this intimate context.

15. Finally, Professor Wade added his own observations which confirmed GU's complete lack of awareness. Further, Professor Wade considered GU *"showed minimal responses"*. That led him to the following conclusion:

> *"I conclude that, beyond all reasonable doubt, [GU] has no awareness of himself or his environment."*

That conclusion could not be bleaker nor less equivocal. There is nobody involved in GU's care who disagrees with it. The family also accept it. E goes further and roundly endorses it. Nobody has suggested that there should be further investigations. The primary diagnosis is severe hypoxic brain damage. There is no alternative treatable diagnosis. There is no secondary subsequently developing complication that obscures the nature and extent of the brain damage.

16. GU is now 70 years old. It is common ground amongst the professionals that, at least statistically, he might live for another 10 years. It is equally possible that he might not fight off his next infection or perhaps suffer a sudden cardiac event. Professor Wade pays tribute to GU's medical and nursing care:

> *"His current medical and nursing management is clearly first class in that he has been kept alive, he is no longer suffering chest infections, he has not had any skin breakdown or other complications, he is not experiencing worsening contractures, and his weight has been kept steady and he looks not unwell."*

17. As I shall relate further below, I attended at the RHND to visit GU. Though I do not bring any expertise to bear, it struck me that GU was extremely well cared for.

18. It is also pertinent to note that it has already been agreed by everybody that there should be no cardiopulmonary resuscitation in the event of collapse nor treatment, in the event of any acute life-threatening illness. The sole decision requiring to be made is whether CANH, via GU's gastrostomy feeding tube is in his best interests.

19. The only individual who challenges the consensus is his son (A). His objections were powerfully articulated and moving both to read and to listen to. They are views which reflect a strong, deeply rooted and instinctive filial love. This is a father and son who were easy, open and spontaneous in each other's company. They would seek each other out and socialise together. I have heard that their conversations were hearty, broad ranging and sometimes liberally lubricated by whisky. GU embraced life to the full. All the family communicated this to me. Quite literally *"a highflier"*, he enjoyed nothing more than being amongst family and friends without formality or pomposity and chatting generally about life and, occasionally, football. I sensed there were more than a few late nights. It is this relationship that cast light on A's opposition to the prevailing view. A was asked to reduce his views to writing. It is obvious that he found that to be a valuable opportunity properly to process his thoughts and beliefs. I propose to set these out in some detail

> *"My view on the removal of my father's feeding and hydration tube has not changed since it was first raised in August 2018. I did not agree then and will not agree now to such a decision. There is nothing that will change my mind on this…"*

20. A cites the universal declaration of Human Rights to support the proposition that *"everyone has the right to adequate food, housing and medical care"*. He states:

> *"To deprive my father from this right is unbearable to accept. I believe if the situation was turned around, and one of his children was in hospital in his condition, my father will fight this as well. He would still have faith and hope, and forbid this. I am holding onto to the fact that my father has the right, which is being fulfilled at the moment, and that should be accepted by all. Being in the state that he is in, being cared for in a hospital and by nurses, he is not being a burden on anyone. When my father's time is up, he will go, but on his own terms, not ours to decide."*

21. He characterises his relationship with his father in moving terms:

> *"My dad was this really cool guy, a pilot who was very loyal to his company and to Jordan. He could have worked anywhere but he stayed with the company (Royal Jordanian) for 30 years. He was my best friend and my superhero. He gave us unconditional love with his family being his number one priority. We, his children always came first."*

22. In so far as GU and his son had discussed death A told me that he had always assumed, as a pilot, he would *"go out with a bang at 36,000 feet"*. His present circumstances are the polar opposite of what he contemplated. A puts it thus:

> "*Dad never discussed death with me, even when I was with him and he'd downed a bottle of whisky and was crying over his father's death. He didn't discuss the sort of state he's in now either. He always thought he'd die in a plane crash at 36,000 feet – go with a bang as you would say. I guess this sort of thing; you think it never happens to you but to someone else. The only time he said anything was when he was in a car crash in Thailand and his car rolled a few times, and he said to me, 'that he was ok. It could have been worse, but my time was not up."*

23. A has reflected on his position, in language which communicates both the intensity of his grief and depth of his loss:

> *"Maybe I'm being selfish and want to hang on to whatever is left of my dad. I don't know who would want to live like this? I'd love to pick up the phone and ask him, "I'm in this situation, what shall I do?', but I can't."*

24. Though A's position has not always been entirely consistent, he distils the core reasoning of his position in the following paragraph:

> *"When it came to not resuscitating him if his heart stops, that I had no issue with and I backed it 100%. If he was on a life support machine, I'd be the first to pull the plug. If my dad was on a machine keeping his heart and lungs going he would say 'pull the plug'. He is not on any machine or anything that is supporting him to stay alive. What he is being given, food and water, are the basics and right to have. I have been told there would be really good palliative care and that it can be peaceful and that I could talk to a palliative consultant, but it is not just that I worry that he would suffer. I've worked over in Africa, you can see a child there walking for miles to get a glass of water and here, in the UK, we'd deny water to my dad? People in the world are starving because they don't have enough money, and here, in the UK, you are going to starve my dad? Starving someone to death will take a long time, the body has to shut down. A vet would put a sick pet down quick and painless. Maybe he did say to some people 'If I'm ever like that shoot me' but ok shoot him, don't starve him."*

25. To my mind this is an instinctive, human and visceral reaction to what is perceived to be depriving food and water from a human being who is, in this case, *"a best friend and superhero"*.

26. It is, however, a mistake to equate CANH with the consumption of food and drink in the ordinary sense, where it is an intrinsic part of life, integral to health and survival. Nutrition and hydration which is "clinically assisted" is properly identified as 'medical treatment' (see: **Airedale NHS Trust v Bland [1993] AC 789**). It requires to be emphasised that the incapacitous patient receiving CANH is deprived of the choice to eat or drink. There is no exercise of autonomy. By contrast, in daily life, the consumption of food and drink frequently involves pleasure and conviviality. Not

uncommonly it is an expression of love. There is no mutuality, pleasure or love where nutrition and hydration are delivered by a gastrostomy feeding tube. CANH incorporates intravenous feeding by nasogastric tube, by percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy feeding tubes through the abdominal wall. It can be provided by intravenous or subcutaneous infusion of fluids through a 'drip'. All this can provide symptom relief or prolong or improve the quality of the patient's life, but equally, it may become burdensome or futile and serve only to extend life in its most vestigial sense, failing to achieve anything that might properly be identified as 'quality of life' for a patient in a prolonged disorder of consciousness. With equal legitimacy, to my mind, this can be viewed as protracting death.

27. A decision to stop eating and drinking often reflects a feeling of powerlessness. This may, for example, be a child using food to exercise tyranny or an individual facing dementia or terminal illness who simply decides to 'turn their face to the wall'. To impose nutrition and hydration on those who would not wish to receive it, particularly for those in the circumstances in which GU finds himself, is to risk suborning autonomy and compromising human dignity.

28. GU has been unaware of himself or the outside world for 7 years. No decision was taken as to his "best interests". His voice remained unheard for what many in this case regard as an unconscionable period. I regret to say, I agree with that view. Respecting human dignity in these circumstances can prove to be challenging and has been the subject of judicial discussion in a number of cases in recent years. The striking facts of this case require me to confront whether GU's dignity has been avoidably compromised and, more generally, how dignity may be evaluated.

29. Sometimes it is difficult to ascertain what a protected party (P) would have wanted, should he or she have found themselves in a prolonged disorder of consciousness, from which there could be no prospect of recovery. Family members, friends and work colleagues are often able to help cast light on P's likely wishes and feelings but sometimes, perhaps for reasons of P's temperament or convictions, no clues have been left. Happily, in this case, GU left nobody in any doubt at all that he would not want to continue in the parlous circumstances in which he finds himself. His views have been communicated consistently, volubly and unambiguously. They require to be recorded, not least because they lay unheeded for too long.

30. I heard evidence from E, GU's brother. He has also filed a statement in the proceedings. He emphasised: *"I do not believe he [my brother] would want ongoing life-sustaining interventions in his situation.*"

He stated:

> "*when my mother had Alzheimer's, towards the end, he expressed very strong views. He said things like: "for God's sake, if ever I get like this, take me out and shoot me"."*

He then goes on to record that they visited their mother on another occasion where:

> "*he again talked to a lot of us saying he would not wish to live like that totally dependent on others. He would say it was no life I would*

> *never forgive anyone who let me be like mum is now. He was like our dad in that way who also had strong views. [GU] understood what our dad did. A few years earlier, when our dad had a terminal problem, he basically opened all the windows in the lounge closed the doors, it was snowing outside and lay down naked on the sofa to die. [GU] was called the next day by my mom to deal with my dad dead naked on the sofa.*"

Later in the same paragraph he records:

> "*[GU] said I hope I have the courage of dad to do as he did if ever I was like that, facing slow debilitating death or worse loss of independence."*

31. He recalls another instance *"when [GU] was around 17 years and [E] was around 14 years"* visiting their grandmother who was bedridden and in a nursing home when "*we both agreed we would never wish to live like that and be dependent."* Much of the rest of the statement reviews the history of GU's management and a failure to consider his best interest at many points.

32. I have read the statement of RB (sister). This is dated 9th February 2020. It starts by stating "*[GU] would not want to be kept alive in his condition*." She explains this by stating "*I believe this because of the type of man my brother was.*" She described him as being somebody who liked to be talking to people, and that:

> *"he was an out-and-about the sort of person. His life was getting in the car, going into town, being on a beach, seeing things, going places.*" She also states "*when [GU] came over in 2013 to England because of my mum's dementia we were talking about things – he was very clear that he would not want to be around if he had dementia. He said things like "if I do not have my mental facilities there is no reason for me to be here".*

She also stated:

> *"if he could have his say now, he would be arguing with anyone who said he had to be kept alive. He would be saying, "we need to talk about it. No, it cannot happen, it is not fair on me"."*

33. Statement of NU, first wife. She was married to him for 17 years. She states:

> "*during that time, we had long, and deep conversations and I know that how he is now is not what he would want in any shape or form. He would want all life-sustaining treatment to stop.*"

She continued:

> "*we often had conversations about death, and he would always say that his greatest fear would to be in a vegetative state. He would make me promise to "pull the switch" so as to end his life rather than be a vegetable. It was a fear of his.*"

34. I have seen an email from PU, his third wife. She was contacted by E, concerning the possibility of withdrawing life sustaining treatment, she replied thus:

> *"Dear [E] and [R]*
>
> *I am very sad that we are having to think about helping [GU] this way but I want to tell you that for me as long as all the family agree I think it is what [GU] would want us to do. You have my support and anything I can do to help make it easier for you please let me know.*
>
> *I now realize after four years that [GU] will not be coming back and it's not good for him to stay like this for much more time. I want to come and see [GU] before anything happens and I hope we can arrange it so that I can say goodbye to him.*
>
> *Love to you both and the family*
>
> *I miss you all very much*
> *[P]"*

35. A statement was filed by Captain H, a work colleague and friend. This statement, within an email dated 9th February 2020, makes it clear that they were very close friends. He was best man to GU at his second marriage. Captain H referred to himself as "*his [GU's] proxy younger brother*". They had discussed death in the context of the death of parents. In his statement Captain H recounts:

> "*my father who was a doctor and professor did not believe in life prolonging interventions just to appease families, and strangely the three of us had conversations about this when family members, friends and colleagues were diagnosed with terminal illness. I remember these conversations as ones in which [GU] took the same view as my father and I.*"

Later he said:

> "*we both agreed that prolonged suffering to the individual and their families was redundant and unnecessary…*"
> *"…he would not want this for himself languishing through clinically assisted nutrition in my opinion."*

36. There are further statements filed, all of which serve to reinforce my clear impression of GU as a man who lived life to the full and embraced the opportunities he was presented with. Each witness and each statement revealed GU's personality with both clarity and perception. I was left with no doubt at all that he would have recoiled from his present circumstances. I emphasise that nobody, son, brother, friend, sister, wife had any ambivalence about what he would have wanted.

37. Ms Powell has made the following submissions on behalf of the Official Solicitor:

> *"3. When Professor Wade assessed GU in April 2021, he concluded that GU was unlikely to be having any experiences, but that if he was, they would generally be unpleasant. At the hearing on 10-11 June 2021 the Court concluded that it was not in GU's best interests to continue to receive CANH.*
>
> *4. The Official Solicitor submits that it is highly likely that this had been the case for some considerable time and that, had the question of GU's best interests been properly addressed in August 2018, when a dispute between family members was clearly apparent, the same decision would have been made then as now.*
>
> *5. It is submitted that there was* ***inordinate and inexcusable delay*** *(my emphasis) on the part of RHND, in giving consideration to the issue of whether continued treatment was in GU's best interests, and in taking steps to enable the Court to determine that issue in the absence of family agreement. This was compounded by further delay on the part of the CCG."*

38. Later, Ms Powell identifies *"a complete abrogation of responsibility to consider properly or at all, and to determine whether it was in GU's best interests and therefore lawful to continue to give him an invasive medical treatment, CANH."*

39. This submission, advanced on behalf of the Official Solicitor, is expressed in uncompromising and trenchant language. The CCG is also criticised for compounding the delay, a complaint which, it seems to me, it broadly accepts. Ms Powell invited me to consider whether the continued treatment given to GU might, at some point, have become unlawful. However, as will become clear later in the judgment, following the death of GU, the Official Solicitor properly recognised that her role had ceased and it was no longer necessary to consider this point. At the end of the June hearing I made declarations confirming that it was not in GU's interests to receive nutrition and hydration. Treatment was withdrawn and GU died peacefully on 26th June 2021.

40. I do not consider it necessary or indeed appropriate for the Court of Protection posthumously to review the lawfulness of GU's past treatment. I do, however, regard it as necessary, as I have foreshadowed above, to evaluate whether GU's dignity was properly protected and, if not, why not. The hearing on 15th July 2021, was specifically convened to afford the RHND an opportunity carefully to review their approach to

GU's treatment and to assist this court in understanding what the Official Solicitor rightly, in my judgement, identifies as the 'inordinate and inexcusable delay' in determining GU's best interests.

41. The RHND is recognised, internationally, as a centre of excellence in the provision of treatment, rehabilitation and long-term care for people who have suffered significant neurological damage. As mentioned above, at the conclusion of the evidence in the June hearing, I visited GU in hospital. When I met him, he was sitting in his wheelchair, accompanied by two nurses who knew him well, overlooking a large rose garden in full and resplendent bloom on a strikingly beautiful morning. The compelling and uncontested evidence is that he appreciated nothing of his circumstances. That he was being cared for physically, to a high standard, was obvious. It was equally clear that he received nursing care that was sensitive, respectful and kind.

Dignity

42. In the, admittedly extensive, passages which follow, I do not purport to provide an exegesis of the law or to review all the international texts, instruments and documents which address the concept of human dignity. I do, however, wish to signal and analyse the emphasis given to human dignity, in order to evaluate its application to this case and more widely to the many challenging decisions that the Court of Protection is required to take.

43. **Bouyid v Belgium (App No. 23380/09)** provides a starting point in identifying the international perspective:

> *"45. The Preamble to the 26 June 1945 Charter of the United Nations affirms the determination of the peoples of the United Nations "**to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small"**.*

44. The concept of dignity is also mentioned in the Universal Declaration of Human Rights of 10 December 1948, the Preamble to which states that **"recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world"**, and Article 1 of which provides that **"all human beings are born free and equal in dignity and rights"**. (my emphasis)

45. Both the above Charter and the Universal Declaration were written in the immediate shadow of the Second World War. It is important to recognise that the events of the first half of that century still constituted lived experience. Thus, the slaughter of the Somme, the insidious and corrosive rise of fascism in Europe and the awful abomination of the Holocaust provide the backdrop to both documents. This was a period when the world had real cause to confront and analyse the importance of human dignity. What is most striking is that dignity does not appear as a mere facet of fundamental human rights but is emphasised as entirely central and integral to them. As is clear from the respective preambles to both instruments, human dignity is afforded paramount status.

46. It is useful to trace the subsequent international human rights texts and instruments which incorporate the concept of dignity. In particular:

i. the **UN Declaration on the Elimination of All Forms of Racial Discrimination, 20th November 1963**, which *"solemnly affirms the necessity of speedily eliminating racial discrimination throughout the world, in all its forms and manifestations, and of securing understanding of and respect for the dignity of the human person"*. The International Convention on the Elimination of All Forms of Racial Discrimination, 21st December 1965, the Preamble to which refers to that Declaration;

ii. the **International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights**, 16th December 1966, the Preamble to which states that the equal and inalienable rights of all members of the human family *"derive from the inherent dignity of the human person"*. Furthermore, Article 10 of the former provides that *"all persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person"*, and Article 13 of the latter states that the *"States Parties ... recognize the right of everyone to education ... [and] agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms ..."*;

iii. the **Convention on the Elimination of All Forms of Discrimination against Women**, 18th December 1979, the Preamble to which emphasises in particular that discrimination against women *"violates the principles of equality of rights and respect for human dignity"*;

iv. the **Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment**, 10th December 1984, the Preamble to which points out that the *"equal and inalienable rights of all members of the human family ... derive from the inherent dignity of the human person"*;

v. the **Convention on the Rights of the Child**, 20th November 1989, the Preamble to which states that *"the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the UN Charter, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity"* (see also Articles 23 § 1, 28 § 2, 37, 39 and 40 § 1);

vi. the **International Convention for the Protection of All Persons from Enforced Disappearance** (Articles 19 § 2 and 24 § 5 (c));

vii. the **Convention on the Rights of Persons with Disabilities**, the Preamble to which states that *"discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person"*, and the aims of which include promoting respect for the *"inherent dignity"* of persons with disabilities (Article 1), this being also one of its general principles (Article 3 (a)) (see also Articles 8 (a), 16 § 4, 24 § 1 and 25);

viii. the **Second Optional Protocol to the International Covenant on Civil and Political Rights on the abolition of the death penalty**, 15th December 1989, the Preamble to which expresses the conviction that **"abolition of the death penalty contributes to enhancement of human dignity and progressive development of human rights"**;

ix. the **Optional Protocol to the Convention on the Rights of the Child on a communications procedure**, 19th December 2011, the Preamble to which reaffirms *"the status of the child as a subject of rights and as a human being with dignity and with evolving capacities"*;

x. the **Optional Protocol to the International Covenant on Economic, Social and Cultural Rights**, 10th December 2008 and the **Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women**, 6th October 1999.

47. The importance afforded to human dignity resonates throughout the world:

i. the **American Convention on Human Rights**, 22nd November 1969 (Articles 5 § 2, 6 § 2 and 11 § 1);

ii. the **Final Act of the Helsinki Conference on Security and Cooperation in Europe**, 1st August 1975, which stipulates that the States *"will promote and encourage the effective exercise of civil, political, economic, social, cultural and other rights and freedoms all of which derive from the inherent dignity of the human person and are essential for his free and full development"* (Principle VII);

iii. the **African Charter on Human and Peoples' Rights of 27 June 1981, Article 5** ,which lays down that *"[e]very individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status"*;

iv. the **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine**, 4th April 1997, the Preamble to which affirms, inter alia, "*the need to respect the human being both as an individual and as a member of the human species and ... the importance of ensuring [his] dignity"*;

v. the **Charter of Fundamental Rights of the European Union of 7 December 2000, the Preamble**, which affirms that being *"[c]onscious of its spiritual and moral heritage, the Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity"*, and Article 1 of which states that *"human dignity is inviolable [and] must be respected and protected"* (see also Article 31 on "*Fair and just working conditions"*);

vi. Protocol No. 13 to the **European Convention on Human Rights concerning the abolition of the death penalty in all circumstances**, 3rd May 2002, the Preamble to which points out that the abolition of the death penalty is essential for the protection of everyone's right to life

and for the full recognition of the *"inherent dignity of all human beings"*;

vii. the **Council of Europe Convention on Action against Trafficking in Human Beings**, 16th May 2005, the Preamble to which emphasises that *"trafficking in human beings constitutes a violation of human rights and an offence to the dignity and the integrity of the human being"* (see also Articles 6 and 16).

48. It is notable in the above texts that human dignity is frequently recognised to constitute a permanent, essential or characteristic attribute e.g. *"the dignity inherent in a human being", "the inherent dignity of all human beings", "the indivisible, universal values of human dignity…"*

49. The Council of Europe has also delivered recommendations and reports which incorporate the concept of dignity e.g. **Convention of the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine** (https://rm.coe.int/168007cf98).

50. Alongside the Preamble (referred to above), Article 1 reaffirms that:

> *"Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine"*.

51. The Convention considers how to protect dignity in a number of identified circumstances, e.g. taking part in medical research, uses of the human genome etc. Of note is the emphasis placed on the importance of consent (Article 5); what to do if the patient is not able to consent (Article 6) and on previously expressed wishes (Article 9).

52. Article 6 requires that any intervention is only carried out for the person's *"direct benefit"* (Article 6(1)) and that it *"may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law. The individual concerned shall as far as possible take part in the authorisation procedure."* (Article 6(3)). Any authorisation *"may be withdrawn at any time in the best interests of the person concerned"* (Article 6(5)). *"The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account."* (Article 9).

All this resonates clearly with the central philosophy of the framework of the Mental Capacity Act 2005.

53. In the context of "end of life", it is useful to consider: **Parliamentary Assembly, Protection of the human rights and dignity of the terminally ill and the dying, Recommendation 1418 (1999).** Again, in what has become a demonstrably clear pattern, human dignity is afforded absolute priority. Paragraph 1 provides:

> *"The vocation of the Council of Europe is to protect the dignity of all human beings and the rights which stem therefrom."*

54. Paragraph 5 expands the above:

> *"The obligation to respect and to protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life. This respect and protection find their expression in the provision of an appropriate environment, enabling a human being to die in dignity."*

55. Atypically, in the context of the other texts considered above, Recommendation 1418 (supra) identifies a variety of particular scenarios likely to compromise a person's dignity. These trigger the obligations of the state:

> 7. "Fundamental rights deriving from the dignity of the terminally ill or dying person are threatened today by a variety of factors:
>
> 7.1. insufficient access to palliative care and good pain management;
>
> 7.2. often lacking treatment of physical suffering and a failure to take into account psychological, social and spiritual needs;
>
> 7.3. **artificial prolongation of the dying process by either using disproportionate medical measures or by continuing treatment without a patient's consent**; (my emphasis)
>
> 7.4. **the lack of continuing education and psychological support for health-care professionals working in palliative medicine**; (my emphasis)
>
> 7.5. insufficient care and support for relatives and friends of terminally ill or dying patients, which otherwise could alleviate human suffering in its various dimensions;
>
> 7.6. patients' fear of losing their autonomy and becoming a burden to, and totally dependent upon, their relatives or institutions;
>
> 7.7. the lack or inadequacy of a social as well as institutional environment in which someone may take leave of his or her relatives and friends peacefully;
>
> 7.8. insufficient allocation of funds and resources for the care and support of the terminally ill or dying;
>
> 7.9. the social discrimination inherent in weakness, dying and death.

56. The Assembly calls upon member states to provide, in domestic law, the necessary legal and social protection against these specific dangers and fears which a terminally ill or dying person may be faced with in domestic law, and in particular against:

> 7.10. dying exposed to unbearable symptoms (for example, pain, suffocation, etc.);
>
> 7.11. **prolongation of the dying process of a terminally ill or dying person against his or her will**; (my emphasis)
>
> 7.12. dying alone and neglected;
>
> 7.13. dying under the fear of being a social burden;
>
> 7.14. limitation of life-sustaining treatment due to economic reasons;
>
> 7.15. insufficient provision of funds and resources for adequate supportive care of the terminally ill or dying."

57. For completeness, I identify three further Council of Europe documents which contemplate the concept of dignity: **Parliamentary Assembly, Protecting human rights and dignity by taking into account previously expressed wishes of patients**(https://pace.coe.int/en/files/18063#trace-4); **Parliamentary Assembly, Ethics in science and technology, Report Doc 13141 (2013)** (https://pace.coe.int/en/files/19501/html); Importantly, this latter document identifies that *"notions such as "human life", "person" and "dignity" will be understood in different ways, resulting in diverging opinions whether priority should be given to individual interests over the interests of the community"* (paragraph 67) and which may require "*re-questioning of even basic assumptions, such as the definition of "human identity" or "human dignity"."* (paragraph 69). All this reflects the challenge the Court of Protection faces when different perspectives on human dignity arise within families or amongst professionals.

58. In **Parliamentary Assembly, Rights of the sick and dying, Report Doc 3699 (1976)** (https://pace.coe.int/en/files/3937/html), amplifying *'Rights defined'*, the document states, at paragraph 16:

> *"Right to personal dignity and integrity. This right implies that medical premises should be so arranged that examinations can be carried out and treatment given without a patient suffering any loss of dignity vis-à-vis other patients, physicians, hospital staff or the outside world.* ***A patient may demand that no information be revealed regarding his presence at the hospital or his state of health***"

59. The above point also has tangential significance in the context of Transparency Orders. The document continues thus:

> "*he may refuse visits from persons he does not wish to see. It should not be forgotten that a patient's human dignity generally implies a right to the truth, which is therefore closely linked to a patient's right*

> *to information. An individual is entitled to respect for the integrity of his being as a whole (body and mind). Naturally, physicians may not violate this integrity, even at the request of the person concerned, unless this is required by the latter's treatment. The law has in fact had to be adjusted to give doctors a say, as it is sometimes difficult to judge whether medical intervention is necessary. This too is a matter for a physician's own conscience."*

60. **Convention on the Rights of Persons with Disabilities**

(https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx). Here, in addition to the wording in the Preamble, dignity is also referred to under the "general principles" provision which includes *"Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;"* (Article 3(1)).

61. Finally, at 'General Comment No 1', an important link is made between the concept of dignity and autonomy:

> "33. Freedom from discrimination in the recognition of legal capacity restores autonomy and respects the human dignity of the person in accordance with the principles enshrined in article 3 (a) of the Convention. Freedom to make one's own choices most often requires legal capacity. Independence and autonomy include the power to have one's decisions legally respected. The need for support and reasonable accommodation in making decisions shall not be used to question a person's legal capacity. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)) is incompatible with granting legal capacity on an assimilationist basis."

62. Whilst it is undoubtedly true that freedom to make one's own choices will usually arise in the context of those who are capacitous, this is not universally the case. I reiterate, the decisions, choices, wishes and feelings of those who have lost capacity may be harvested in a variety of ways in order to assert their autonomy. Friends, colleagues, family members may be able to bring the voice of P into the decision-making process. This will require evidence to be carefully garnered but may also be available by way of written advanced decisions relating to treatment.

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:

i. human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;

ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;

iii. 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;

iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;

v. 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;

vi. 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.

65. The case law of the Court of Protection reveals this exercise, in my judgement, to be receptive to a structured, investigative, non-adversarial enquiry which, as here, frequently establishes a secure evidential base, illuminating P's wishes and feelings. This investigation requires sensitivity, intellectual integrity and compassion on the part of all those involved. The beliefs and/or prejudices of others are entirely extraneous to the question of what P would want in the circumstances which he or she finds themselves in. Sometimes, where P has become isolated and alone the investigation may be inconclusive but experience shows and the case law reveals, that many of us leave a mark on those around us and closest to us which is clearer, stronger and more enduring than perhaps we might anticipate (See: **N, Re [2015] EWCOP 76; Sheffield Teaching Hospitals NHS Foundation Trust v TH & Anor [2014] EWCOP 4**). The outcome of this investigation will, of course, never achieve the same evidential weight as a strong, clearly expressed wish by a capacitous individual. But, the evidence of the code by which P has lived his life and the views he has expressed (which cast light on the decision to be taken) frequently provide powerful evidence when evaluated against the broad canvas of the other forensic material.

66. Although it is not an issue in this instant case, evaluating the codes and values by which an individual has lived his life will, in many cases, involve taking account of both religious and cultural beliefs. This is not to be equated with a superficial assumption that because a person is a member of an identified faith, he will inevitably have wanted a particular medical decision to be taken. It must be recognised that within any faith or culture there will exist a diversity of interpretation and practices, some of which will be extra-doctrinal and not easily reconcilable with the theological strictures of the faith.

Thus, for example, some Roman Catholics whilst having a clear religious identity may nonetheless choose to practice birth control; some Jews may not adhere to prescribed dietary requirements; some Muslims may not observe Ramadan. Even those who do not regard themselves as having a faith may have grown up in countries or families where faith-based beliefs have migrated into more general cultural values. All this is in sharp focus when considering what is often referred to as the 'sanctity of life', a phrase which is rooted in religious lexicon, though it has developed a broader meaning in the law (e.g. sanctity of contract). When considering what P would want, it is his own religious views and practices that need to be focused upon and not the received doctrine of the faith to which he subscribes. The latter approach risks unintentionally subverting rather than promoting the autonomy that is integral to human dignity.

67. It is important to highlight that there is a recognition within many faiths that effective surgery or other medical intervention is not synonymous with beneficial treatment; sustaining vital functioning is not the same as promoting health. Intervention which may have a powerful effect on the body may be antagonistic to the integral well-being of the patient. Once treatment is identified as both burdensome and futile and where death becomes inevitable, the prolongation of death is recognised as disproportionate.

68. It is instructive to consider both the domestic and European case law (ECHR).

ECHR case law

The concept of dignity engages both Article 8 and Article 3. In the Fourth Section judgment of **Pretty v UK (app no. 2346/02)**, the court held that an undignified death may fall within the ambit of Article 8:

> *"65.* ***The very essence of the Convention is respect for human dignity and human freedom.*** (my emphasis) *Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.*
>
> *66. In Rodriguez v. the Attorney General of Canada ([1994] 2 Law Reports of Canada 136), which concerned a not dissimilar situation to the present, the majority opinion of the Supreme Court considered that the prohibition on the appellant in that case receiving assistance in suicide contributed to her distress and prevented her from managing her death. This deprived her of autonomy and required justification under principles of fundamental justice. Although the Canadian court was considering a provision of the Canadian Charter framed in different terms from those of Article 8 of the Convention, comparable concerns arose regarding the principle of personal autonomy in the sense of the right to make choices about one's own body.*

> *67. The applicant in this case is prevented by law from exercising her choice to avoid what she considers will be an undignified and distressing end to her life. The Court is not prepared to exclude that this constitutes an interference with her right to respect for private life as guaranteed under Article 8 § 1 of the Convention. It considers below whether this interference conforms with the requirements of the second paragraph of Article 8."*

69. The court in **Haas v Switzerland (App no. 31322/07)** drew on **Pretty** (supra) stating at paragraph 51 that: *"In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention."* The court concluded at paragraph 61 that "*even assuming that the States have a positive obligation to adopt measures to facilitate the act of suicide with dignity, the Swiss authorities have not failed to comply with this obligation in the instant case."*

70. The objections articulated by A in this case found expression in **Lambert v France (App no. 46043/14)**, where the dissenting opinion placed emphasis on the fact that food and water are intimately linked to human dignity (drawing on General Comments No. 12 and 15 of UN Committee on Economic, Social and Cultural Rights): *"What, we therefore ask, can justify a State in allowing a doctor ... in this case not so much to "pull the plug" (Vincent Lambert is not on any life-support machine) as to withdraw or discontinue feeding and hydration so as to, in effect, starve Vincent Lambert to death?"* (paragraph 4 of dissenting opinion).

Article 3

71. In **D v United Kingdom (App no. 30240/96)**, the court held that removing the applicant from the UK, who was in the advanced stages of a terminal illness, *"would expose him to a real risk of dying under most distressing circumstances and would thus amount to inhuman treatment"* paragraph 53. This case law has been interpreted by domestic courts to mean that Article 3 includes *"the right to die with dignity" (***A National Health Service Trust v D [2000] 2 FLR 677**, at 695).

72. In the ECtHR jurisprudence, dignity is inevitably scrutinised in the context of claims of inhuman and degrading treatment. For example, in **Bouyid v Belgium (App No. 23380/09**) the court held that:

> *"81. Article 3 of the Convention enshrines one of the most fundamental values of democratic societies... Indeed, the prohibition of torture and inhuman or degrading treatment or punishment is a value of civilisation closely bound up with respect for human dignity.*
> *...*

87. Ill-treatment that attains such a minimum level of severity usually involves actual bodily injury or intense physical or mental suffering. However, even in the absence of these aspects, where treatment humiliates or debases an individual, showing a lack of respect for or diminishing his or her human dignity, or arouses feelings of fear, anguish or inferiority capable of breaking an individual's moral and physical resistance, it may be characterised as degrading and also fall within the prohibition set forth in Article 3 (see, among other authorities, Vasyukov v. Russia, no. 2974/05, § 59, 5 April 2011; Gäfgen, cited above, § 89; Svinarenko and Slyadnev, cited above, § 114; and Georgia v. Russia (I), cited above, § 192). It should also be pointed out that it may well suffice that the victim is humiliated in his own eyes, even if not in the eyes of others (see, among other authorities, Tyrer v. the United Kingdom, 25 April 1978, § 32, Series A no. 26, and M.S.S. v. Belgium and Greece [GC], no. 30696/09, § 220, ECHR 2011).

...

89. The word "dignity" appears in many international and regional texts and instruments (see paragraphs 45-47 above). Although the Convention does not mention that concept – which nevertheless appears in the Preamble to Protocol No. 13 to the Convention, concerning the abolition of the death penalty in all circumstances – the Court has emphasised that respect for human dignity forms part of the very essence of the Convention (see Svinarenko and Slyadnev, cited above, § 118), alongside human freedom (see C.R. v. the United Kingdom, 22 November 1995, § 42, Series A no. 335-C, and S.W. v. the United Kingdom, 22 November 1995, § 44, Series A no. 335-B; see also, among other authorities, Pretty v. the United Kingdom, no. 2346/02, § 65, ECHR 2002-III).

90. Moreover, there is a particularly strong link between the concepts of "degrading" treatment or punishment within the meaning of Article 3 of the Convention and respect for "dignity". In 1973 the European Commission of Human Rights stressed that in the context of Article 3 of the Convention the expression "degrading treatment" showed that the general purpose of that provision was to prevent particularly serious interferences with human dignity (see East African Asians v. the United Kingdom, nos. 4403/70 and 30 others, Commission's report of 14 December 1973, Decisions and Reports 78-A, p. 56, § 192). The Court, for its part, made its first explicit reference to this concept in the judgment in Tyrer (cited above), concerning not "degrading treatment" but "degrading punishment". In finding that the punishment in question was degrading within the meaning of Article 3 of the Convention, the Court had regard to the fact that "although the applicant did not suffer any severe or long-lasting physical effects, his punishment -– whereby he was treated as an object in the power of the authorities – constituted an assault on precisely that which it is one of the main purposes of Article 3 to protect, namely a person's dignity and physical integrity" (ibid., § 33). Many subsequent judgments have highlighted the close link

> *between the concepts of "degrading treatment" and respect for "dignity" (see, for example, Kudła v. Poland [GC], no. 30210/96, § 94, ECHR 2000-XI; Valašinas v. Lithuania, no. 44558/98, § 102, ECHR 2001-VIII; Yankov v. Bulgaria, no. 39084/97, § 114, ECHR 2003-XII; and Svinarenko and Slyadnev, cited above, § 138)."*

73. In **Svinarenko and Slyadnev (App no. 32541/08)**, the court considered the *objective* notion of degrading treatment and once again analysed human dignity as *"the very essence of the convention"*, extrapolating that the object and purpose of the convention requires that its provisions be interpreted in a manner which makes its safeguards both practical and effective:

> *"138. Regardless of the concrete circumstances in the present case, the Court reiterates that the very essence of the Convention is respect for human dignity and that the object and purpose of the Convention as an instrument for the protection of individual human beings require that its provisions be interpreted and applied so as to make its safeguards practical and effective. It is therefore of the view that holding a person in a metal cage during a trial constitutes in itself – having regard to its objectively degrading nature which is incompatible with the standards of civilised behaviour that are the hallmark of a democratic society – an affront to human dignity in breach of Article 3."*

74. Further, in **Campbell and Cosans v United Kingdom (App No. 7511/76)**, the court is clear that the subjective element (*"humiliated in his own eyes"*) is not the only consideration:

> *"a threat directed to an exceptionally insensitive person may have no significant effect on him but nevertheless be incontrovertibly degrading; and conversely, an exceptionally sensitive person might be deeply affected by a threat that could be described as degrading only by a distortion of the ordinary and usual meaning of the word."* [paragraph 30].

Domestic case law

75. The leading case in this area and one which has been subject to most scrutiny is **Airedale NHS Trust v Bland [1993] AC 789** Sir Thomas Bingham held that

> *"account may be taken of wider and less tangible considerations. An objective assessment of Mr. Bland's best interests, viewed through his eyes would in my opinion give weight to the constant invasions and humiliations to which his inert body is subject; to the desire he would naturally have to be remembered as a cheerful, carefree, gregarious teenager and not an object of pity; to the prolonged ordeal imposed on all members of his family, but particularly on his parents; even, perhaps, if altruism still lives, to a belief that finite resources are*

> *better devoted to enhancing life than simply averting death."* (Page 813)

76. Lord Hoffman identifies dignity as an *"ethical principle"*:

> *"But the sanctity of life is only one of a cluster of ethical principles which we apply to decisions about how we should live. Another is respect for the individual human being and in particular, for his right to choose how he should live his own life. We call this individual autonomy or the right of self-determination. And another principle, closely connected, is respect for the dignity of the individual human being: our belief that quite irrespective of what the person concerned may think about it, it is wrong for someone to be humiliated or treated without respect for his value as a person. The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person."* (page 826)

77. Further,

> *"Similarly, it is possible to qualify the meaning of the sanctity of life by including, as some cultures do, concepts of dignity and fulfilment as part of the essence of life. In this way one could argue that, properly understood, Anthony Bland's death would not offend against the sanctity of life."* (page 827).

78. Lord Hoffman also recognised that which is now imbedded in the jurisprudence of the Court of Protection, namely the dignity abides even where consciousness is lost and indeed, beyond death:

> *"I think that the fallacy in this argument is that it assumes that we have no interests except in those things of which we have conscious experience. But this does not accord with most people's intuitive feelings about their lives and deaths. At least a part of the reason why we honour the wishes of the dead about the distribution of their property is that we think it would wrong them not to do so, despite the fact that we believe that they will never know that their will has been ignored. Most people would like an honourable and dignified death and we think it wrong to dishonour their deaths, even when they are unconscious that this is happening. We pay respect to their dead bodies and to their memory because we think it an offence against the dead themselves if we do not. Once again, I am not concerned to analyse the rationality of these feelings. It is enough that they are deeply rooted in our ways of thinking and that the law cannot possibly ignore them. Thus, I think that counsel for the Official Solicitor offers a seriously incomplete picture of Anthony Bland's interests when he*

> *confines them to animal feelings of pain or pleasure. It is demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity, in how he lives or dies."* (Page 829)

79. In a dissenting judgment, Lord Browne-Wilkinson considered *"personal dignity"* to be an *"impalpable factor"* which could only be evaluated in a way which reflected the moral stance of an individual judge and as such had no legitimacy:

> *"The position therefore, in my view, is that if the judges seek to develop new law to regulate the new circumstances, the law so laid down will of necessity reflect judges' views on the underlying ethical questions, questions on which there is a legitimate division of opinion. By way of example, although the Court of Appeal in this case, in reaching the conclusion that the withdrawal of food and Anthony Bland's subsequent death would be for his benefit, attach importance to impalpable factors such as personal dignity and the way Anthony Bland would wish to be remembered but do not take into account spiritual values which, for example, a member of the Roman Catholic church would regard as relevant in assessing such benefit. Where a case raises wholly new moral and social issues, in my judgment it is not for the judges to seek to develop new, all embracing, principles of law in a way which reflects the individual judges' moral stance when society as a whole is substantially divided on the relevant moral issues. Moreover, it is not legitimate for a judge in reaching a view as to what is for the benefit of the one individual whose life is in issue to take into account the wider practical issues as to allocation of limited financial resources or the impact on third parties of altering the time at which death occurs."* (pages 879 – 880).

80. Though the case law in the decades that have followed has eschewed Lord Browne-Wilkinson's analysis, it is, to my mind, always helpful to keep this passage in mind when evaluating whether that which is identified as human dignity is genuinely attributable to P's humanity and not to the moral and ethical judgements of others. Lord Mustill noted that:

> *"...it seems to me to be stretching the concept of personal rights beyond breaking point to say that Anthony Bland has an interest in ending these sources of others' distress. Unlike the conscious patient he does not know what is happening to his body, and cannot be affronted by it; he does not know of his family's continuing sorrow. By ending his life the doctors will not relieve him of a burden become intolerable, for others carry the burden and he has none."* (page 897)

81. In **A and others v East Sussex County Council and another [2003] EWHC 167 (Admin)**, when considering the idea of "physical and psychological integrity" founded in Article 8 (citing **Botta v Italy (App No. 21439/93**)), the court commented that it

embraced two important concepts: dignity and the right of disabled individuals to participate in the life of the community. In relation to dignity, the court stated:

> *"86. The first is human dignity. True it is that the phrase is not used in the Convention but it is surely immanent in article 8, indeed in almost every one of the Convention's provisions.* ***The recognition and protection of human dignity is one of the core values -in truth the core value - of our society and, indeed, of all the societies which are part of the European family of nations and which have embraced the principles of the Convention. It is a core value of the common law, long pre-dating the Convention and the Charter.*** (my emphasis) *The invocation of the dignity of the patient in the form of declaration habitually used when the court is exercising its inherent declaratory jurisdiction in relation to the gravely ill or dying is not some meaningless incantation designed to comfort the living or to assuage the consciences of those involved in making life and death decisions: it is a solemn affirmation of the law's and of society's recognition of our humanity and of human dignity as something fundamental. Not surprisingly, human dignity is extolled in article 1 of the Charter, just as it is in article 1 of the Universal Declaration. And the latter's call to us to "act towards one another in a spirit of brotherhood" is nothing new. It reflects the fourth Earl of Chesterfield's injunction, "Do as you would be done by" and, for the Christian, the biblical call (Matthew ch 7, v 12): "all things whatsoever ye would that men should do to you, do ye even so to them: for this is the law and the prophets".*
>
> *Further, the court highlighted at [94] - [95] that "the demands of human dignity fall to be evaluated in the particular context – not merely of place but also of time … As Lord Hoffmann said, "The content may change but the concept remains the same", reflecting Professor Ronald Dworkin's distinction between the "concept" which does not change and changing "conceptions of the concept": see R (ota Smeaton on behalf of the Society for the protection of unborn children) v Secretary of State for Health [2002] EWHC 610 (Admin), [2002] 2 FLR 146 at 226 (paras [324]-[325]).*"

82. The court at [121] also distinguished between *'dignified ends'* and '*undignified means'* in the context of dignity. The analysis here illuminates the difficult balance that may require to be struck. However, it is also important to note that in the intervening years (i.e. approaching 20 years), palliative medicine has evolved to such a degree that the hypothesis posited in the judgment is rarely likely to arise in modern medicine:

> *"But, and this is the first point, insistence on the use of dignified means cannot be allowed to obstruct more important ends. On occasions our very humanity and dignity may itself demand that we be subjected to a certain amount - sometimes a very great deal - of indignity. Dignified ends may sometimes demand the use of undignified means … But this does not mean that means must be allowed to triumph over*

> *ends. There is a balance to be held—and it is often a very difficult balance to strike. It is difficult enough to balance the utility or possible futility of means against the utility or possible futility of ends: it is all the more difficult when one has to assess in addition the dignity or possible indignity of the means against the end in view. Modern medical law and ethics illustrate the excruciating difficulty we often have in achieving the right balance between using undignified means in striving to achieve dignified ends."*

83. In **Sheffield Teaching Hospitals NHS Foundation Trust v TH and another [2014] All ER (D) 209 (May)**, the court observed as follows:

> *"53. If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation. I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want."*

84. In **M v N [2015] EWCOP 76**, I made the following observations:

> *"[71] As I have already set out and at some length, I am entirely satisfied that Mrs. N's views find real and authoritative expression through her family in this courtroom. I start with the assumption that an instinct for life beats strongly in all human beings. However, I am entirely satisfied that Mrs. N would have found her circumstances to be profoundly humiliating and that she would have been acutely alert to the distress caused to her family, which she would very much have wanted to avoid. LR told me that Mrs. N would not have wanted to have been a burden; that I also believe to be entirely reliable.*

> *[72] There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain. There will undoubtedly be people who for religious or cultural reasons or merely because it accords with the behavioural code by which they have lived their life prefer to, or think it morally right to, hold fast to life no matter how poor its quality or vestigial its nature. Their choice must be respected. But choice where rational, informed and un-coerced is the essence of autonomy. It follows that those who would not wish to live in this way must have their views respected too."*

85. I also, at [76] referred to the following passage from **R (Purdy) v DPP [2009] UKHL 45**:

> *"66 ... If we are serious about protecting autonomy we have to accept that autonomous individuals have different views about what makes their lives worth living. There are many, many people who can live with terminal illness; there are many, many people who can live with a permanent disability at least as grave as that which afflicted Daniel James; but those same people might find it impossible to live with the loss of a much-loved partner or child, or with permanent disgrace, or even with financial ruin."*

86. In **Tafida Raqeeb v Barts NHS Foundation Trust and others [2020] 3 All ER 663**, Macdonald J considered that the *"concept of human dignity"* must contain *"a significant element of subjectivity"* and thus be influenced by, for example, *"the religious or cultural context in which the question is being considered"*. Whilst identifying what constitutes human dignity for a particular individual in a given situation will inevitably be subjective, the *"concept of human dignity"* is not. Rather, it is objectively predicated on what emerges as a universal understanding of a unique value intrinsic to the human condition.

87. When considering the likely wishes of an incapacitated adult, the religious codes and community values within which he or she has lived will be an important facet of the subjective evaluation of best interests. These are however, for the reasons considered at para 59 above, essentially extraneous and contextual factors which can never be permitted to occlude the far more rigorous exercise of identifying what P most likely believed and what he or she would have wanted in circumstances where medical treatment had become burdensome and futile.

88. In **Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight [2021] EWHC 25 (Fam)** Poole J held at [86] that:

> *"The concept of "dignity" to which MacDonald J referred in Raqeeb at [176] to [177] (above) and which has influenced the view of Dr B, is, I believe, problematic and does not assist me in identifying what is in Pippa's best interests. In an adult or older child the concept of dignity might be linked to their exercise of autonomy and be a crucial factor in determining what is in their best interests, but that factor*

> *does not apply in the case of a young child like Pippa, whose values, beliefs, and wishes cannot reliably be ascertained or inferred. Perhaps we all think we can recognise human dignity when we see it, but there is obviously a high degree of subjectivity involved in describing someone's life or death as having dignity The protection of an individual's dignity has been deployed in support of decisions to continue life sustaining treatment – Raqeeb – and to withhold it - Alder Hey Children's Foundation Trust v Evans [2018] EWHC 308 (Fam) at [62]. For some, there is dignity in enduring suffering; for others, prolonged suffering constitutes a loss of dignity. There is a wide range of opinion as to what constitutes a dignified death. In the present case the Trust contends that the withdrawal of ventilation in a planned manner within the hospital and with appropriate palliative care, would allow Pippa to die peacefully with her family around her. Witnesses for the Trust told me of "chaotic" deaths they had witnessed, and which might occur if Pippa were at home, where a complication such as an uncontrollable desaturation could lead to her sudden death, perhaps without family members present. It might be said that Pippa's dignity would be protected in the former case and lost in the latter. Her mother would strongly disagree. She says, "I could not think of anything more undignified than Pippa's death being planned and for it to be carried out in the corner of the PICU when there is a procedure that can be done to potentially get her out of the ward and home." I take into account the views of Pippa's mother and of others about her best interests, but given the very different ideas expressed to the court about what would constitute dignity for Pippa in life and in her dying, I shall not presume to adopt some supposedly objective concept of dignity to determine her best interests."*

89. Lord Justice Baker found himself confronted with the question of how the Court should address the question of human dignity in **Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust [2021] EWCA Civ 362**. However, as it was not identified as a ground of appeal by either the Appellant or the Trust, Baker LJ was not required to address it:

> *"[99] … I commend him for the thought and care with which [the counsel for the Guardian] has prepared those submissions and I intend no disrespect to him in saying that I do not think it necessary or appropriate on this occasion to embark upon a detailed analysis of the arguments he deployed [about the concept of dignity]. The judge [of the High Court] declined to attach any weight to the concept of dignity in reaching a decision about Pippa's best interests…Neither the appellant nor the Trust has sought to argue that he was wrong in adopting that course.*
>
> *[100] Other judges, dealing with cases involving different circumstances, have taken a different approach: see for example MacDonald J's decision in Raqeeb. In a future case, it may be*

> *necessary for this Court to address arguments akin to those put forward by Mr Davy about the role played by the concept of dignity in decisions of this sort. That necessity does not arise on this appeal."*

90. In **Manchester University NHS Foundation Trust v Alta Fisher and others [2021] EWHC 1426 (Fam)**, the court having reviewed the history of the case law starting with *Raqeeb* and the two judgments in *Knight*, stated:

> *"[70] Within this context, the judgment of this court in Raqeeb sought to recognise that some of the wide range of considerations relevant to the evaluation of best interests, such as the role of religious belief, futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, will be ones that admit, as the best interests principle itself can admit, of more than one "right" answer capable of driving the best interests decision of the court, particularly in the absence of factors which tend to attract societal consensus, such as the undesirability of pain and suffering. However, and consistent with the long-established process of evaluation conducted by the court with respect to best interests, whether, in a given case, those more subjective or value laden factors will drive the best interests decision will depend on the totality of the welfare factors that fall to be considered in that case."*

91. In **Alder Hey Children's NHS Foundation Trust v Evans & Anor [2018] EWHC 308 (Fam)** I made the following observations which I do not consider need amplification:

> *"54. In her evidence the Guardian expressed her clear support for the Trust's application. Her view had been foreshadowed in her report. The evidence, she told me, had served ultimately to confirm her recommendation. She stated that in her view Alfie's life now lacks dignity and his best interests can only be met by withdrawing ventilation. This evidence from an experienced children's guardian requires to be considered very carefully. I have done so. With great respect to her I disagree with her view on Alfie's dignity. As I had promised the family I attended the PICU at Alder Hey to meet Alfie. I was greeted not merely with courtesy by the parents and a number of aunts and uncles but with a sincere and genuine warmth. I was and remain grateful to them. Alfie's pod in the unit is large, comfortable and he is surrounded by some of the world's most up-to-date technology. F was, in my presence, assiduous to Alfie's care. He is entirely besotted with his son. M, both parents agree, is far less involved in Alfie's practical care and less confident. Her contribution, in my assessment, is of an entirely different complexion. She has, if I may say so, a zany and delightful sense of humour entirely free from self-regard or pomposity. Her love for her partner and her son was obvious. The atmosphere around Alfie was peaceful, dignified and*

> *though some might find it surprising for me to say so, very happy. The primary engine for all this is Alfie's mum.*
>
> *55. Alfie's bed is festooned with toys. His walls are plastered with photographs and his many supporters have delivered a variety of football shirts to him. One, in particular, was signed by the entire Everton squad specifically for him.*
>
> *56. Supporting all this is the diligent professionalism of some truly remarkable doctors and the warm and compassionate energy of the nurses whose concern and compassion is almost tangible. All this creates an environment which inherently conveys dignity to Alfie himself. In my judgment his life has true dignity. The far more challenging question is whether and if so how that can be maintained."*

Lessons to be learned

92. I have gone to such lengths to review the concept of human dignity in this case because from my first reading of the papers, I was alarmed to discover the extraordinary delay that had occurred in addressing GU's best interests and the profoundly perturbing period in which he had been in a prolonged disorder of consciousness. In the 7 years since his dreadful accident it is regarded as highly unlikely that he had any experience at all but that if he did, it would have *"generally been unpleasant"*. Having concluded that it was not in GU's best interests to continue to receive CANH at the hearing on 11th June 2021, I considered it was necessary to afford RHND the opportunity of explaining what had happened. On 11th June 2021, I delivered an extempore judgment in which I indicated why the continued provision of nutrition and hydration to GU, in the manner outlined above, was contrary to GU's interests. The Court could not compound the delay. It was also important that the family, who were all present, could understand the reasons supporting my decision. I have repeated that judgment here in broadly similar language, though I have refined some of the concepts. Because it was contended by the Official Solicitor that GU's dignity had been so seriously compromised, I invited a response from RHND. I wanted to ensure that delays of this magnitude were not repeated in cases of this kind, or indeed, at all. I also wanted better to understand how the failure to identify GU's best interests had occurred.

93. Ms Walker, on behalf of RHND, has not sought to justify the delay in referring the question of withdrawal of CANH to the court. It seems to me she could not have done so. She makes a number of submissions which I record:

> *"RHND considers it important to emphasise at the outset of this part of the submissions that it is a charity, it is not a Trust, this has clear resourcing implications which are addressed further below. The charity was set up with the aim of giving "permanent relief to such persons as are hopelessly disqualified for the duties of life by disease, accident or deformity," (originally called the Hospital for Incurables). RHND has always taken seriously its approach to ensuring a strong ethical position on the end of life care, and as*

> *explained at F1, this has involved the appointment until April 2018 as chair of the Ethics Committee of Laurence Oates CB (former Official Solicitor to the Supreme Court). Without diverging too far from the specifics of GU's case, RHND does consider it important to emphasise that its ethos is to provide rehabilitation and long-term care for its patients and that this coupled with the more limited experience of staff in withdrawing life sustaining treatment had an impact on its approach to CANH withdrawal cases."*

94. Whilst I recognise the commitment and professionalism of all involved in the RHND, I regret to say that the failure of the hospital to ensure that its ethos evolved to incorporate the very clear guidance of the Royal College of Physicians and the British Medical Association is troubling. Ms Walker amplifies her above submission thus:

> *"The Official Solicitor has been critical of RHND's reliance on its ethos in its representations. RHND understands why this criticism is being made, but is simply and honestly reflecting the cultural factors within RHND which meant that its policy in 2017 and 2018 did contain gaps which could lead to the sorts of delays experienced in GU's case. The policy produced by RHND in 2017 referred to the guidance produced by the Royal College of Physicians in 2013. However, RHND's policy then (and to the same extent as produced in October 2018) was a reactive one in the sense that it indicated that when it was appropriate to do so there would be discussions with the family about what options are open to them but the policy was not specific as to the processes that needed to be followed if it were not possible to obtain agreement. It is important to acknowledge this past practice and to acknowledge that RHND has been and will continue to take steps to ensure that there are no obstructions to RHND taking action. It should also be noted that a detailed Guidance and governance process (based on the prevailing National Guidance) was developed under the Policy, adopted by the RHN in October 2018 and revised in the light of experience in March 2019. This shows a firm commitment by the RHN to properly considering and progressing cases where this was appropriate."*

95. It is trite to say that medicine has progressed very significantly since the establishment of the charitable Hospital for Incurables. It is manifest that the identified aim of providing *"permanent relief"* to those *"hopelessly disqualified for the duties of life"* requires to be interpreted in the context of good, contemporary medical practice. Underpinning the original aims of the hospital is a clear recognition of the importance of human dignity. It does not strain even this now antiquated language to identify that the objective is to provide "relief" to those who have lost the capacity to assert their own autonomy. GU was not provided with relief; he should have been. His treatment became both burdensome and futile and entirely contrary to what he would have wanted. His dignity was avoidably compromised. Even the most summary assessment of his best interests would have revealed this many years ago.

96. The obligation to review a patient's best interests falls upon the treating clinical team. In this case any consideration of a best interests meeting was triggered by E who had

discovered the judgment of the Supreme Court in **NHS Trust v Y [2018] UKSC 46**. The following passage in that judgment by Lady Black, with whom the majority agreed, is apposite here:

> *"125. If, at the end of the medical process, it is apparent that the way forward is finely balanced, or there is a difference of medical opinion, or a lack of agreement to a proposed course of action from those with an interest in the patient's welfare, a court application* ***can and should be made*** *(my emphaisis). As the decisions of the ECtHR underline, this possibility of approaching a court in the event of doubts as to the best interests of the patient is an essential part of the protection of human rights. The assessments, evaluations and opinions assembled as part of the medical process will then form the core of the material available to the judge, together with such further expert and other evidence as may need to be placed before the court at that stage."*

97. This judgment finds clear expression in the guidance of the Royal College of Physicians **"Clinically – Assisted Nutrition and Hydration (CANH) and adults who lack the capacity to consent"** (2018). Further guidance can be found in the document published by this court, **Serious Medical Treatment, Guidance [2020] EWCOP 2**.

98. I accept the submission, on behalf of the Official Solicitor, that there was *"a wealth of professional guidance"* available to the RHND and certainly by 2018. Moreover, I think it is fair to say that the judgment in the Supreme Court in re: Y (supra) and the available guidance make it pellucidly clear that the person responsible for making decisions in this sphere, where P lacks capacity, is the individual with overall responsibility for the patient's care, as part of their clinical responsibility to ensure that treatment provided is in the patient's best interests. This will usually be a consultant or general practitioner. This is reflected, almost verbatim within the Royal College's guidance and it does not permit of any ambiguity. To the extent that the RHND have suggested that there is any lack of clarity on this point, I disagree.

99. After what I strongly suspect were years of real distress and concern, the pressure to convene a best interests meeting was, ultimately, generated by E (GU's brother). Even a moment's reflection will reveal that this puts a family member in a highly invidious position. The RHND's failure to act led to a situation in which E had to press for the discontinuance of treatment in order that his own brother (GU) might be permitted to die with dignity. Many in E's situation might have found themselves unable or unwilling to take this course. They should not have to do so.

100. The guidance emphasises that the central point to keep in mind is that the decision-making process is about the best interests of the individual patient not what is best for those who are close to, or around them. I was told by the CEO of RHND that the discontinuance of life sustaining treatment in the kind of circumstances arising here causes distress to staff, other patients and their families. It was clearly intended to signal that this was, in some way, a reason to delay the best interests decision-making process. I have no doubt that these cases cause deep distress to others in the hospital. Indeed, it would be concerning if they did not. I have equally no doubt that these considerations

have no place at all in evaluating GU's best interests. Factoring these matters into the decision process is both poor practice and ethically misconceived.

101. Ms Walker has drafted a number of suggestions as to how guidance might need to be updated. Within those suggestions is an observation that the experience of the pandemic has revealed how the use of technology can be very effective in achieving easier access to key individuals and the wider recognition that best interests meetings can be entirely effective when conducted 'remotely'. This may well be right, but it is a distraction from the central issue in this case.

102. I am not persuaded that there is a need for further guidance, beyond that which is folded into the analysis of this judgment. Indeed, I have come to the conclusion that the existing guidance must be restated and emphatically so. This Court's guidance (supra) was released as recently as 17th January 2020 and is condensed into five pages. It is intended to be an easily accessible document. I am aware that it is widely consulted. It is, I hope, a convenient gateway to the wider case law and to the other available professional guidance.

103. What does require to be spelt out, though it ought to be regarded as obvious, is that where the treating hospital is, for whatever reason, unable to bring an application to the court itself, it should recognise a clear and compelling duty to take timely and effective measures to bring the issue to the attention of the NHS commissioning body with overall responsibility for the patient.

104. Ms Powell has emphasised the Royal College of Physicians PDOC Guidelines:

> *"Annual review should include a consideration and discussion of best interests. Appropriate ceiling of treatment arrangements should be discussed and agreed at each annual review. Treating teams and commissioners should not simply continue treatment because it is the easiest option. Family members must be given ongoing opportunities to discuss withdrawal of life-sustaining treatment, including the practical, legal and emotional aspects"*

It is submitted, on behalf of the Official Solicitor, that:

> *"as soon as there is any doubt over whether it is in the patient's best interests to continue to receive CANH, appropriate steps must be taken in every case to ensure that a timely decision is made on that issue, one way or the other. If it is not possible to achieve unanimity amongst the treating team and all those with an interest in the patient's welfare, or if it is considered that the decision is finely balanced, then steps must be taken to bring the matter before the Court, in a timely way, for a determination."*

105. This latter point is an important one. The Royal College has issued guidelines, they are to be treated as such and not regarded as set in stone. Consideration of a patient's best interests arises in response to clinically identified need. The need for an assessment is driven by what the patient requires and not confined to the structure of annual review. In simple terms, it requires to be kept in constant and unswerving focus. (see e.g.; **Cambridge University Hospitals NHS Foundation Trust v AH & Ors (Serious**

Medical Treatment) [2021] EWCOP 51). Regular, sensitive consideration of P's ongoing needs, across the spectrum, is required and a recognition that treatment which may have enhanced the patient's quality of life or provided some relief from pain may gradually or indeed quite suddenly reach a pivoting point where it becomes futile, burdensome and inconsistent with human dignity. The obligation is to be vigilant to such an alteration in the balance.