



Neutral Citation Number: [2023] EWCOP 45

Case No: 14013508

**COURT OF PROTECTION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 20/10/2023

**Before:**

**THE HONOURABLE MR JUSTICE HAYDEN**

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**Between:**

- (1) NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS  
FOUNDATION TRUST  
(2) CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST  
(3) NORFOLK COMMUNITY HEALTH AND CARE NHS TRUST

**Applicants**

**-and-**

- (1) JORDAN TOOKE  
(BY HIS LITIGATION FRIEND, THE OFFICIAL SOLICITOR)  
(2) CAMILLA TOOKE  
(3) NORFOLK AND WAVENEY INTEGRATED CARE BOARD

**Respondents**

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**Katie Gollop KC** (instructed by Kennedys) **for the Applicants**  
**Parishil Patel KC** (instructed by the Official Solicitor) **for the First Respondent**  
**Ben McCormack** (instructed by Irwin Mitchell) **for the Second Respondent**  
**Bridget Dolan KC** (instructed by Mills and Reeve) **for the Third Respondent**

Hearing dates: 10<sup>th</sup> and 11<sup>th</sup> October 2023  
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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.

MR JUSTICE HAYDEN:

1. The earlier reporting restrictions will be lifted to enable Jordan's name to enter the public domain for reasons I refer to below. The names of his treating clinicians will, however, remain undisclosed.

The application

2. This application concerns a 29-year-old young man, Jordan Tooke. He has a diagnosis of autism, severe learning disabilities, and William's syndrome, which is characterised by developmental delay and other variable features. He is unable to communicate verbally but is effective, indeed dextrous, in non-verbal communication. He has, during the course of the last twelve months, been diagnosed as suffering from chronic kidney disease and has now entered end-stage renal failure. This application which I have heard during the course of today and yesterday was to have been heard later this month but Jordan's condition deteriorated to such a degree that the case had to be brought forward. For the avoidance of doubt, with end-stage renal failure, without haemodialysis treatment, Jordan will further succumb to the disease, deteriorate and die.
3. Jordan, in consequence of the challenges that I have identified, developed a long-standing phobia of hospitals in general and needles in particular. When this case last came before me, substantively, on 21<sup>st</sup> April 2023, it was thought by all concerned, not least Jordan's parents, that he would not be able to tolerate the considerable restrictions and privations involved in haemodialysis treatment. The proceedings in April concentrated on whether it might be possible for Jordan to receive a kidney transplant. Dr T was consulted. Dr T is a Consultant Nephrologist, who has 20 years' experience as a Transplant expert and has been involved in the care of more than 3000 kidney transplant recipients. He has played a significant role in advising on kidney transplantation to NHS England Renal Services Transformation Program and is an Executive member of the British Transplantation Society. He was clear that if haemodialysis were to take place it was essential that the patient was spontaneously compliant. Moreover, he considered that the capacity to participate, co-operatively, in haemodialysis was a prerequisite of eligibility to be placed on the transplant list.
4. On 21<sup>st</sup> April 2023, I heard evidence, as I have done at this hearing, from Dr T. He told me that in the not-so-distant past, before society began to develop a more enlightened understanding of the needs of people with disabilities, a patient like Jordan would almost certainly not have been considered suitable for a transplant. It was agreed, in April 2023, that Jordan should go on the transplant list. The time involved in waiting for a suitable transplant, as the public is well aware, is considerable. It was thought that unavoidable delay could be utilised to best effect by ensuring that Jordan started upon what has been called a "desensitisation plan". By this, it was meant that specialist nurses would work with him to replicate the circumstances of haemodialysis, to enable him to adjust and prepare for it.

5. It is a feature of Jordan's condition, by which I mean, in particular, his autism, that he struggles with the unfamiliar. However, the evidence shows that he has a real capacity to learn and adapt even to intrusive procedures. Nobody was certain how Jordan would respond to the desensitisation plan, but I think it is accurate to describe that response as having exceeded everybody's expectations. I think it is important to say that these achievements have been both remarkable and transformative. They are due to the work and commitment of a number of people, most obviously and most importantly Jordan himself, for whom it cannot have been easy. Jordan has been supported by the unwavering commitment of his insightful, intelligent and endlessly patient parents, and also, the dedication of the nurses whose daily and regular task it has been to implement the work.
6. Though the disabilities I have referred to have impaired Jordan's life, he has had one great asset in his armoury. He is possessed of almost universally irresistible charm and has been from the very beginning of his life. I have not met him, but I have seen, thanks to his mother, videos of him at his day centre and watched his beguiling smile, his irrepressible sense of fun and his astonishing capacity, notwithstanding the challenges he faces, to interact with other people, not merely on a basic or transactional level but with subtlety, sophistication, and with an incredible sense of fun. He is, as his father describes, "*very cheeky*", but all agree that he is an "*absolute charmer*". His zest for life, his enthusiasm for the world, is striking and voracious. I recall that, in April, his mother told me that Jordan greatly enjoyed the company of people. He also is a "*people watcher*". Like many of his generation he is umbilically linked to his iPad, and one of the things he most delights in is to watch videos of ordinary people going about their everyday business.
7. His mother's counsel, Mr McCormack, described Jordan as having "*joie de vivre*", and it is certainly true that he communicates a real joy for the life he lives. His parents, both of whom are professional people, and who have worked with youngsters and adults facing challenges, interpret his behaviours as displaying a real determination to live. His father commented in a way which illustrates, not merely his experience as a professional, but his instincts as a father, that Jordan is, in many ways, "*happier than most of us...*". "*He enjoys interacting with people*". "*The worries of the world are taken from his shoulders*", I would add, that his mother and father, and his carers deliver that freedom to him everyday. He has been freed to get on with the undiluted business of enjoying his life. His father said, "*sometimes, he even wakes up in the morning smiling*". His mother spontaneously agreed.
8. There was no doubt that the desensitisation process was going to be a challenge. It would have been quite remarkable if it had not been characterised by some disappointment and inevitable difficulties. But it has been able to achieve a gradual but clear diminishment of Jordan's anxiety about attending hospital. His father stresses that his condition does not stop him learning from his experiences. There is a great deal of

evidence of that. On a practical, utilitarian level, that is achieved by endless repeat and reward cycles. Jordan, who has had to use the NHS services periodically throughout his life, has, as his father said, come, eventually, to associate hospital as a place where he goes when he is in pain or unwell and ultimately feels better. Recently, and very surprisingly, against the backdrop of the past, he had to attend at A&E because his radiologically inserted gastrostomy ('RIG') tube was dislodged. His mother told me that there was no priority made for his disabilities, nor for a moment did she suggest there should be. Jordan waited for many hours in A&E and cooperated with the treatment ultimately required. That is a significant milestone in his life and must, at least in part, be due to the desensitisation work he has been participating in. His mother's pride in this achievement was almost palpable. I had the real sense that she had not considered that Jordan would ever have been able to manage it. Long hours of delay at A&E are now sadly commonplace. They are a challenge for all of us but for Jordan, it is a real accomplishment and rightly identified as such by his family.

9. Jordan was, as I have stated, placed on the transplant list. However, despite his achievements on the desensitisation programme, a conclusion was reached that he would not be able to undertake haemodialysis without sedation. Haemodialysis will involve Jordan attending the hospital three times a week for three to four hours at a time and remaining quiet and still for that period. I note that absent sedation, Jordan has on occasion in fact been able to achieve a three-hour stint in hospital without moving around. I am not sure that when I heard the case in April 2023, I really thought he would be able to achieve that. Thus, what I am emphasising, and what all the clinicians have, at different stages, referred to, is the 'dynamism' of this case, by which I mean that circumstances change regularly and perhaps more significantly than are always readily grasped or absorbed. This presents a real challenge for all involved in Jordan's care, particularly, in trying to evaluate where his best interests lie. It requires there to be regular and efficient sharing of information between different professionals in different areas of medicine and with repeated updating. It also imposes on very busy professionals a requirement to absorb new material and readjust their views to a changing landscape. This is always difficult but, I recognise, particularly so when services are under pressure.

### The Legal Framework

10. The key principle was succinctly stated by Lord Justice Ward and Lady Justice Butler-Sloss in *Re B (Care: Expert Witnesses)* [1996] 1 FLR 667:

*"The expert advises but the judge decides ...An expert is not in any special position and there is no presumption of belief in a doctor however distinguished he or she may be. It is, however, necessary for the judge to give reasons for disagreeing with experts' conclusions or recommendations... A judge cannot*

*substitute his own views for the views of the experts without some evidence to support what he concludes.”*

11. As Dame Elizabeth Butler-Sloss P observed in *Re T* [2004] EWCA Civ 558, [2004] 2 FLR 838 at 33:

*“Evidence cannot be evaluated and assessed in separate compartments. A judge in these difficult cases must have regard to the relevance of each piece of evidence to other evidence and to exercise an overview of the totality of the evidence in order to come to the conclusion whether the case put forward by the local authority has been made out to the appropriate standard of proof.”*

12. Whilst careful attention must, obviously, be afforded to the opinions and analysis of experienced medical professionals, these opinions always require to be considered in the context of all the other evidence. The roles of the court and the clinician or expert are entirely distinct. It is, ultimately, the court that is usually best placed to weigh expert evidence against and alongside the other available evidence (see *A County Council & K, D, & L* [2005] EWHC 144 (Fam); [2005] 1 FLR 851 per Charles J). It will be rare for the evidence of one doctor or indeed one area of specialism to be determinative of the outcome of a case. At the end of the day, it is the Judge not the doctor who determines the case and, always on the totality of the available evidence.
13. Evaluating best interests of a protected party (P), where there is dispute, can truly only fall to the responsibility of the Judge because it will always require a survey of the broad canvas of material that frequently can only be properly assessed when it has been ventilated in a courtroom and put to the assay in cross-examination.
14. As Lady Hale observed in *Aintree University NHS Trust v James* [2013] UKSC 67 at [39], the approach to the framework in Section 4 Mental Capacity Act 2005, should be as follows:

*“...in considering best interest of this particular patient at this particular time, decision makers must look at welfare in the wider 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 the outcome of the treatment will be. They must try and put themselves in the place of the individual patient and ask what his attitude towards the particular treatment is or is likely to be and must consult others interested in his welfare of what the attitude might be.”*

15. The above paragraph stands as one of the most significant passages in the jurisprudence of the Court of Protection. The fact that Jordan has autism and severe learning disabilities, does not in any way weaken the obligation to achieve the objectives that Lady Hale identifies. For Jordan and others in similar circumstances, the process requires creativity, imagination, and determination to elicit what their likely views and attitudes to treatment may be. One of the witnesses expressed the view that Jordan's situation effectively deprived him of a voice. That is not the case. As the case law of this court has consistently demonstrated, challenging though it may be, understanding the wishes and feelings of those who have experienced lifelong incapacity, across a sphere of decision making, is achievable. It has been achieved, in this hearing, as in so many others by focusing on Jordan's personality and approach to life. The primary conduits for this crucial information have been his remarkable parents. This is not only through the videos they have sent to me, which show Jordan interacting with familiar carers at his day centre but by their descriptions of him: his approach to life, his enjoyment of people, his bold, slightly zany sense of humour which pokes fun provocatively but always in a good-mannered way. Their descriptions have not only brought Jordan's views and attitudes into the evidence, but they have, through their words, secured him an almost tangible presence in this courtroom. It is amazing how the description of friends, relatives and parents can achieve this with the frequency that they do. To observe it is one of the great privileges of hearing cases in the Court of Protection. I also recall how at an earlier hearing, Jordan's parents described to me his utter delight in watching a particularly flamboyant former President of the United States of America and similarly extravagant former Prime Minister of the UK. Jordan's fascination with these two large personalities, in many ways, is further illustration of his curiosity for life, his vibrant humour, and his determination to look outwards towards the world rather than inwards to his circumstances. His inquisitiveness about everything but particularly people, demonstrates a real engagement with life.
16. As Mr Patel KC, on behalf of Jordan, through the Official Solicitor, rightly says, *"stripped to its basics this case is truly about life-sustaining treatment"* i.e., whether it would be lawful, right and in Jordan's best interests to receive haemodialysis even where that can only be achieved by the unusual measure of intravenous sedation throughout the process. I agree with that characterisation, it follows that we are really considering matters of life and death.
17. Judges have repeatedly emphasised the importance of the sanctity of human life in many of the difficult cases that have come before the Court of Protection and the Family Division in recent years. Sir Thomas Bingham MR in the Court of Appeal in *Airedale Trust v Bland* [1993] AC 789 said at [808]:
- "a profound respect for the sanctity of human life is embedded in our law and our moral philosophy"*.
18. Lady Black, more recently, in *NHS Trust v Y* [2018] UKSC 46 observed [91]:

*“Permeating the determination of the issue that arises in this case must be a full recognition of the value of human life, and of the respect in which it must be held. No life is to be relinquished easily.”*

19. There have been a number of well documented cases, over the last few years, where the court has been driven to determine that continuing a patient’s treatment is both futile and burdensome and that on a proper analysis, it could not be in an individual’s interest for it to be further protracted. Sometimes, the court confronts circumstances which, when analysed, contemplate the protraction of death rather than the promotion of life. However, the preservation of life will always weigh heavily in the balancing exercise that the court has to conduct. Intrinsic to that exercise must be an unswerving recognition of the obligation to promote personal autonomy, human agency and dignity. These underpin the ECHR and are integral to it.
20. In *North West London Commissioning Group v GU* [2021] EWCOP 59, I attempted a survey of a raft of international conventions and drew from them (at [63]), a number of principles illuminating the concept of human dignity, which it is convenient to set out here:

*“[63] Though it is an ambitious objective to seek to draw from the above texts, drafted in differing jurisdictions and in a variety of contexts, unifying principles underpinning the concept of human dignity, there is a striking thematic consistency. The following is a non-exhaustive summary of what emerges:*

- i. Human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
- ii. an individual has an inviolable right to be valued, respected, and treated ethically, solely because he/she is a human being;*
- iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*
- iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
- v. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*



vi. *compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.”*

21. Thus, when considering Jordan’s best interests, I weigh into the balance his unique value as a human being, the obligation of the State to ensure that he is afforded the same opportunities as those who do not share his disabilities and his fundamental right to life where that can either be achieved or, where it can be strenuously promoted.
22. The Trusts in this case have garnered evidence from a range of disciplines as they are bound to do. I have heard from two nephrologists but read statements from a total of six. I have also heard from a Consultant Anaesthetist, a specialist psychologist and a learning disability and autism specialist nurse. It is obvious to me that this case has been given great care and attention by extremely skilled professionals.
23. The aspiration in April 2023 was to see whether Jordan could comply with dialysis without IV sedation, the conclusion ultimately was that he could not. Dr C, Consultant Clinical Psychologist, who conducted a wide ranging and data-based assessment of the desensitisation process came to the following conclusion:

*“In my opinion, Jordan would not be able to safely undergo haemodialysis on an ongoing basis without sedation. Jordan is a young man who enjoys life away from medical treatment procedures and is a much-loved member of his family. He has shown remarkable resilience throughout his life, having endured numerous invasive and often painful medical interventions, but the relative success of the first desensitisation programme in my view suggests he can learn to tolerate procedures when they are carried out in a Jordan-centred way.*

*I believe the use of sedation would be in Jordan’s best interests. This opinion is based on the impact sedation had on Jordan during the desensitisation session on 18th August but also draws from my experience supporting an autistic woman with severe learning disabilities (who also presented with behaviours that challenge), whose clinical team regularly used sedation to help her manage haemodialysis over a number of years.”*

24. There is now full agreement amongst all involved, that some level of sedation will be required to enable Jordan to comply with dialysis. The observations of Dr C above were echoed both by the nurses and Jordan’s parents. Nurse W noted the following:

*“I understand that transplant surgery will require a long hospital admission to CUH and a long period of time for Jordan to have lines, cannulae and catheters in place. In addition, he*

*will inevitably have some pain and discomfort which may increase his distress and sensitivity and impact adversely upon his tolerance for these medical interventions. From my experience of working with Jordan, I think that this procedure and post-operative treatment is only going to be possible with heavy sedation. The risks and benefits of that are for the anaesthetists and intensive care teams at CUH to consider. I would of course be happy to liaise with my counterparts at CUH to help them plan for any admission for Jordan with my knowledge of him.”*

Nurse W in her oral evidence also commented on the very significant achievements that Jordan had made in the desensitisation training. I was left with the clear impression that he had outstripped her expectation. That said, she did not avoid the reality that he can become agitated and distressed. As Nurse W infers above, the evaluation of risks and benefits of any regime of sedation relies heavily, albeit not determinatively, on the evidence of the general anaesthetist. It is important that I record that notwithstanding the above, Nurse W ultimately considered that haemodialysis, with sedation would not be in Jordan’s best interests. She viewed his historical reluctance to attend hospital and his anxiety about needles as reflecting a resistance to treatment which she takes as him indicating that he would not want the intrusive haemodialysis regime. I found Nurse W to have conducted a thorough and insightful analysis of the desensitisation work but on this last point, i.e., her interpretation of Jordan’s wishes, she has not had the benefit of the much broader range of information that I have and for that reason, I consider this aspect of her analysis is incomplete.

25. Dr V, in both his oral evidence and reports, sets out his firm view that haemodialysis, with sedation, is not in Jordan’s best interests. I found his evidence to be carefully considered and clearly expressed. I did, however, note that he was inclined to argue a case, rather than conduct a balancing exercise. Sometimes, as here, the dialectic generated by that approach can be a constructive exercise, in that it stimulates focus on the alternative analysis. It is helpful to set out Dr V’s views in full:

*“Jordan demonstrated that he is likely to pull at and dislodge the dialysis CVC. This could happen between dialysis sessions or during a session. There is a moderate risk of pain or discomfort if he forcibly pulled out a dialysis CVC that had been given time (usually 2-3 weeks) to ‘bed in’ underneath the skin. There is a small unquantifiable risk of bleeding if the dialysis CVC is removed in an uncontrolled manner. There is a very small unquantifiable risk of a fatal air embolism if the dialysis CVC is removed in an uncontrolled manner.*

*There is a risk of infection and sepsis if the aseptic technique for CVC connection and disconnection is not adhered to or if the*

*CVC itself is handled in an unclean way between sessions. These risks are definite but not quantifiable and would result in the need for additional treatment such as intravenous antibiotic treatment which may require admission to hospital, further procedures under sedation or general anaesthetic such as removal of the existing CVC and a delayed insertion of a new CVC, critical illness or death.*

*Insertion of the tunnelled CVC is a procedure usually performed under local anaesthetic with the patient in a flat and stationary position for close to 45 minutes. Jordan would require a general anaesthetic for this procedure as he did for his previous procedures such as the RIG, kidney biopsy and gastrointestinal endoscopy. The procedure would be carried out in a theatre or the interventional radiology suite of the hospital. The timing of the procedure would depend upon the availability of the anaesthetist and the operator inserting the CVC (either a renal physician or an interventional radiologist).*

*The timing of insertion of a new tunnelled CVC following controlled removal or accidental dislodgment of the previous CVC would depend on other factors such as the urgency of dialysis and concern over infection in the bloodstream. An infection in the bloodstream may result in a need to wait for at least 48 hrs after removal of the old CVC to allow intravenous antibiotics to work before a new CVC is inserted. An increased blood potassium would represent urgency and may require the insertion of a CVC during non-routine hours with Jordan having to be placed on an emergency theatre list to obtain an anaesthetist to attend.*

*Removal of a tunnelled CVC due to infection is a procedure usually performed under local anaesthetic with the patient in a flat and stationary position for close to 15 to 30 minutes. Again, this would require the presence of an anaesthetist and an operator performing the procedure who would be a renal physician. Jordan would require at least intravenous deep sedation and perhaps general anaesthesia.*

*Repeated insertion of CVCs results in the veins being 'used up' with a subsequent difficulty in establishing dialysis access. There is a small and finite number of suitable veins that can be used for a tunnelled CVC.*

*Repeated use of intravenous deep sedation and general anaesthesia puts Jordan at repeated risks from these interventions and on which the anaesthetics team will elaborate in their report.*

*Jordan demonstrated unpredictable severe mood changes. There has been extensive input from the learning disability team of the hospital as well as external input from a learning disability nurse from the intensive support team (from Norfolk and Community Health and Care) who has experience in positive behaviour support. The consensus of the medical and learning disability team is that we cannot eliminate the risk of these mood changes which poses health risks to Jordan when dialysis is administered and physical risks to staff caring for Jordan at the time of dialysis.*

*Jordan would not be able to receive dialysis without regular chemical restraint. This would involve administration of intravenous deep sedation or general anaesthetic. In order to safely deliver the dialysis treatment we consider a proactive approach is in Jordan's best interest to allow for a safer delivery of haemodialysis. This would involve Jordan being sedated or anaesthetised on arrival to the designated area in hospital where he would subsequently be dialysed and then allowed to recover from his sedation before leaving for home. This would need to be done three times per week. An alternative option to delivering treatment, which we consider to be a less safe way would be to attempt to connect and dialyse with Jordan awake and to administer intravenous sedation on a reactive basis, leading to potential risk to Jordan or staff during the dialysis treatment. This would involve a heightened risk of loss of dialysis CVC access and ability to dialyse in addition to risks such as bleeding, air embolism and inadequate CVC care with infection. It would involve the need for trained security personnel at his bedside who would need to implement physical restraint which would cause potential distress to Jordan, carers and staff. Either approach would involve a deprivation of Jordan's liberty at least three times per week on an open-ended basis until the prospect and success of a transplant materialised.*

*Each session with intravenous deep sedation carries its own related risks to Jordan's health and life and on which the anaesthetics team will elaborate in their report.*

*Deep sedation or anaesthetisation of Jordan for each dialysis session three times a week would require an anaesthetist and ODP (operating department practitioner) to attend to Jordan for each session for the entire peri-dialysis period. This would represent a significant use of Trust anaesthetics time that would impact the existing service provision. If Jordan was admitted to hospital for a separate reason and needed dialysis on a non-scheduled day, he would need to be placed on the emergency theatre list to obtain an anaesthetist who would be able to attend to his session.*

*Jordan has had a historical dislike of the main hospital environment. His desensitising sessions were conducted at the offsite dialysis unit which is located around 3 miles from the main hospital site. It does not have the continual presence of doctors should an emergency arise. Dialysis treatment under chemical restraint as outlined above would need to be conducted at the main hospital.*

*Jordan has a love of hydrotherapy or swimming. He will not be able to swim with a dialysis CVC in place as this is a medical recommendation to reduce the risk of infection and sepsis.*

*If Jordan does not receive haemodialysis then he will eventually succumb to renal failure. Under these circumstances we would want to treat Jordan along a supportive and palliative line. This involves prioritising comfort and treating any symptoms that Jordan may develop. My opinion, which is shared by my colleagues from the Trust, is that the burden of treatment including both the risks to Jordan and levels of restraint constitute a form of treatment that are prohibitive and not in his best interests. Although a palliative approach would involve certain death it would be predictable and controlled and would not subject Jordan to risky and potentially distressing treatment over an unspecified length of time nor deprive Jordan of the liberties and aspects of his life that he currently enjoys.”*

26. Dr V, in that final paragraph, recognises that the alternative to the undoubted challenges identified, is to put in place a palliative plan, involving certain death but one which would be “*predictable and controlled*”. Dr V and others have referred to the sedation proposal as “*chemical restraint*”. That is, I think, accurate. But in the context of what is being contemplated here, I find it an emotive term which does not, to my mind, really do justice to the skill and subtlety of what the general anaesthetists can provide.

Jordan's parents do not contemplate his decline in end-stage renal failure quite as benignly or phlegmatically. They are far more sanguine about Jordan's potential. As I have stated, they are both educated and articulate people. They have researched end-stage renal failure and consider that the "*predictable an controlled*" decline cannot be guaranteed and would be, in any event, be distressing to Jordan.

27. Miss Gollop tells me that the clinical team have given considerable and anxious thought to this case. If I may say so, that is very clear from all I have heard and read. Although the Trust has asked me to conclude that dialysis, whilst sedated, is not in Jordan's best interests, they have very properly and impressively constructed an alternative care plan, designed to facilitate sedation if I take a contrary view. This is a very careful and well thought through care plan. What is striking is its unswerving focus on Jordan, not just in terms of his personality but by harnessing the positive experiences of the desensitisation programme. I do not propose to set out the care plan here in any detail. Precisely because it is so "Jordan focused", it is also rather an intimate and private document. It is enough to say that it contemplates gradual familiarisation with the kidney centre therapy room, led initially by staff who Jordan knows and is comfortable with but gradually introducing others. It involves simulating a line, preparing him for the sounds that the dialysis machine makes and constructing incentives and positive reinforcement which both the nurses and Jordan's parents have found to be effective. The plan is staged to go at a pace that it is thought Jordan will tolerate. What I find so impressive about the plan is how clearly it is drafted and how accessible it is to anybody reading it for the first time.
28. I heard evidence from the Consultant Anaesthetist, Dr M. Dr M has extensive experience of working with adults with disabilities. She was asked to advise on how it might be possible to manage Jordan both prior and subsequent to a renal transplant. Jordan remains on the list but suspended until this issue is resolved. Nonetheless, his name is working its way up, during the period of suspension. If he is able, ultimately, to tolerate haemodialysis there is a prospect of a transplant. Dr M has already navigated the insertion of a RIG tube for Jordan, under general anaesthetic, and considers that went well. What is proposed here, however, is very significantly more complex and intrusive. In her report, Dr M proffered the following observations:

*"Consideration on how to safely rationalise the duration and amount of monitoring postoperatively, along with having detailed plans in place if Jordan becomes distressed at various times postoperatively would be essential. This could include removing unnecessary monitoring, Camilla and familiar carers calming Jordan if possible or administering sedation either as a planned continuation postoperatively or in a response to agitation. When Jordan had his renal biopsy he was kept sedated afterwards to allow the period of bed rest that was needed. The risk of extended sedation compared to bleeding post kidney*

*biopsy was taken into account. There is always a possibility that Jordan may pull at the IV access. It was obvious when Jordan was ready for the cannula to be removed as he kept pulling at the bandage.*

*Jordan has adapted to procedures over time eg blood tests and face mask with desensitisation. Therefore, desensitisation with ECG dots/leads/ pulse oximeter/ BP cuff maybe a possibility. IV access desensitisation: cannula on the skin (not in a vein) under a dressing could be considered (this may be more tricky to achieve).*

*Inevitably there would be a difference between an admission for a live donation (which can be planned) and a cadaveric donation (which would be an urgent admission with no notice). These events would need to be addressed with careful planning. Planning for an urgent event is always more challenging. How it would affect Jordan I do not know but he will know it is different to his normal routine.*

*I would be happy to share my experiences of looking after Jordan with the anaesthetists at CUH to assist them in planning for an admission if a renal transplant is going to take place.”*

29. I found Dr M’s oral evidence to be measured, reflective and expressed in terms of enviable clarity and succinctness. She supported the Trusts’ application but was clear that the decision as to whether haemodialysis should be pursued was, ultimately, one for the court. However, it was very clear that she was not in any way compromised ethically about combining dialysis and sedation, in principle. There had been a lot of discussion, both amongst the doctors and nurses, and during the course of the hearing about whether Jordan might satisfactorily be sedated by buccal midazolam. Dr M quickly identified that as a red herring. She told me that the titration of what she referred to as “*clean*” intravenous medication, enabled the anaesthetists to titrate according to need and to do so quickly and reactively. She contemplated a scenario where Jordan might sometimes only require sedation at such a level that it was effectively equivalent to the buccal midazolam (“*just to let him chill*”) but equally, that there might be periods where his anxiety required significant sedation. Importantly, when that passed, the sedation level could be quickly lowered. Dr M told me that she was satisfied that she could deliver this with very limited distress to Jordan. She also told me that the recovery period from sedation could, in some patients, be very quick, perhaps only a matter of minutes. In others, it might be longer, even as much as 40 or 50 minutes. Sometimes, the same patient might react to the sedative in a different way.

30. In preparation for this regime, it would be necessary for Jordan to starve for a period of 6 hours. The plan would be to commence haemodialysis in the morning so that much of the fasting would be overnight. His mother told me that this would not present the kind of problem for Jordan that it might do for many of us. Jordan frequently has to be reminded, by prompting, to eat. If he is not, it is unlikely to occur to him. Something of this lay behind the decision to insert the RIG tube.
31. There is no doubt that the proposals contemplated by the plan are beyond what has previously been undertaken with other patients. The plans may properly be characterised as pioneering. At every dialysis session, there would need to be an anaesthetist, an operating department practitioner, and airway equipment, including anaesthetic machine/ventilator. This would require haemodialysis to be on the main site and, inevitably, involve allocating important resources which are much in demand. Dr M confronts the risks directly.

*“The generic risks for a general anaesthetic are:*

*Sore throat, nausea/vomiting - common*

*Chest infection - more common if renal failure and multiple comorbidities*

*Hypotension: exacerbated by haemodialysis*

*Confusion*

*Anaphylaxis 1:10000*

*Death 1:100000*

*Generic risk for sedation:*

*Aspiration*

*Anaphylaxis*

*Respiratory depression*

*Risk of conversion to a GA*

32. Dr M has also focused on the risks that are specific to Jordan. She identifies the following:

*“Cardiac risk: greater risk than general population as patients with CKD have a greater chance of having coronary/heart disease so greater risk of death than the general population;*

*Electrolyte disturbance: we would only pick up after sedated or GA as that is when we are likely to take bloods which can lead to arrhythmias and death;*

*Buccal midazolam needed to achieve GA/sedation*



*All of our drugs are excreted by the kidneys but not renal toxic. Lower doses may be required but the drugs we used intravenously have a short half-life (this is what I understood Dr M to mean by “clean drugs”). Midazolam has a longer half-life so we would use as low a dose as required to help with Jordan’s anxiety;*

*Multiple starvation periods within a week: For either proactive or reactive sedation, Jordan would require to be nil by mouth for food for 6 hours proceeding each dialysis session and nil by mouth for free clear fluids for 2 hours before dialysis and allowed water only after that. This means that every single time he is dialysed he will have to be starved and miss a meal. I note that on one occasion Jordan had eaten while having the session and got up and walked out. Eating and then giving sedation of general anaesthetic has a high risk of aspiration which can lead to chest infection, bronchial obstruction with food particles or death.*

*Greater risk of reflux in CKD so if GA then likely ET tube and therefore if dialysis likely repeated intubations which may cause tracheal damage;*

*Multiple cannulations unless PICC line is used: Risk of cannulation includes: multiple cannulations over the repeated session may mean more difficult venous access over time, cannula tissing. However, risk of PICC line also includes infection and ability for Jordan to pull out easier.*

*Level of distress for JT for each of these interventions;*

*Logistics of this in a remote setting;*

*If Jordan becomes unwell with cough/cold/covid/chest infection risks of GA/sedation are greater and increases the risk that Jordan will need to be admitted to ITU;*

*Jordan’s ability to enjoy life, including activities such as swimming and meals will have to be removed from his daily routine and replaced with an environment which Jordan does not like, along with intrusive, intensive treatment.”*

33. There can be no doubt that the sedation plan carries significant and troubling risks. Some of those risks involve potentially very serious consequences. But the calibration

of risk really requires confrontation with the alternatives. Jordan's parents have been both intellectually and emotionally rigorous in the way that they have addressed this issue. They have identified Jordan's quality of life, as I have set out. They have reflected on Jordan's temperament and personality and concluded that he would choose to live. I agree with that conclusion. The parents have also been measured and unsparing in their response to Dr M's identification of risk. They entirely accept her views.

34. However caring and diligent clinicians may be, it is not difficult to see how parents in this situation may sometimes feel isolated, not listened to, or at least not regularly and with full attention. Hospitals are busy and inevitably bureaucratic; they must sometimes feel impersonal and institutional. It does not require great imagination to see how parents under stress might sometimes feel resentment, and perhaps conflict. I have no doubt that Jordan's parents will at some times have experienced all of this but they have recognised its inevitability and worked around it. They have great respect for all the doctors and nurses involved and a strong and constructive working relationship with them. Jordan is the undoubted beneficiary of this. They have concluded that even in the face of the significant risks that may lie ahead, the point has not come to relinquish Jordan's life. They consider that respect for his dignity and autonomy points to affording him this opportunity for life however difficult the path ahead may be.
35. In many cases where the Courts are asked to consider issues of this magnitude, the contemplated treatment, usually advanced by the family, is often burdensome but ultimately futile. Here, though dialysis is undoubtedly burdensome, it is certainly not futile. On the contrary, it holds out the possibility, by transplantation, of a restoration to health. The real issue is whether the process of dialysis with all its attendant risks is so contrary to Jordan's best interests that it should not be pursued. Having regard to Dr M's clear view that Jordan's sedation can be managed, I have come to the view that the opportunity of dialysis ought to be afforded to Jordan and that such opportunity can properly be said to be in his best interests.
36. Although my judgment may, at least on a superficial reading, appear as if I am departing from what might appear to be a medical consensus, I do not consider, for the reasons I have analysed, that is accurate. The interplay between general anaesthesia and nephrology is key to a proper evaluation of the broad medical picture, again, for the reasons set out. In addition, and with no apology for repetition, I have had extensive opportunity to explore Jordan's own likely wishes and feelings to a degree that has not, hitherto, been possible. It is important that I record that the Official Solicitor, on Jordan's behalf, has, on the conclusion of the evidence, come to the same view that I have arrived at and for largely similar reasons.

### Reporting Restrictions

37. Jordan's parents are both intensely committed to promoting the rights of people with disabilities and keen to take opportunity to signal to the wider public the importance of

those rights. How society treats some of its weakest and most vulnerable is undoubtedly a measure of its own health and maturity. They have asked me to lift the reporting restrictions which have, to date, anonymised Jordan's name in order to promote these principles. Additionally, there are two more practical objectives which have caused me to yield to their application. Firstly, publicity may be effective in achieving for Jordan what is known as an 'altruistic donor'. By that is meant the receipt of a 'live' kidney.

38. The advantages of receiving a live kidney for Jordan are significant. Most importantly it means the transplant procedure can be planned and prepared for. For Jordan, that is particularly important, for so many of the reasons I have alluded to above. It also serves to enhance the prospect of his compliance. Moreover, there is also real potential that the follow-up treatment might be significantly less burdensome for Jordan than in the case of a cadaveric donation. It is not necessary for me further to burden this judgment with the details underpinning this. Addenbrooke's Hospital are prepared to keep Jordan on the transplant list, with what is referred to as "suspended status". The parents hope that they might be able to utilise some degree of publicity in order to seek a suitable kidney match.
39. The second objective, which might seem minor, but in my view is not, is the family's desire to hunt down specialist clothing for Jordan which might help in the dialysis process. The central venous catheter (CVC) remains in situ permanently throughout dialysis. There is an ever-present risk of Jordan pulling it and perhaps detaching it. His parents have assiduously researched to see whether there is any bespoke clothing that can effectively cover the line to diminish risk of Jordan accidentally or intentionally disconnecting the CVC. They have not been able to identify an operative supplier at the moment. They consider that some publicity for this issue, might assist. It strikes me that there is every possibility of this being successful. Having seen photographs of the CVC in situ, in other patients, it strikes me as distinctly possible to achieve some simple and practical solution. In many ways, this might be central to help Jordan achieve the identified goals.
40. Jordan is a remarkable young man, with equally remarkable parents. They are supported by dedicated medical professionals. The procedures that I have endorsed as in Jordan's best interests are bound to create difficulties at times. I hope that the strengths I have identified above will enable them all to surmount the obstacles that will undoubtedly arise.

### Postscript

41. In view of the urgency of the application, I delivered this judgment, ex-tempore, at the conclusion of the hearing. I am grateful to the lawyers in the case for taking such an accurate contemporaneous note. I have, considering the significance of the issues, made a number of short refinements to the judgment, in order that it can be placed properly in the public domain.