Neutral Citation Number: [2022] EWCOP 16

Case No: 1354439T

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 31/03/2022

Before:

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

- -

Between:

PH **Applicant**
(by his litigation friend, the Official Solicitor)

- and –

Betsi Cadwaladr University Health Board **Respondent**

- -
- -

Ian Brownhill (instructed by **the Official Solicitor**) for the **Applicant**
Roger Hillman (instructed by **Legal & Risk Services, NHS Wales**) for **the Health Board**

Hearing dates: 24th March 2022

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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

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 incapacitated person 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 October 2021, I delivered a short ex tempore judgment, in this case, in which I was critical of the Health Board. My criticism focused upon two central concerns. The first, and in many ways, most alarming, was that PH, the protected party in these proceedings, had been subject to physical restraint in order to take blood samples from him at a time when there were reasons to believe that he lacked capacity to consent to medical treatment. No application had been made to the Court as to whether this was in PH's best interests. I described what had happened as corrosive of PH's dignity. It transpired that those actions were contrary to the advice of the Health Board's own highly experienced legal team. What was also deeply troubling was that at the time that this occurred, PH was represented by the Official Solicitor in proceedings before the Court of Protection. A report addressing issues of capacity, commissioned at the request of the Official Solicitor, appeared to have been entirely ignored by the then treating clinicians. The Official Solicitor had not been informed of what was happening.

2. There was no doubt that PH's behaviours could be very challenging at the time, but though this was a facet of his condition, it appeared to be interpreted, by his then treating psychiatrist, as something for which he was responsible and which she considered attracted censure. Two important developments followed. Firstly, the appointment of Dr W as PH's new psychiatrist, whose impact on PH's life has been transformative. Secondly, a thorough overview of the history of the case was undertaken by a recently appointed Chief Executive (CE). Both were manifestly shocked by the history of the case and properly made no attempt at all, to defend it. Like Dr W, CE was determined to establish a proactive commitment to PH's welfare in the widest sense. This was not merely platitudinous, but as the case has evolved, it is clear that it has been converted into real action. I should add, that prior to Dr W's involvement in the case, PH had been attributed the label of having "an Emotionally Unstable Personality Disorder". Dr W was clear that this was a diagnosis that could not be rooted in the available clinical evidence. It has served historically to eclipse both the recognition of PH's symptoms as well as features of his personality. In short, there was a complete sea change in the understanding of PH, his needs, his personality, and his capacity for progress.

3. The second concern was the extraordinary period of time that PH had remained in hospital, notwithstanding his pressing need for rehabilitative care to enable him to maximise his potential for independent living. In hospital, he has not received occupational therapy, nor the stimulation of the outside world to which he manifestly responds. All this has been further complicated by the many exigencies of the pandemic.

4. I have set this brief summary out not in any way to reawaken the distress that the clinical team feel about the history of the case, but because it is important in understanding the context of the hearing before me today. PH is 41-years of age, he has, since his late twenties, a complex and challenging medical history. In 2016, he drank corrosive hydrogen peroxide which resulted in the removal of his oesophagus and spleen. He has a tracheostomy and requires percutaneous endoscopic gastrostomy (PEG) feeding into his stomach. In 2019, he suffered from a hypoxic brain injury following a fit. For a complexity of reasons, there have been a considerable number of hearings, in these proceedings, to a degree which is unusual in the Court of Protection. PH has participated

in all of them by way of video conferencing platform. During the course of the hearings, I have listened to him display a real understanding of his medical condition.

5. PH is unable to eat and drink and has challenges communicating verbally. But, for those who know him, and understand something of his nature and personality, PH communicates clearly and unambiguously. In many ways, despite its obvious unsuitability, PH has, to some degree, begun to flourish in this hospital. It is obvious that the nurses, Dr W and all the doctors caring for PH have come to view him affectionately. I have spoken with PH on numerous occasions now. The video conferencing platform has proved to be an invaluable tool in facilitating the participation of P in Court of Protection proceedings. If I may say so, I too have come to appreciate the warmth and force of PH's personality. It is also important to state that PH has had, throughout the many challenges he has faced, the unstinting love, loyalty, and support of his partner, N.

6. In February 2022, I was asked to resolve a dispute concerning PH's transfer from a general surgical ward to a mental health rehabilitation placement. One further complicating feature was that, in November 2021, PH fell and sustained a fracture to the neck of his femur which required hip replacement surgery. The Court approved the planned surgery, and it was successful.

7. PH had plainly become unsettled by the prospect of change. Above all else, he wanted a life that was as 'normal' as possible. He articulated the wish for space and privacy. The rehabilitation unit was not attractive to him. I would reemphasise that notwithstanding its apparent unsuitability, PH has made good rehabilitative progress at the hospital. A private residential property was identified near Bangor. PH really wanted to go to his home village in Anglesey. Bangor was at least heading in the right direction. In the period leading up to these decisions, PH had stopped taking nutrition. He took medication, and he took water. In early February, PH was asked if he would like to visit the property. He agreed. He also started receiving nutrition to make himself strong enough, both to visit and, if he liked it, to move to live there. As it transpired, he did like it and accordingly, on 7th February 2022, I was able to approve an agreed order. In that order, I did not make any declaration in relation to PH's capacity to consent to medical treatment. The presumption, therefore, as I believe was perfectly clear, was that PH had such capacity.

8. Sadly, in the weeks that followed, events have taken a different turn. PH has now refused to take nutrition for 41 days. It is difficult to say what has led him to take this position. Dr SP, the psychiatrist who is currently caring for PH, during Dr W's greatly deserved annual leave, has made the following comments in his statement dated 23rd March 2022:

> *"We talked about refusing food at various points through the conversation. Whenever I returned to the subject PH would discuss the matter, but his response was consistent. PH is very clear he does not want food. That without it he will die. When speaking to PH in previous meetings he has said his situation is "hell". When I asked him today about dying, he clearly said, "I want to die". I asked him why this was his response? His reply was "lots of things" and "I don't like talking about death". We*

> *again talked about his alternatives, such as feeding, moving on from ward 5. He acknowledged these. He then somewhat surprised me by telling me [N] wanted children and he felt he had let her down.*
>
> *"We spoke of the medication PH is prescribed. He was aware that he is prescribed medication, however, initially said he did not know why. He then told me he was prescribed "one to sleep". He thought that was a good idea, even after I described the possible side effects. I had to tell him he was on two antidepressants. He offered a view that they "help mood". With prompting, he was aware of being on painkillers. He told me his hand was painful and they helped. He seemed unaware of being on an antiepileptic, but when I described why he seemed to think it was a good idea."*
>
> *I asked him why he had accepted fluids or antibiotics but not feeds. PH's initial response was "[N] told me" I again suggested I had witnessed [N] telling him she wanted him to accept feeds. His response was "I don't like, I don't need the feed, I will die". I pointed out that by accepting fluids he was prolonging his life. His response was to say "I need water". I asked why? He replied with "thirst". I asked him if thirst was unpleasant? and he said "yes". He acknowledged that water resolved thirst.*
>
> *I asked PH how he would react if people forced him to take feed against his wishes. He repeatedly told me the staff would not do that. I am asked to consider what would happen if that situation arose, what he would do? His response was "I would probably fight". When I asked how it would make him feel, he initially would not answer, but when I asked to imagine how he would feel? his response was "pissed off".*

9. I heard oral evidence from Dr SP. I found him to be a thoughtful and impressive witness. He was very clear that PH had the capacity to accept feeding. His opinion has been settled for some time, but it was clear that he had been prepared to revisit and reconsider it. Nonetheless, he remains strongly of the view that PH is able "*to weigh up the pros and cons, to come to a decision, and to communicate it"*. This is the essence of capacity. Dr SP considers that whatever fortitude PH may have displayed, he regards his situation as *"a living hell"* in which he perceives himself to be a *"burden to others"* and particularly to, his partner. This may be his perception; indeed, I do not doubt that it is, but it does not reflect N's feelings nor those who care for him. Everybody who has had contact with PH has tried, as best they can, and as sensitively as they are able, to encourage him to accept feeds. I see visible warmth and affection for him, and I note that Dr SP has observed that too. PH feels, as Dr SP said, that it should be his own choice to decide what treatment he receives and ultimately, whether he lives or dies.

10. Last week, it came to light that PH had been scheduled to have a video assessment with a consultant from a Birmingham hospital, who has been reviewing any potential for

gastro-reconstructive surgery. Neither PH nor his partner, N have ever let go of this as a possibility for the future.

11. Dr RP, Consultant in Respiratory Medicine, told me that on the 16th March, PH had reported a pain in his right hand and experienced a period of low oxygen saturations, *"low even for him"*, which were treated with, and improved by, nebulised medication. Although PH had been refusing blood tests, he consented on this occasion. The test showed low serum levels of magnesium and potassium, but were otherwise quite remarkably fine given his refusal to feed. PH did not want to correct the low serum levels with supplements. However, a few days later when it had been explained to him that such readings would effectively count against him if there were any prospect of reconstructive surgery, he changed his mind and accepted the supplements. Dr SP infers that the two are connected in PH's mind (i.e., supplements and prospective surgery) and I am inclined to agree, having regard to the broader evidence of PH's general functioning. I regret to say, that PH's general level of health is such that he is not eligible for reconstructive surgery, nor indeed, anywhere close to it. He is frail. He recognises this. For the first time in all the hearings in this case, PH did not want to show himself on camera. I saw his nurse and his hospital room only. The nurse relayed to me that PH did not think he was looking very good at the moment.

12. PH has continued, over the last few days, to receive the magnesium and potassium supplements. They offer some advantages. Dr RP told me that they maintain strength, reduce the risk of seizure, and minimise the risk of arrythmia. Manifestly though, they can only be of very limited utility where a patient is not taking feeds. Dr RP recorded the following in his statement:

> *"After further discussion, PH agreed to Magnesium and Potassium supplements to try and correct the electrolyte levels and have further bloods taken. I discussed with PH that supplements are not a replacement for food, which he indicated he understood. I explained to PH how the levels ultimately will get worse without feeds and supplements will not keep him alive in the long term alone.*
>
> *I queried with PH if he was accepting the supplements and the taking of bloods, to gain further time to reconsider his position, which I thought would be an explanation for accepting supplements but refusing feeds, but PH said no."*

13. It is this proposition i.e., whether PH may be accepting the supplements and taking of bloods *'to gain further time'* to consider his position which has, as I analyse it, generated this application. It is a concern that has been shared by the Official Solicitor, who recognises that PH has not always been consistent in his approach to taking feeds. However, logically, given that all now agree that PH has the capacity to take these decisions for himself, there is no jurisdictional basis for bringing the case to court. That said, I appreciate that the history of this case which, for this reason, I felt it necessary to summarise above, has led to a degree of professional anxiety in circumstances which are undoubtedly complex. I certainly make no criticism of the Board for bringing the case.

14. It is important to emphasise that PH strongly and consistently rejects the posited analysis that he is accepting the supplements to buy himself time. Dr SP said that in his view, PH agrees to treatment which he thinks can be useful to him, but which is not inconsistent with his refusal to feed. Thus, pain relief is accepted, so too is water, *"because I get thirsty"*. Antibiotics were accepted because it helps with sputum management and makes day-to-day life a little easier. I asked Dr SP whether he thought that PH had in fact constructed his own palliative care regime. Dr SP considered that he had. Dr SP thought that the supplements were inconsistent with this plan but had been determined upon solely by way of an attempt to get better serum level readings for the assessment for gastro-reconstructive surgery. It remains to be seen whether PH will continue with them.

15. Both Mr Brownhill and Mr Hillman sought to argue that the Court could make declarations pursuant to the inherent jurisdiction to the effect that supplements should be provided if PH requests them. With respect to both of them, I reject this submission. In *London Borough of Redbridge v SNA [2015] EWHC 2140 (Fam)*, I made the following observations which strike me as having resonance here:

> *"[33] The concept of the 'inherent jurisdiction' is by its nature illusive to definition. Certainly, it is 'amorphous' (see paragraph 14 above) and, to the extent that the High Court has repeatedly been able to utilise it to make provision for children and vulnerable adults not otherwise protected by statute, can, I suppose be described as 'pervasive'. But it is not 'ubiquitous' in the sense that it's reach is all- pervasive or unlimited. Precisely because its powers are not based either in statute or in the common law it requires to be used sparingly and in a way that is faithful to its evolution. It is for this reason that any application by a Local Authority to invoke the inherent jurisdiction may not be made as of right but must surmount the hurdle of an application for leave pursuant to s100 (4) and meet the criteria there.*
>
> *[36] The development of Judicial Review, as illustrated by ex parte T (supra), has also served to curtail the exercise of the powers of the inherent jurisdiction. No power be it statutory, common law or under the prerogative is, in principle, unreviewable. The High Court's inherent powers are limited both by the constitutional role of the court and by its institutional capacity. The principle of separation of powers confers the remit of economic and social policy on the legislature and on the executive, not on the Judiciary. It follows that the inherent jurisdiction cannot be regarded as a lawless void permitting judges to do whatever we consider to be right for children or the vulnerable, be that in a particular case or more generally (as contended for here) towards unspecified categories of children or vulnerable adults."*

16. It is also important to highlight the applicable statutory framework:

15 Power to make declarations

(1) The court may make declarations as to—

a) whether a person has or lacks capacity to make a decision specified in the declaration;

b) whether a person has or lacks capacity to make decisions on such matters as are described in the declaration;

c) the lawfulness or otherwise of any act done, or yet to be done, in relation to that person.

(2) "Act" includes an omission and a course of conduct.

17. Whilst the court may not make interim declarations, it may make orders and directions:

48 Interim orders and directions

1. The court may, pending the determination of an application to it in relation to a person ("P"), make an order or give directions in respect of any matter if—

a) there is reason to believe that P lacks capacity in relation to the matter,

b) the matter is one to which its powers under this Act extend, and

c) it is in P's best interests to make the order, or give the directions, without delay.

18. The above must be placed in the context of the overarching principles of the Act:

The principles

1. The following principles apply for the purposes of this Act.

2. A person must be assumed to have capacity unless it is established that he lacks capacity.

3. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

4. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

5. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

6. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

19. Thus, in the absence of a lack of capacity within the scope of Section 15 MCA, or any reasons for believing that P might lack capacity, as prescribed within the ambit of Section 48, there is no other gateway to a best interests' decision. There are good reasons for this. The court has no business in telling capacitious individuals what is in their best interests nor any locus from which to compel others to bend to the will either of what capacitious individuals may want or what the court might consider they require. Such a regime would be fundamentally unhealthy in a mature democratic society and would have the collateral impact of undermining the principle of autonomy which is central to the philosophy of the MCA.

20. The limited scope of the inherent jurisdiction is circumscribed by particular, albeit non-exhaustive, criteria which relate to vulnerable adults whose capacity for decision taking is being overborne in some way (see *Re SA [2005] EWHC 2942 (Fam); Southend-On-Sea Borough Council v Meyers [2019] EWHC 399 (Fam) (20 February 2019).* Nobody has suggested that that is the case here. Additionally, and practically speaking, it is difficult to formulate a declaration which is flexible enough to incorporate a turning point (which may not be immediately clear), where provision of supplements, upon request, is contraindicated medically. Taking of blood samples e.g., to assess serum levels, will not be appropriate if the deterioration of skin tissue makes that difficult and potentially painful for no clinical benefit.

21. It is perhaps surprising given the challenges that PH faces, that his voice, his wishes and feelings have been so voluble in the course of these hearings. His personality is fretted through the documentation. Shortly before this hearing, he was visited by the representative of the Official Solicitor. There was a note of that meeting which to my mind, requires to be set out in full.

> *"RH visited PH on Ward 5. He was asleep when I arrived and did not hear me knocking but woke when I called his name.*
>
> *He told me he was willing for me to come and in and nodded to the chair where he wanted me to sit. He had several blankets covering him and was wearing a hat. He was initially very sleepy and even when he was talking there was no sound coming out but this soon improved when he became a little more alert. He appeared to me (as a person with no medical qualification) that his face was more gaunt than when I had last seen him (5.2.22). I was not able to see the rest of him as he had blankets up to his chin. He looked tired and weary but he was, I felt, orientated to place. He showed some humour when he needed a tissue which I couldn't see but he pointed me in the right direction and was smiling/laughing at me when I commented I would never make a nurse.*
>
> *He did not appear distressed in answering any of my questions despite some of them being very difficult and personal. He answered each one without any prompting. He seemed thoughtful but at ease with the answers he was giving. The*

answers were not given flippantly in my view but with conviction in what he was saying. He was very calm throughout.

I asked PH how he was feeling?

PH "I am alright"

RH asked PH if he had any feeds and PH shook his head.

RH asked if he had anything to even taste?

PH: "some sweets"

RH "what is the likely result of you continuing to refuse feeds?"

PH "I will die"

RH: "How does that make you feel?"

PH "I really don't mind"

RH: Do you feel scared?

PH: "No"

RH: Do you feel sad?

PH "No" and he shook his head

RH" If not sad do you therefore feel happy or if not happy content?

PH "yes maybe"

RH asked if he was in pain

"No"

RH "What changed your mind about accepting feeds because after seeing Carreg Hafan you then did have some feeds?

PH "Lots of things really"

RH " I am sorry to ask but are you absolutely sure you have really thought this through?"

PH "Yes a lot"

RH: "Have you seen [N] recently ?

PH "Yes"

RH "Has she been here to see you or on facetime?"

PH "Yes here yesterday"

RH: "Does she know how long you have been without a feed?

PH "Yes….not happy with me, wants me to have a feed"

RH saying that I could understand [N] feeling like that and I may feel the same in her position and PH nodded and said "yeah I know"

RH "Do you know what will happen as time goes on if you continue to refuse feeds, how your body will react?"

PH "No don't know"

RH asking if this worried him but PH said "no I don't mind as long as not in pain…. Want pain relief"

RH "What is important to you as time goes on"

PH "Pain relief yes"

RH "Are you in pain now?"

PH "No not know"

RH asking PH if there was anything that could persuade him to accept a feed but PH shook his head.

RH explained that if he could think of anything I would make sure that was made loud and clear to people involved with his care. PH shook his head again.

RH explaining that [the accommodation] was, if not ready for him now, not very far at all from being ready for him. "With whatever is ahead of you would you want to move there with it being more like a house than a hospital?"

PH "No thanks"

RH questioning this with PH in that [the accommodation] is more homely, it will be quieter give him more privacy.

PH "No I don't want to, I want to stay here. The nurses I know and good to me. Stay here"

RH trying again to promote [the accommodation] as a better option than hospital but PH shook his head at it all saying "I will stay here"

RH asked if he was offered to him to go today would he go?

PH "No, I don't want to. I want to stay here. I know it and nurses"

RH asking how he felt about a more specialist unit if and when he gets weaker like an Intensive Care Unit possibly

PH "No…. I won't go"

RH asked PH if there was anything else he thought or felt about the situation or if there was anything I could say on his behalf to anyone

PH "Thank the Judge – he listened to me"

RH thanked PH for speaking to me. PH confirmed he was happy for RH to come and see him again"

22. I consider that this interview conducted by RH had been carefully prepared, fully thought through and sensitively conducted. This document particularly, but in conjunction with the other matters that I have analysed above, leave me to be entirely satisfied that PH has the capacity to decide upon his treatment. His decision to refuse feeding is distressing to all who have got to know him, in whose ranks, I include myself. But it is his decision. In whatever time may be left for him, he and the medical team will have to work together. It is clear that the relationship, notwithstanding the history of this case, is now not merely a functional one, but a mutually respectful one. There is no further role for the court.