



Neutral Citation Number: [2022] EWHC 515 (Fam)

Case No: FD21P00983

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 11/02/2022

Before:

MRS JUSTICE MORGAN

Between:

Pennine Care NHS Foundation Trust	<u>Applicant</u>
- and -	
Mrs T	<u>1st Respondent</u>
- and -	
Mr T	<u>2nd Respondent</u>
- and -	
Northern Care Alliance NHS Foundation Trust	<u>3rd Respondent</u>
-and -	
Amy (By Her Children's Guardian)	<u>4th Respondent</u>

Mr Vikram Sachdeva Q.C (instructed by **Hempsons**) for the **Applicant**
Mr Parishil Patel Q.C (instructed by **Hill Dickson LLP**) for the **3rd Respondent**

Ms Shabana Jaffar (instructed by **Cafcass Legal**) for the **4th Respondent**

Mr & Mrs T Appeared in Person

Hearing dates: 11th February 2022

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.

MRS JUSTICE MORGAN

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published. 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.

Mrs Justice Morgan:

1. Amy, the young woman with whom I am concerned, is 17. She is talented, intelligent and a much-loved sister and daughter. She is academically very able, socially popular, considerate of others, kind and has a keen interest in social justice and environmental issues. She has in every imaginable sense a great deal to live for and her whole adult life before her. Yet from about September of 2019, in ways that I will examine further in the course of this judgment, her mental and then her physical health began to decline such that the application before me today under the inherent jurisdiction is to authorise the use of a highly invasive, very unusual medical procedure so as to attempt to preserve her life and to try to buy time for her to be given – and to have the physical strength to benefit from - treatment and therapy.
2. Two striking features of the situation before the court today are these: the medical procedure which I am asked to authorise itself carries with it significant risks; it is out with the experience both of the acute care clinicians involved in her care and of the mental health team looking after her. It is proposed only because the professional view of those proposing it is that there is nothing else to be done which may achieve a positive outcome. Her trajectory is towards death. The second feature is that if somehow sufficient time and physical strength can be found to permit it, those treating her are optimistic that there are treatment options which can help her. They are not regimes, as has been impressed on me, in the realms of palliative care.
3. The application is brought by the Pennine Care NHS Foundation Trust - that trust is one of the Trusts involved in Amy's care. The application has the support of Amy's parents. The third respondent to the application is the Northern Care Alliance NHS Foundation Trust ['The Acute Trust'] which is the other Trust with involvement in Amy's care and the Trust which will be responsible for carrying out the procedure if permitted. The Acute Trust adopts a position which is best expressed as follows: it does not mount any argument amounting to opposition of the order sought nor does it advance any other or alternative plan of treatment which it argues would better meet Amy's needs but in the light of the novelty of the treatment, the risks and the uncertainty of the care plan it does not positively agree the application but rather submits it must be the decision of the Court.
4. In describing shortly, as I will now, the background which has led to the situation in which I am asked to make the order sought today I do so with as little detail as is necessary to provide context. There is no need to add to the pain and anguish lived through by Amy and her family by recounting the full detail here. In September 2019, Amy started to show signs of what was later diagnosed as 'Obsessive Compulsive Disorder' [OCD]. There was, at first success with intervention and treatment but there came a time when her family noticed that she had started to show marked weight loss. She was restricting her calorific intake and increasing her use of those calories she did take in by exercising in an excessive way. She was referred to Community Eating Disorder services by which time her weight and her 'Body Mass Index' [BMI] were at less than 75% of that which would be desired. An intensive community re-feeding regime produced at first some improvement but matters deteriorated such that by April 2021 she was admitted (informally) to Royal Manchester Children's Hospital (RMCH). She refused all oral nutrition and 5 days after her admission tried to abscond. Following detention under s3 of the Mental Health Act 1983, the operation of s 63 of the Act meant she could be, and / or was, fed by means of restraint. Two

months later she was moved to a small unit specialising in the care of young people with significant and or enduring mental health difficulties. Over time her refusal of nutrition and of treatment was accompanied by self-harm. Self-harm at a serious level. The refusal of treatment is characterised by those treating her as an ‘inability’ to accept it and is described as being pitched at ‘*an extremely high level*’. That inability to accept interventions and assistance for herself is one of the manifestations of her mental illness.

5. It is important that in all of this, the sense of Amy the person is not lost, and so I pause to observe that although the inability to accept treatment care for herself is enduring and near absolute, I was told that she has throughout been cooperative with the taking of lateral flow tests to detect the Covid 19 virus, because, as she sees it, that is necessary for the wellbeing and care of others in the unit. That makes visible briefly to all, the young woman her parents describe as caring, thoughtful, considerate, and kind. Although because of her illness she has felt unable to allow herself to have much contact with her family, she does communicate with them in a limited way using notes and small messages. They are affectionate and caring communications.
6. Those who are looking after her mental health are firmly of the view that she wants to live but that her will to accept the interventions she needs to be able to do so is overborne by the mental disorder from which she suffers. That firm view is shared by her parents and is borne out by some of the material I have seen in the bundle where in her notes to her parents and siblings, Amy touches on the possibility of a future in which she would be able to see them were she able to recover. There are also generous and warm expressions of delight in her sibling’s exam success which clearly contemplates their prospects for the future and her interest in their future.
7. The current position is that she continues to refuse all medication, examinations, treatment, intervention or assessment save and except that there has been one recent instance in which she was compliant with a particular imaging assessment. She is fed involving restraint but has developed a mechanism whereby she is able to expel a significant proportion of the nutrient even when restrained. The result of this is that she is taking in so little of her required nutrition - an estimate of about half her minimum nutritional needs is what I have been given – that she is now on a downward trajectory which is overwhelmingly likely to end in her death. The extent and degree of supervision and restraint required to try to reduce her opportunity to harm herself is such as to markedly diminish her dignity.

The Relevant and Applicable Law

8. It is well established that every adult of sound mind has the right to consent to or refuse treatment: *St George’s Healthcare NHS Trust v S* [1998] 2 FLR 728. The position differs in relation to a child. Those who are a child’s treating doctors require the authority either of someone authorised to provide consent or of the Court: *Re R (A Minor) (Wardship: medical treatment)* [1992] 1 FLR 190. In Amy’s case, she lacks capacity to make the decision for herself. Her parents, as it happens do consent. This is in no sense one of those cases where the clinicians and the parents are at loggerheads and the Court intervention is the only way to resolve the impasse. The reason this case comes before me is because so unusual is the nature of the treatment proposed that the Trust seeks for the court to make an order, if treatment is to be given.

9. It is also a well-established principle per (Dame Butler-Sloss (P) *Re MB (an adult: medical treatment)* [1997] 2 FCR 541 at 555) that best interests encompass medical, emotional and all other welfare issues. The principles governing the Court's approach to the question of best interests have been helpfully distilled by Mr Justice Hayden in *University Hospitals of North Midlands NHS Trusts v AS M and F* [2021] EWHC 2927 which it is useful to set out here:

41. The legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not 'Gillick' competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

- i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment;
- ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be;
- iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

"This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."

- iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests;

v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great;

vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment;

vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive;

ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

"The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

42. These principles have been reiterated repeatedly at appellate level. In *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:

"[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

And

"[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."

10. Those principles reflect among other things the anxious consideration previously given by the Courts to the proper approach to be taken to parents' views about best interests. As Per Ward J in *Re A* [2000] EWCA Civ 254 at 525F: "*Since the parents have the right in the exercise of their parental responsibility to make the decision, it should not be a surprise that their wishes should command very great respect. Parental right is, however, subordinate to welfare.*" I have heard at this hearing, directly from Amy's parents about their wishes, their view and why they think the course proposed is in Amy's best interests.
11. In the case before me, the decision does not concern the withdrawal of treatment, I accept however the submission of Counsel that the principle of objective best interests is applicable to Amy's case given the serious nature of the treatment proposed. To put it another way I accept that I must be satisfied that Amy's best interests are met in the widest sense so as to justify the treatment proposed

The Proposed Treatment

12. It is proposed that Amy should be transferred to an intensive care unit at a nearby general teaching hospital for a period of sedation under General Anaesthetic. The anticipated sedation is for a duration of 3-7 days so as to provide physical investigation and treatment and most significantly a sustained period of re-feeding. It is then intended that Amy should be returned to continue intensive mental health treatment and treatment to support her physically in that. That course of treatment carries with it considerable risks. These include but are not limited to: her death, albeit on present information an inevitable end point in the relatively near future of her trajectory, could be hastened; there is a risk of organ shutdown and/or failure – including in a way which might affect the absorption of nutrients thus defeating the

very purpose of admission; there will inevitably be muscle wastage; there is a risk of delirium once re-awakened from sedation, which risk would be exacerbated by her already troubling mental health history; a form of Post-Traumatic Stress Disorder [PTSD] is a recognised consequence of a period in Intensive Care Unit [ICU].

13. The timing of the proposed intensive care admission is critical: on the one hand the nature of what is intended is such that there is a recognition that it would be only undertaken once Amy is showing significant decompensation but balanced against that on the other hand is that it must be undertaken before she has deteriorated to a point where there is an acute emergency situation in which circumstances the prognosis of a positive outcome is likely as I understand it to be very poor. Her entry to the ICU would thus differ from the usual route there which is either broadly speaking arising from an unexpected, emergency situation or in a planned elective way following on from, for example a surgical procedure. The intended plan for Amy has been characterised in the hearing before me by clinicians as ‘semi-elective’
14. What I have described is the outline of the plan for her. The intended treatment is set out in a document which is headed Proposed Treatment Care Plan and is agreed as between the Mental Health Trust and the Acute Trust who are parties to this application. It is a plan which has been drawn up having had the input and careful consideration of a range of highly skilled and very specialised clinicians and medical professionals. The intention of it, so it emerged in oral evidence is to provide a plan within which the on the ground clinical decisions, in particular as to timing of any interventions, will be taken when required and in a way which involves Multidisciplinary Team meetings regarded so I heard in oral evidence as ‘key’ by those clinicians who would be putting any sedation into effect.
15. There is clear assessment that Amy lacks capacity. The mental disorder by which she is afflicted means that whilst she is perfectly well able to receive information and on one level to understand the meaning of it, she is prevented from using or weighing that information so as to make decisions. Her own views have been exceptionally hard to obtain in any direct way. The Guardian appointed for Amy in this application went urgently to visit her at the unit to try to ascertain her views. She was not able to engage Amy in any direct conversation. Amy has been electively mute in recent times, and so she remained during the Guardian’s visit. She was, during the Guardian’s visit even when closely supervised showing signs of intense distress and concerted attempts to behave in ways which would cause her physical harm. Following on from her visit the guardian filed a position statement. She raised within it some real anxieties about the risks of the admission to Intensive Care which I am asked to approve but she ultimately takes the position that on what she describes as a ‘narrow’ balance, she supports the application made. Since the guardian had raised a number of questions about Amy, the possibility of alternative courses of action, and her prognosis, I have received as a result, very up to date evidence as to Amy’s present condition in the form of a statement signed this morning by Dr Cooper. What emerges from that statement is that although there had been an unexpected period of relative medical stability in the period since the end of December when the decision was taken to make an application to the Court, there appear now to be indications of deterioration. At best her position can no longer be regarded as medically stable

Evidence

16. In addition to the written evidence and the detailed medical recordings provided to me. I have heard oral evidence from Drs Cooper; Damle and Ferris at this hearing. I wish to record here my gratitude for their attendance and for the thoughtful and impressive evidence they each contributed. The outstanding care of Amy and the commitment to doing their very best for her was obvious to me from each of them. So too was the extent to which each of them worried about what that might be.
17. Dr Cooper told me that he knows Amy very well, better in fact than any other patient for whom he has cared, having treated her now for a considerable time. He estimates that 40 –50 % of his working time is spent on her case alone. He and Dr Damle the consultant in charge have worked closely with and sought guidance from South London and Maudsley trust ('SLAM') the national centre of excellence for the treatment of OCD related mental disorders. He told me that this application, or at least the care plan which gives rise to it has its origins in the very great optimism from SLAM that if time could be found Amy would recover. The word he told me in evidence had been in those discussions about the prospect of recovery was 'certain'. When I asked him about the use –unusually- of that word in a medical context he said that OCD was eminently treatable and that those with whom he had been in discussion had said in terms: *what we tell all our patients with OCD is you will recover you will get better*. The anxiety for him, in the face of so much hope for Amy's recovery, is that she will die before anything can come of that hope.
18. Dr Damle has not treated her for as long as Dr Cooper but she too has optimism for the future – if Amy's life can be preserved. What she is not at all optimistic about is her present physical state. The early signs, she told me, are there, of a further deterioration. Her blood chemistry which had been low or deficient in significant readings for some time had at least been stable until recently and, with supplements of key elements, could be maintained. The most recent bloods however have started to show decline. A further shift along the downward trajectory. Amy has survived for months on minimal nutrition. It has not been possible to obtain readings for her weight. She is however undoubtedly losing weight, for her mid upper arm measurements are reducing at such a rate that within a week there has been a reduction which, were it to be extrapolated, represents 10% of her body mass. Inevitably it is an estimate, but Dr Damle told me it is a measurement which is regarded as having some reliability amongst those treating anorexia nervosa patients. Her view is that put bluntly Amy is starving to death and that the timescales for effective treatment of her mental health whether by pharmacological or other therapy fall beyond the time by which she will have died.
19. Dr Damle was asked by Mr Patel QC, for the acute care trust, as was Dr Cooper about the possibility of pursuing more aggressively the psychiatric interventions. Those interventions in and of themselves are not accompanied by the risk of the Intensive Care admission. However with all those psychiatric treatments contemplated and for which there was a solid evidence base there was the issue of time. In relation to ECT there is no evidence base for treatment of the particular mental health configuration operating on Amy. Or for a person of her age. It would be said Dr Cooper "*a shot in the dark*". So too of course is the course of treatment which I am asked to approve. ECT may or may not alleviate some of her mental health symptomology but aside from the risks attendant on anaesthesia and transport it does not pose active risk to Amy – certainly not to the extent of the prolonged sedation in intensive care. In two

particular respects it carries with it its own disadvantage however – first it does not attract the same optimism as to outcome as the other interventions recommended by SLAM (who do not recommend ECT); second it does not have the potential to improve her physical condition by nutrition.

20. I have heard at this hearing from Dr Ferris whose careful and detailed report I had read before he gave evidence. Within that report he had included the following observation “... *the proposed benefit of admitting [Amy] to ICU for re-feeding is entirely speculative. It may cause significant harm or even hasten death; it may be wholly successful. Nobody knows, but experience tells me it will be somewhere on a spectrum between these two extremes. There is no evidence base that I or my colleagues can draw on when assessing risk/benefit analysis to make any predictions hence it should be tried as a last resort. The role of intensive care is to physiologically support the body while any underlying illness is treated.*” In his evidence before me, Dr Ferris articulated the way in Amy’s case had been the subject of detailed and anxious discussion for he and his intensivist colleagues and the combination of circumstances meant that the *first do no harm* obligation by which all doctors live their professional lives was thrown into sharp relief for them as they thought about how best to help her.
21. It was not, Dr Ferris impressed upon me that he and his intensive colleagues would be unwilling to carry out the procedure if my decision is that they should. Nor did he want me to think that he was trying to say it shouldn’t happen if it had to but, running through all of his thinking was that there were lots of things that might go wrong, it might not help, it could make things worse. Added to all of that was that none of those involved in the discussions had anything in their professional experience with which to compare it.

Discussion

22. In this case there is not the heated and passionate disagreement between the parties which sometimes accompanies this sort of decision. It has seemed to me to be all the more important to look with greater care to see what would or even might be proposed to me as an alternative course if there were such disagreement. Similarly whereas here I do not have Amy’s explicitly expressed view, because despite attempts to give her a voice it has proved impossible for her to allow herself to use it, it is important to take particular care that when I hear from those who love her most that; of course she would want to live, that is something more than simply a reflection of the fact that to believe otherwise would be for them unthinkable.
23. Such communications as there are from Amy have glimmers of her own occasional daring to contemplate a future in them: – her own previously expressed ambition for a particular future career; her pride and more importantly her encouragement of her siblings towards their ambitions showing explicitly an interest in their future. In the course of this hearing I saw a card she had sent to her parents in which she expressed herself in terms as wanting to get better and wanting to be able in the future to go home. Those expressions of hope for her own future are not, I am satisfied, consistent with someone who does not want to live. In the context of the decision which I have to make, they are inconsistent with an outcome which does not permit the deployment of the treatment I am asked to sanction. It is important for reasons which need not be elaborated on here to note that in the course of the hearing that Mr Sachdeva QC

agreed that the staff on the unit did not need to see the detail of that communication. Within the medical records, I was directed during the hearing to other instances in which there are albeit infrequently direct written communications from Amy which are consistent with a wish to live and not consistent with a wish to die.

24. Set against that of course is that seemingly contrary to what may be gleaned from what she from time to time communicates, appears on one view of it to be a steadfast and robust determination to reject all attempts to provide nutrition. This might well be understood as putting into effect a clear intention by an intelligent young woman to end her life by starvation. I accept however, the evidence of Drs Cooper and Dr Dalme that this is not an intention by Amy but is a manifestation of the symptom of her illness. Dr Cooper most helpfully illustrated what he meant when he was asked by Mr Sachdeva whether he had previously encountered a patient who had developed the skill to expel nutrition in the way Amy has. Dr Cooper was at pains to distance himself from the use of the word '*skill*' because, he told me it implied for him a misunderstanding of Amy's actions as something intentional and for a purpose. It was he told me, and I accept, important to understand it properly as a manifestation of the mental disorder in the grip of which she found herself and which she could not at this stage overcome.
25. Dr Cooper, as well as her parents, was unequivocal that were Amy able to form and to express a view, she would want to live. Having heard the three doctors give their evidence, Amy's mother said to me that whilst it had been as she put it *hard to listen to* and had given her, and Amy's father, a much better understanding of the risks which there were, it made her feel all the more that it should be done because she really believed that Amy did want to live and this would give her a chance whereas doing nothing would not. Her father said to me that although it might sound a strange thing to say, he didn't feel it was difficult to support the decision because the alternative was to do nothing and, as things are, that will lead only to one outcome. The difficult thing as he saw it was the timing, deciding when to instigate the treatment which, he felt had to be left to the Doctors to give her the best chance of life.
26. Dr Ferris at the end of his evidence in chief said this: *I think we all feel uncomfortable but here is a very unfortunate young woman who desperately needs help and I think the right thing to do is to offer that help at the right time.* I agree. Cross examined by Mr Sachdeva about whether he could see any other option to the proposed plan if Amy continues to deteriorate against a background where the timescales for the psychiatric treatment are measured in terms of months, Dr Ferris's response was *No I don't think there is any other choice.* I agree with that also. There is nothing else which will help Amy and the risks that undertaking the treatment proposed entails could be avoided but only at the cost of her certain death if it is not undertaken at all, or at the cost of Amy being too weak to have any chance of surviving it if it is delayed too long.
27. I understand, having heard his most impressive and thoughtful evidence, why Dr Ferris, is content that on the ground, clinical decisions and decisions about timing are ones that should be taken by those treating Amy if there is to be an admission to ICU, but does not feel that the decision in principle to undertake such an admission is one that should be for him or his colleagues. Again I agree.

28. The Trust was right to make the application to the Court in the exquisitely difficult circumstances in which those who are treating Amy find themselves. I am grateful both to the Applicant Trust for the way it put its application and to the third respondent Acute Trust for the way in which it pitched its response. It is right that the decision should lie with the Court, and I will make the declaration sought.
29. The conspicuous dignity of Amy's parents, facing as they do the unimaginable situation resulting in this hearing, has been striking. I very much hope that the situation for Amy and her family will improve.