Neutral Citation Number: [2022] EWCOP 13

Case No: 13892144

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 21/03/2022

Before :

THE HONOURABLE MRS JUSTICE JUDD DBE

- -

Between :

London North West University Healthcare NHS Trust	**Applicant**
- and -	
M	**1st Respondent**
and	
A	**2nd Respondent**
and	
H	**3rd Respondent**
and	
T	**4th Respondent**

- -
- -

Caroline Hallissey (instructed by **Capsticks Solicitors LLP**) for the **Applicant Trust**
Katie Gollop QC for the **Official Solicitor**
Sophy Miles (instructed by **Irwin Mitchell Solicitors**) for the **2nd and 3rd Respondents**
T was unrepresented

Hearing dates: 14 & 15 March 2022

- -

JUDGMENT

If this Approved Judgment

I direct that 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 MRS JUSTICE JUDD DBE

This judgment was delivered in private. 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.has been emailed to you it is to be treated as ‘read-only’. You should send any suggested amendments as a separate Word document.

The Hon Mrs Justice Judd :

1. This is an application by the London North-West University Healthcare NHS Trust for a declaration that it is lawful and in the interests of a young man, M to be put on the palliative care pathway and for IV fluids and other artificial life-prolonging treatments to be discontinued. The proposals are contained in a treatment plan set out in the court bundle and include the withdrawal of oxygen therapy and hydration, and the provision of palliative care including morphine and midazolam to eliminate (as far as possible) any pain, discomfort or distress.

2. The application is opposed by M's family, including his mother (A), his father (H) and his partner (T). Until the morning of the hearing the Official Solicitor was maintaining a stance that there might be an option for M to have some limited treatment in accordance with the wishes of the family, because although M was clearly dying there was a wider benefit to him of this because it would better enable his family to come to terms with his death.

3. By the morning of the hearing it became apparent that there were no options available whereby M could be actively treated. The current unit would be required to discharge him to another hospital, most likely the one where he was initially treated, Charing Cross. The clinicians there had indicated they were in agreement with the plan being put forward and therefore unlikely to propose anything different. There is no other option available for hospices and nursing homes are not able to manage patients having this type of treatment and it is extremely unlikely another hospital would take a different view.

4. Miss Gollop QC on behalf of the OS therefore invited the court to consider whether there was any useful purpose in holding the hearing. Given that the case was listed for one day only, that the start of the case had been delayed for a variety of reasons and could only be delayed more by hearing submissions on this point I decided to hear the evidence in any event. M's family had all come to court and would, I think, have found it very difficult if they had not been heard.

Background

5. M is a 23 year old man. Until 5th November, 2021, he lived at home with his parents and girlfriend in south-west London. He had been home schooled. Although he did not sit GCSEs or A levels he attained qualifications in IT and had worked as a computer engineer in the city. I am told that he is very intelligent and enjoyed playing poker and online computer games. He was said to be fit and well and would walk to work and back (an hour each way). I have seen pictures of him, and they show a happy and engaging looking young man. There is a lovely picture of him with his partner, T.

6. At the beginning of the pandemic in March 2020 M was furloughed from his job and then made redundant, which must have been very difficult for him. At about the same time, he attended a clinic for a painful but apparently minor condition where he was found to have high levels of glucose and ketones in his urine, suggestive of diabetes type 1.

7. M was advised he should be admitted to hospital for investigation and treatment. For reasons that are not clear from the evidence before me, he refused. Over the ensuing months he lost a very great deal of weight so that when admitted to hospital he was emaciated and weighed only 39 kg. His girlfriend, T suggested he believed that his blood results were affected by his recent diet and that he tried to manage things by going on a fruit diet only, and then fully plant based. He was anxious about catching Covid. When his weight continued to drop he resumed a normal diet but still he lost weight. He still did not seek medical attention even when he became ill with what appeared to be a chest infection in the last few days he was at home.

8. On 5th November 2021, M suffered a cardiac arrest at home in the presence of his mother and father. They dialled 999 and also called a neighbour to help, as they did not believe M would wish to go to hospital. The ambulance crew arrived and continued with CPR for an extended period of 45 minutes and 20 cycles when spontaneous cardiac output was restored. On admission to hospital, M was found to be emaciated with pressure sores. A safeguarding referral was made. M was placed into an induced coma, intubated and ventilated. He also required inotropic support. He remained in an induced coma for 12 days, but when sedation was withdrawn he still remained in a state of disordered consciousness.

9. M was diagnosed with Type 1 diabetes mellitus, which was initially hard to control. He was fed by nasogastric tube. CT and MRI scans demonstrated hypoxic ischaemic damage to his brain and his liver. He underwent a tracheostomy on 26th November, and as is common in such circumstances, he had episodes of hospital-acquired pneumonia treated with intravenous antibiotics. He suffered what is known as 'storming', namely increases in heart rate, blood pressure, temperature and sweating.

10. His condition was such that the team at the hospital concluded that he should be registered as DNR, a decision with which the family objected. On 25th January M was transferred from the first hospital to the hyper-acute rehabilitation unit (RU) for assessment, where he remains.

11. M's condition deteriorated after his arrival at the RU, and there were particular problems with providing nutrition after M developed an ileus. The treating clinicians came to the conclusion that providing enteral nutrition was no longer possible and that the focus of M's care should move to being palliative only. It became apparent that there was profound disagreement between the hospital and the family, and the former consequently made an application to the court.

12. The case came before Moor J on 25th February 2022, where directions were given as to the instruction of two experts. Dr. Christopher Danbury and Dr. Andrew Hanrahan were instructed. Dr. Danbury is a Consultant Intensive Care Physician at University Hospital Southampton, and Dr. Hanrahan is a Consultant in Neurohabilitation at the Royal Hospital for Disability in Putney. The case was set down for hearing on 14th March with a time estimate of one day.

13. At that hearing the OS suggested that the applicant should give further consideration to providing M with nutrition via TPN (total parenteral nutrition) pending the trial. This has not happened, for reasons which are set out in the second statement of the treating consultant. M has continued to be provided with oxygen therapy, suctioning, and hydration.

He is being given limited amounts of morphine and midazolam, more limited than the treating team consider that M should have.

14. If M is not accorded end of life care in accordance with the applicant's care plan he must be transferred to another hospital. It became apparent by the morning of the hearing that there are no real options for M to be actively treated anywhere. Charing Cross hospital (which is the hospital to which M was originally admitted) is the obvious option, but it is very likely the treating team there would determine that active treatment should cease as well. Indeed, the two consultants who treated him there have indicated that they would support the applicant's plan. There is no other hospital or unit which has indicated it would be able or willing to give M active treatment. Hospices and nursing homes will not accept patients with tracheostomies and who need oxygen therapy and suctioning.

15. The available options for M are therefore to be treated in accordance with the applicant's plan or to be discharged back to Charing Cross to be treated in accordance with the decisions made by the clinical team there which are likely to be the same as they are at the RU.

16. For this hearing I have read all the documents in the bundle which included two statements from Professor Turner-Stokes (which were also signed by Professor Playford), reports from Professor Wade, Dr. Danbury and Dr. Hanrahan. I have read statements from M's mother, A and his partner T. I heard oral evidence from all these witnesses and also from M's father, H.

The medical evidence

The evidence of Professor. Turner-Stokes

17. In her statement for these proceedings, Professor Turner-Stokes, the treating consultant at the RU stated that examination on admission revealed M was thin and wasted and that he appeared restless and distressed. He was doubly incontinent and paralysed in all four limbs, with established contractures. His heart rate was very high. The

tracheostomy was in situ with the cuff inflated all the time. Neurologically he was said to be in a prolonged disorder of consciousness. On the PDOC pain score he scored 3-4/17 at rest but showed evidence of significant discomfort on movement and suction, raising a concern that he could perceive pain and discomfort despite his level of consciousness.

18. Following his admission to the RU he suffered a number of episodes of oxygen desaturation, and following an attempt to change his tracheostomy was transferred to the intensive care (IC) unit for a few days. His condition remained unstable and there were several interventions by the medical emergency team (MET) which included chest physiotherapy which was of short term benefit only and distressing. A CT scan of his lungs showed severe damage, which was said to be due to chronic aspiration and a decision was made not to continue this intervention due to his overall deteriorating condition.

19. Added to this, M developed an ileus, which is a condition whereby the gut ceases to propel food along the intestine by the process of peristalsis, causing distention, regurgitation and aspiration of vomit into the lungs. Therefore naso-gastric feeding was discontinued, and following consultation with the Consultant in charge of the nutrition team, it was concluded that no other sort of feeding (including total parenteral nutrition ‘TPN’) would be futile and indeed might cause serious complications. Since 15th February M has received no further nutrition.

20. The multi-disciplinary team carried out an assessment – the Wessex Head Injury Matrix – to establish M’s level of awareness. His score levels carried out over two days were found to be 4 and 6 respectively out of 62 which amounts to a vegetative state. A few days later, however, on 19th February, M was observed to fixate on his mother’s face, and the direction of his eyes changed when she moved position. He also blinked 10 seconds after his father asked him to do so, although the doctor stated that M blinks at a rate of 3 times every minute in any event. The family reported that M was tracking more consistently with his eyes at the previous hospital.

21. In her oral evidence, Professor Turner-Stokes said that M is gradually fading. If he was to be moved from the unit it is more likely than not that he would die in the ambulance because movement of this sort causes him to have mucus plugs which reduce his already very limited lung function. When turning him he will often suffer from oxygen desaturation. Further, the palliative care on offer at the RU may be better tailored to M's needs than at Charing Cross, because they are able to provide IV rather than sub-cutaneous morphine and Midazolam (sub cutaneous being the usual route in acute hospitals). Also, M would there be likely to be on a busy and acute ward with less attention from nurses and other medical professionals.

22. Professor Turner-Stokes was of the opinion that M may have some awareness and this caused her to be concerned that he would be able to feel pain, discomfort and distress.

Professor Wade

23. Before making the application to the court, the applicant sought a second opinion from Professor Derick Wade, Consultant in Neurological Rehabilitation. He examined M on 19th February and also met with members of the family. He concluded that M was, without doubt, in a prolonged disorder of consciousness, at the low end of awareness and responsiveness. His life expectancy is limited to a few weeks at most, and is unable to have food and hydration given enterally. TPN might extend his life expectancy but it is not safe or realistic given his many other problems. He concluded that he should be given good palliative care, saying that he did not think it was morally acceptable to continue to deny this to M.

Dr. Danbury

24. Dr. Danbury examined M and reported on 2nd March. He considers that the cardiac arrest suffered by M on 5th November 2021 was caused by Type 1 Diabetes, leading to autonomic neuropathy and consequent failure of the gastro-oesophageal sphincter, reflux, aspiration of the stomach contents and pneumonia. His opinion is that M's care in both hospitals has been of a high standard.

25. He states that initiation of TPN is possible but will have no impact on M's pulmonary pathology. He is at risk of infection and thrombosis, particularly because of his chronic malnutrition. Dr. Danbury opines that re-establishment of enteral nutrition will shorten his life because it will increase the aspiration of stomach contents into M's lungs. Dr. Danbury states that M is dying, and that nutrition by any process will not change this. If he was the treating doctor he would not be prepared to initiate nutrition. He considers that M is benefitting from the low level of midazolam and morphine that is being administered.

26. In his oral evidence Dr. Danbury agreed with Professor Turner-Stokes' assessment that it is likely M would die as a result of being transferred to another unit. He said he would be willing to support M's move to another unit, with continuing hydration and oxygen therapy if such was available because of the relationship between the treating team and the family. There could be a potential benefit to him for his family to have a better memory of his death than could happen if he stays where he is. Nonetheless, he said that it was extremely unlikely another unit would take him and acknowledged that the current regime of treatment whereby M is given deep suction could be extremely painful and needed to be given sufficient pain relief to counter it.

Dr Hanrahan

27. Dr. Hanrahan found M to be thin and wasted, restless and distressed, doubly incontinent and paralysed in all four limbs. He had contractures and deformities in his wrists and ankles and resting tachycardia. He believes M to be in a vegetative state with some very infrequent and non-reproducible behaviours to suggest the minimally conscious minus state. This state is highly unlikely to change, and his life expectancy is severely reduced to days or weeks. Invasive and frequent suctioning is likely to be burdensome to him. He said in very clear terms (and emphasized in bold in his report) "**It would be remiss of me if I did not state, clearly and urgently, that this situation M, his family and team find themselves in, has all the hallmarks of a need for a terminal care plan. It must be addressed immediately if a good death is to be had and witnessed. There is no ceiling to care, just treatment'.**

28. Dr. Hanrahan's opinion is that it cannot be in any of M's known interests to perpetuate a life of permanently disordered consciousness, by

continuing treatments that have no clinical or moral value. IV fluids are merely prolonging the dying process and serving only to interrupt a natural cascade of events leading to death. Whilst M is almost certainly completely unaware of his surroundings, it is usual practice to allow for the small chance that experiential distress is possible and to treat him as such. M has features which would commonly be interpreted as distress.

29. Finally, and tellingly he says this 'I am uncertain as to the best interest decision needed when such decisions can only be made from available options. M is at the end of his life and dying; there seems to be a choice only between a well-managed, reconciled and dignified death and a contested, adversarial and ultimately futile situation'.

30. It is therefore abundantly clear that all the doctors who have been consulted are in agreement about M's condition, prognosis and effect (or lack of it) of any treatment. Despite careful questioning by Ms Miles on behalf of the family, none of them considered that there is any doubt about M's terminal condition and the medical futility of any further active treatment.

The family evidence

M's parents

31. I have a long and detailed statement from A, M's mother, in which she speaks for herself and M's father, H. She strongly opposes the applicant's plan. In paragraph 4 she states, bluntly that they she does not believe they care for M's interests. Their application, she says is 'prejudicial, punitive and constitutes vexatious proceedings'. Later in the statement she says that members of the clinical team have lied and that they wish to euthanise M. She says she believes there are individuals who have a vested interests that M does not survive.

32. Much of A's statement sets out what she considers to be the contradictions between what was said during various meetings (which have all been recorded by her) between the family and clinicians, and between the transcripts and the minutes.

33. She says that the family believe that it is important for new scans to be done of M’s lungs, stomach and intestinal tract to find out what is going on, and that he should continue to be treated. They consider that the administration of midazolam and morphine is harming him and hastening his death.

34. In her oral evidence, A said that the family would like M to be given nutrition (whether via a PEG or TPN), and scans to verify his current situation with a view to finding out for certain what is the medical prognosis. They wish for him to be given a chance to recover. She said that they all believe that M would wish to be given a chance to live. She believed that the clinicians were showing bias, and simply closed the door to further treatment and that whatever further options the family could consider were closed off. She cited Professor-Stokes getting in touch with the clinicians at Charing Cross as an example of this.

35. Although H did not give a statement I could see that he was anxious to speak during the proceedings. He therefore gave oral evidence. He told me how very clever and accomplished M is, and how much he enjoyed life and would have wished to live. He said he had seen M reacting in various ways to the family, including responding to commands. He said that there was an occasion when the oxygen mask had fallen to M’s chest but M still had high levels of oxygen saturation, which meant, he thought, that M was able to breathe in sufficient oxygen in ambient air, at least for some of the time.

M’s partner, T

36. T, M’s girlfriend has also filed a lengthy statement setting out her opposition to the declarations sought by the applicant. She and M have been in a relationship for some four years. She said that M made her aware that he had attended a clinic in March 2020 where he had been told he had high blood sugar and ketones, but that he thought the results may have been skewed because of what he had eaten in the hours preceding it. He refused to go to hospital because he was worried about catching Covid-19. Over the months that followed she said M wished to lose weight and eat more healthily and so she helped with this by preparing him fruit only meals. He lost a great deal of weight and so she persuaded

him to agree to a whole food plant based diet, but he did not put on weight as a result. She said he then switched to a normal diet but this did not work either. In the three or four days before he went into cardiac arrest she said that he did appear to have an infection.

37. Much of T's statement is concerned with setting out her disagreements with the treating clinicians and how she believes that they have let M down. She believes that M's brain injury is in the early or acute stages post injury and is likely to heal with assistance and opportunity for rehabilitation. His recent reduction in consciousness, she believes, is due to the administration of midazolam and morphine. As to lung damage, she believes that there are discrepancies in what the experts are saying.

38. Within her statement T sets out a number of reasons why she does not think that M is suffering from significant pain and distress. She believes that he is able to experience pleasure, as he has responded (she says) to music that she has put on for him to listen to, widening his eyes to demonstrate what music he would like to listen to, blinking and moving his mouth. The administration of palliative drugs will reduce his ability to interact with the family and have positive experiences as a result.

39. T does not accept that TPN is futile, on the contrary she believes it will improve M's quality of life. She does not believe he is imminently dying, and points to a variety of statements by the treating doctors which she says undermine the evidence that has been given to the court. She believes that, even if he is at the end of his life he should not be deprived of fluids. She says that certain members of the clinical team have lied to her about his medical condition and have incorrectly inferred that he is going to die a lot sooner than he is. She says that they do not have his best interests at heart and have lied to her as well.

40. In her oral evidence, T said very much the same as what she had said in her statement. It is plain that the family are close knit and are working together to support M as best they can and in the light of what they think is in his best interests.

41. The love that all the family have for M was plain for all to see as was their grief and pain at what is happening now. They are completely committed to him and genuine in their views. It was clear to me, however, that they are simply not able to bring themselves to face the overwhelming nature of the medical evidence or to assess it in a rational way. I do not criticise them for this because it is an utterly tragic and emotional situation for them all.

The submissions of the parties

42. The applicant’s case is that it is not in M’s interests to continue any active treatment, and that he should now move to the care plan put forward by the hospital trust. The doctors are not prepared to give M active treatment which they consider is futile and against his interests.

43. Although the parents were represented together by Ms Miles, and T was unrepresented it is clear that the family are entirely united and present the same case together. They hold the hope and belief that M will be able to recover. The family wish for treatment with oxygen and hydration to continue and for M to be given nutrition in some form. They ask for further medical investigations and for M to be given the chance to live. They say that M would have wanted to recover and that his determination to address his health problems independently should not be confused with ambivalence about wanting to live. On their behalf, Ms Miles submits that the continuation of some treatment such as hydration is not burdensome to M and may allow the family to spend some more precious time together.

44. Ms Gollop QC for M suggested in her position statement at the start of the hearing that there may be a third way which was neither the sedated withdrawal of all treatment advocated by the trust or the lightly medicated continuation of all treatment that the family would want. If, it was submitted, a hospital and different team could be found to continue end of life hydration, oxygen and suction, together with end of life sedation then that might be the best option. It is, she said the OS’s ‘strong view’ that it is in M’s best interests to be provided with pain relief

and sedation in accordance with the applicant's care plan. If the court did not endorse this, it might change the stance as to the continuation of hydration, suctioning and oxygen.

45. Until the morning of the hearing there appeared to be some doubt as to what the available options were for M. The applicant had made it clear that as an tertiary unit (under extreme pressure of demand) the RU is not able to treat patients long term (which includes periods of two weeks or outside of the tertiary specialist service remit). Such patients must be transferred to another hospital. Given the severe condition of some of the patients who are admitted there some will be very sick indeed and die, and therefore RU is able to administer end of life care but patients not in this category will be transferred and treated elsewhere.

46. In those circumstances, Miss Gollop submitted at the end of the hearing that a transfer from the current hospital would serve no constructive purpose, and that therefore there is no real choice for the court to make.

Law

47. M's best interests are to be determined in accordance with section 4 of the Mental Capacity Act 2005. This provides as follows:-

> *(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of (a) the person's age or appearance or (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.*
>
> *(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.*
>
> *(3) He must consider*
> *(a) whether it is likely that the person will at some time have the capacity in relation to the matter in question, and*
> *(b) if it appears likely that he will, when that is likely to be.*
>
> *(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or improve his ability to participate, as*

> *fully as possible in any act done for him and any decision affecting him.*
>
> *(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.*
>
> *(6) He must consider, so far as is reasonably ascertainable, (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity); (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so.*
>
> *(7) He must take into account, if it is practicable and appropriate to consult them, the views of (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind; (b) anyone engaged in caring for the person or interested in his welfare; (c) any donee of a lasting power of attorney granted by the person, and (d) any deputy appointed by the court.*

48. The Code of Practice states as follows

> *5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.*
>
> *5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any*

> *statements that the person has previously made about their wishes and feelings about life-sustaining treatment.*
>
> *5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests.*

49. In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, Baroness Hale stated as follows:

> *"[22] Hence the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."*
>
> *"[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are*

> *interested in his welfare, in particular for their view of what his attitude would be."*

50. At paragraph 45 she added:

> *"[45] The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are… But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which are important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being"*

51. The rights of M are protected by Articles 2, 3 and 8, recognising the strong presumption in favour of prolonging life where possible. His family, namely his mother, father and T have the right to respect for their private and family life.

As MacDonald J noted in *Re Y (No 1)* [2015] EWHC 1920 (Fam) at paragraph 37, "*the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment, but that obligation does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the treatment would not be in the best interests of the patient concerned* (see *R (Burke) v The General Medical Council* [2005] EWCA 1003)".

52. In *Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2012] 1WLR 1653, Baker J (as he then was), stated

> *"235. Able-bodied people frequently feel (even if they do not say so) that disability invariably restricts the enjoyment of life. With the growth in understanding about disability in recent years, however, has come an awareness that people with disability often experience profound enjoyment of life, within the limitations that their disability may impose..."*

53. In *Re N v ACCG and others* [2017] UKSC 411 , the Supreme Court emphasised that the Court of Protection only has power to take a decision that P himself could have taken and that it has no greater powers to oblige others to do what is best than P would have himself. In paragraph 35 Lady Hale stated that this must mean, that just like P, the court can only choose between the 'available options'. In paragraph 40, she pointed out that the extensive case management powers of the court include a power to exclude any issue from consideration, which must (paragraph 41) include a decision that no useful purpose will be served by holding a hearing to resolve a particular issue.

Discussion

54. It is agreed that M lacks capacity to make these decisions for himself and will continue to do so. That is clear from all the evidence I have read and heard.

55. The matter for the court to determine is what is in M's best interests, although this can only be done on the basis of the options that are available.

56. The medical evidence in this case is unanimous, compelling, and overwhelming. I accept what Professor Turner-Stokes and all the other experts have said. Tragically, this young man of only 23, is dying. If he continues to be treated as he is he will die within a few weeks. If he is given palliative care only he is likely to die within hours or days. There is nothing that can be done about it. I appreciate that T and M's parents struggle to accept the evidence that he will die very soon whatever my decision, but, whilst their views are sincerely held and entirely understandable, they are not based on a rational assessment of what they are being told or what is observable. They believe that M has a chance of life and that this should be given to him. This is understandable but the medical evidence is completely to the contrary. So strong are the family's convictions that at some point in their written statements they have suggested that the clinical team are lying and that they have malign motives. They believe that the instructed experts did not spend sufficient time with M to be able to come to their conclusions.

57. The evidence of all the doctors is that to provide M with nutrition, hydration, or any other active (as opposed to palliative) treatment is

medically futile and in some respects, burdensome. Initiation of TPN would put him at risk of infection and thrombosis, and enteral nutrition will actively shorten his life because it will increase aspiration of stomach contents. Hydration will lengthen his life a little, but the medical evidence is that this will not make him more comfortable at all. If he has any awareness, suctioning him is intrusive and uncomfortable. Dr. Danbury said that recovered patients had described the sensation to him as being like having a hot poker thrust down the throat.

58. I do not know a great deal about M's views and wishes during his lifetime. Unsurprisingly as a young man he did not discuss what he might want for himself were he to become incapacitated with anyone. What I do know is that he decided on what many might think was an unwise course of action when he refused medical advice to seek treatment for what might be diabetes, a fatal condition if not treated, but eminently manageable if it is. He did not want to see (or even consult) a GP, or to go to hospital about his blood sugar although I do note he sought treatment for an apparently more minor and painful condition in the first place.

59. Notwithstanding his refusal to engage with investigations or treatment in the last eighteen months of his life, I do accept that M enjoyed life and wished to live. I accept that he sought medical treatment in the past and so start from the assumption here that he would have wished the doctors to do all that they could to treat him and, if possible, to make him better. If there was a chance of life, I believe it would be in accordance with his wishes and best interests for him to have active treatment. But this is not the case.

60. If he was able to make decisions for himself based upon the evidence that I have before me it is very difficult to see how he would make a choice to be given nutrition (whether TPN or enteral) when it would be at best futile and at worst actively harmful. I accept the evidence of Professor Turner-Stokes as to why he was not given TPN following the last hearing before Moor J when it was canvassed.

61. It is easier to see how M might wish to continue to be hydrated, but this wish would be unlikely to persist in the face of the very strong evidence that this would simply prolong his existence for a short while without any benefit to him in terms of quality of life. Having heard and read the evidence it is difficult to see how this could be in his best interests. In any

event, even if M had capacity, he would not be able to insist on this in the face of clinicians who consider it to be against their professional and moral judgment to provide it. Nor, in those circumstance can the court.

62. I consider that it is in M's best interests to receive the full palliative care that is on offer. The family believe that these drugs are reducing his consciousness and hastening his death. Whilst there seems to be very little or no support in the medical evidence for this view, it is true that the administration of these drugs may derive no benefit to someone who is unconscious. Professor Wade explains in his report why he believes that someone in this state is not able to experience pain or discomfort. Dr. Hanrahan, however, states that it is usual to give such drugs to allow for the small chance that M is able to experience some pain or discomfort and notes (as do other doctors) that there is some evidence that M does so. Palliative care will, as much as is ever possible, guarantee the absence of pain, emotional distress and discomfort in the last days and hours of M's life. It is true that it will reduce or eliminate such awareness as he has of his loved ones around him which is very difficult, but if he does have such awareness that brings with it the likelihood of distress and discomfort. This would mean suffering in a way which he cannot communicate or avoid and would be very negative. In my judgment the benefits of this treatment strongly outweigh the burdens.

63. The options for M are really very limited. It would be possible for him to be transferred to Charing Cross, at least to remove him from the current environment where the relationship between the treating team and family is so very difficult and challenging. However, I must bear in mind the following matters. First M is likely to die in transit. If he does not, then the likelihood is that the treating team there will take exactly the same view as the current team. The relationship between that team and the family might well break down for the same reasons. In any event, at Charing Cross M would likely be treated on an acute ward with fewer staff who will change and rotate over time. IV transmission of morphine and midazolam, which works so well may not be available. So the possibility of a better situation for him or the family if he is to die there seems very remote.

64. I cannot see that, looking at M's best interests in the widest sense, including the importance to him and his family of being able to die in a peaceful and

dignified manner are met by such a move. It is far and away in M's best interests to remain where he is and to be treated in accordance with the plan. I note that Professor Turner-Stokes said she would do all that was in her power to ensure the family could all be with him when he dies. I note too that the family are able to get on with the nursing staff for much of the time they have been visiting. Of the options available, this is the one which is in his best interests.

65. In all the circumstances, I will make the declarations sought.

66. I know the family will be even more devastated than they already are by this decision. I wish to extend to them my profound sympathy for the situation in which they find themselves, for it is obvious that M is much loved and treasured by them all.

67. I wish to thank counsel for the assistance they have given to the court.

Postcript

68. I distributed my draft judgment on Tuesday, and very sadly M died on Thursday before the care plan was put into action. I understand the family was able to be by his side.