Neutral Citation Number: [2022] EWHC 500 (COP)

Case No: COP 13866627

IN THE COURT OF PROTECTION
SITTING AT THE LIVERPOOL CIVIL
AND FAMILY COURT

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 8th March 2022

Before :

MRS JUSTICE ARBUTHNOT

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Between :

MANCHESTER UNIVERSITY NHS FOUNDATION TRUST	**Claimant**
- and -	
WILLIAM VERDEN (BY HIS LITIGATION FRIEND, THE OFFICIAL SOLICITOR)	**1st Respondent**
- and -	
AMY MCLENNAN	**2nd Respondent**

Hearing dates: 28th February – 3rd March 2022

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Helen Mulholland (instructed by **Hill Dickinson**) for Manchester University NHS Foundation Trust
Emma Sutton (instructed by **the Official Solicitor**) for the **1st Respondent**
Victoria Butler-Cole QC (instructed by **Irwin Mitchell**) for the **2nd Respondent**

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.
THE HONOURABLE MRS JUSTICE ARBUTHNOT

Mrs Justice Arbuthnot:

Introduction

1. These proceedings in the Court of Protection concern William Verden who was born on 25 January 2005 and is now aged 17 years old. He lacks capacity to conduct these proceedings and make decisions regarding his medical treatment due to his learning disability, autism and ADHD.

2. The application before this court is made by Manchester University NHS Foundation Trust ("the Trust") which is responsible for Royal Manchester Children's Hospital. The Trust's clinicians and the independent witnesses have set before the court the risks and benefits to William of having a kidney transplant with post operative sedation and ventilation for his end stage renal failure.

3. The Trust applies for a declaration in relation to William's capacity and for the court to consider whether an order should be made that it is in William's best interests that he should have a kidney transplant with sedation and ventilation post-operatively in light of the risks to William of the treatment.

4. The respondents are William represented by the Official Solicitor and his mother Amy McLennan. They have weighed up carefully the risks and benefits to William of a transplant and of the post operative care and their position is that it is in his best interests for him to have the transplant.

5. I would like to acknowledge the considerable help I have received in this case from extremely able and experienced counsel, all three have been alive to the difficulties in the decisions to be taken and have done all they can to assist this court in its decision-making.

Background

6. William was born on 25th January 2005. In 2012, he was diagnosed with a complex learning disability. William went to specialist schools, and I have a report from one of them in the bundle of evidence.

7. William has diagnoses of moderate to severe learning disabilities with autistic spectrum condition and ADHD, with accompanying behavioural disturbances. He has hypersensitivity to anything on his skin and it is not unusual for him to pick at dressings protecting lines or tubes going into his body.

8. William lives at home with his mother, his father, Will and his sister, Ruby. He also has an older brother Levi. There is an extended family including grandparents, and an aunt. William is described by his mother as being at the "heart" of the family. William uses respite care for one to two nights per week and there are overnight carers to support William and his family at home four nights per week as William suffers from disturbed nights and poor sleep.

William and his family

9. William is at the centre of the decisions I have to take. I had the pleasure of meeting him remotely on Monday evening when he was with the Miss Sutton, her instructing

solicitor Mr Edwards and Miss Varley who was instructed by the Official Solicitor to support William during the meeting.

10. His first question to me was to ask when it was that he was going to have the operation. I said I was unable to answer that. He told me he was worried about people seeing the tubes he might have in his leg, feet and arms. He said he was scared about the operation and worried about the tubes getting knocked by children.

11. William mentioned security on the ward and from what I gathered he was concerned that he may want to go for a walk after the transplant and that security may prevent him from doing so. He said if he stayed in hospital for a bit, he would like to go out for a walk to get some fresh air, he would want to be able to exercise and as he put it "get my energy back".

12. William told me he liked to play golf even though his arms hurt afterwards, football and kerby. I had never played kerby so he explained that it was played with others and involved kicking a football against the kerb. I noted William's excitement when describing the game which he clearly enjoyed.

13. William told me about the jobs he likes doing. He was at the respite centre when we spoke and he said he liked to make tea, do jobs like mopping, putting pictures up, getting wood from the shops and making picture frames. Another job he enjoyed is laminating documents. We agreed this is a very useful thing to be able to do. It is very clear he enjoys the life he leads, playing games, doing odd jobs, going to school and the respite centre and being with his family.

14. I saw how close he is to his family. Ruby, his 15-year-old sister, was in court the first day, Levi his adult brother was there the second. Levi had been in the hospital at William's side for three days, 24 hours a day, to keep his brother company when an infection brought him into the hospital unexpectedly on 27th December 2021.

15. The first respondent attended each day, I was struck by her dignity, I noted the way that she had advocated for her son in every way she could from the moment it was clear he had learning disabilities.

16. The mother is a 'doer' who fights for her child. An example of this was that Ms McLennan recognised that what William really needed was a kidney from a live donor, so she launched a public appeal to find an altruistic donor to ensure her son had the best chance of living. William is very lucky to have the family he has, and they feel lucky to have him.

William's health

17. In November 2019, William presented with signs of kidney failure. After various tests, on 9th December 2019 he was placed on steroids, but they did not reduce his symptoms. Quite the reverse, the second line medications appeared to accelerate his kidney function decline. He was therefore diagnosed with a disease called Steroid Resistant Nephrotic Syndrome ("SRNS") on 30th December 2019.

18. In April 2020, peritoneal dialysis commenced. Unfortunately, this form of dialysis was ultimately unsuccessful and from 21st September 2021, when the peritoneal dialysis

catheter was removed and a right-sided central venous haemodialysis catheter was inserted, William's treatment plan became haemodialysis ("HD") via a line or catheter for four hours a day, three days a week (Monday, Wednesday and Friday) and for two hours once a week on a Thursday.

19. HD is dependent on venous access. The amount of access reduces if the HD line comes out or is dislodged in some way and has to be replaced. A number of disturbances to the HD line have taken place, two in September 2021, four in October 2021, two in November 2021 and two in December 2021. These disturbances were caused by William's pulling off the dressings covering the central line or touching the site of the line. On occasions the site had to be cleaned and re-dressed and on others the line had to be reinserted by surgery. The last occasion that a new line had to be inserted was on 10th December 2021.

20. There have been occasions recorded by the hospital leading up to early January 2022 when William had been aggressive or violent, this was aimed usually at his parents although on a few occasions staff have been hit.

21. The witnesses were agreed that incidents involving the central line dressing had reduced in the recent weeks as William had become more accustomed to the HD routine at the hospital. There had been fewer outbursts recently too.

Prognosis

22. The HD treatment requires venous access which reduces as the veins become compromised until there are no veins left to use. The clinicians treating William say that having used new venous access to insert the dislodged lines, he has just two access points left when the present venous access point fails. They consider that venous access will be possible only for up to around 12 months.

23. The only alternative to HD is a kidney transplant which will, if it is successful, give William a future of about 15 to 20 years before another transplant is required. If SRNS recurs the 15 to 20 years is halved to 7.5 to 10 years.

24. The difficulties in William having a transplant are two-fold, first, from his diagnosis that the SRNS is not due to an underlying genetic abnormality means the chance of a successful transplant without disease (SRNS) recurrence is at best 47% and at worse around 80% or above. If SRNS recurred, William would need Plasma Exchange ("PE") for a number of sessions over an unspecified period when he would have a number of lines going into his body.

25. The second difficulty is significant, William is hypersensitive to anything on his skin and has a habit of scratching at dressings which means there is a real risk that, as has happened in the past, lifesaving lines or tubes could be dislodged or moved. It is the potential for compromising the numerous lines which will be required post-operatively which are of particular concern to the clinicians and the question for them is how this can be managed.

26. A further issue is that William is unpredictable and is sometimes aggressive towards others due to his autism, ADHD and learning disabilities and he has poor impulse control. William does not cope with change and would have difficulty adapting to the

sudden changes which inevitably would occur in a Paediatric Intensive Care Unit ("PICU") if he were to have a transplant and to the many lines that would enter his body post-operatively.

Issue

27. The Trust has completed capacity assessments of William in the past, Dr Carnaby the jointly instructed independent psychologist completed one on 12th February 2022. The professionals agree that William lacks capacity to make the relevant decisions under the Mental Capacity Act 2005. It is not in issue therefore that William lacks capacity to decide whether to consent to a kidney transplant and any associated treatment and that he will not acquire capacity to make the decisions about the transplant or treatment.

28. The Trust originally sought a declaration that it was not in William's best interests to undergo a kidney transplant on the basis that the harm to him from a transplant and the post-operative treatment was greater than the continuation of haemodialysis until venous access was no longer possible.

29. I had no doubt that the Trust's initial position had been reached after careful multi-disciplinary discussion. The Trust's position was reached too in the light of two second opinions as well as a consideration of the risks and benefits to William of the treatment by the Trust's Ethics Committee which endorsed the position taken by the clinicians treating him.

30. During the hearing, however, the evidence presented by the Trust's witnesses, in a finely balanced case, had become more nuanced as they were able to reflect on and consider the oral evidence.

31. The Trust's final position was that it was for the Court to decide what was in William's best interests, the decision to be taken in the light of the evidence of the considerable risks to William particularly of post-operative treatment including a lengthy period of sedation and ventilation.

32. William, the first respondent, is represented by his litigation friend, the Official Solicitor, she accepts it is a finely balanced case as regards the risks associated with post-operative sedation and ventilation, but after hearing the evidence she submitted strongly in favour of a kidney transplant with post-operative sedation and ventilation, for the shortest period possible, despite the risks that that would entail.

33. The second Respondent is William's mother, Amy McLennan. She, and indeed the Official Solicitor, set out in stark terms the issue for the court: if transplantation is not attempted, William will die in about 12 months. At the same time the mother accepted that there were considerable risks to William of having a transplant.

34. The issue for this Court was whether the combination of the risks from the transplant, from disease recurrence and the post operative treatment of PE which would involve a lengthy period of sedation and ventilation was such that it was not in William's best interests to go down that path.

Evidence

35. I have been provided with a bundle of the core evidence including various statements and several bundles of medical records. I heard evidence remotely from the Trust's clinicians: Dr A, a Consultant Paediatric Nephrologist, Dr B, a Consultant in Paediatric Intensive Care and Dr C, a Consultant Child and Adolescent Psychiatrist. I also heard remotely from the independent experts Professor Moin Saleem, a Consultant Paediatric Nephrologist, Dr Chris Danbury, a Consultant in Intensive Care and in person from Dr Steve Carnaby, a Consultant Clinical Psychologist. Finally, I heard from Amy McLennan, William's mother.

36. As set out above, the original position of the Trust became more nuanced as the hearing proceeded but before that occurred the clinicians and independent witnesses met to discuss William on 16th February 2022 and were able to agree on a number of issues set out in a joint statement at E108 of the bundle.

Dr A and Professor Saleem – the nephrologists

37. The prognosis for William without transplantation but with the continuation of his HD line was said to be two to three years in the joint statement but in evidence Professor Saleem and Dr A agreed that William's life expectancy was more likely to be about 12 months and that they would be surprised if he lived as long as three years.

38. The clinician and expert agreed that the success of a transplant would be apparent from about 24 hours afterwards if the kidney was from a living donor and from about day three or four if the kidney was from a deceased donor. In their evidence Professor Saleem and Dr A agreed that chances of the graft functioning were 50%. Professor Saleem said the life span of a graft was 15 to 20 years but with disease recurrence the life span would be halved to seven and a half to ten years.

39. Disease recurrence would be apparent from three days after the operation although recurrence could appear later. A biopsy may have to be performed and treatment for recurrence could start that day or the day after.

40. The opinions of the risk to William of the recurrence of SRNS differed considerably between Professor Saleem and Dr A. Professor Saleem, who had undertaken a study of 187 patients of which a number matched William's clinical and genetic characteristics, said that the risk of recurrence was 47%. Dr A who had had eight patients with SRNS had experienced 100% recurrence. Professor Saleem described this as bad luck and said it was not a reflection on the care the patients had received.

41. An area of agreement between the experts which did not change was that PE was the usual treatment for disease recurrence. Although Professor Saleem suggested there could be alternatives to PE, he called it the gold standard although he accepted that with a success rate of 75%, PE was not the end of the story as the patient might encounter difficulties later with only partial remission and then a big risk of cardiovascular disease.

42. In William's case, PE would need to be administered for a minimum of ten sessions over a period of fourteen days after disease recurrence was detected before the frequency dropped to three times a week and then later less. The duration of PE when William would be hooked up to a machine would be three to four hours. The success rate for PE of 75% was if the course was substantially finished.

43. If the kidney graft had not functioned William would also need HD as well as PE and that would be required, every other day or three times a week. That process would take three to four hours and although it would use the same central line, it could not run at the same time as the PE. The experts agreed if William needed both he would have to be attached to machines for six to eight hours at a time.

44. Dr A and Professor Saleem said that William and his disabilities made treatment planning particularly difficult for the clinicians. The complexity arises not so much from his renal problem along with disease recurrence but because of the ADHD, autism and consequential behavioural issues. They were concerned about his ability to tolerate the numerous lines involved in the procedure and the dressings protecting them whilst remaining still for such a protracted period. Any dislodging of the lines would put William and his treatment at serious risk.

45. There were drugs that would be given alongside PE if there was disease recurrence. Professor Saleem suggested high doses of Methylprednisolone, the use of Rituximab and following PE for two weeks, daily lipoprotein (LDL/ A) as it involved fewer sessions, otherwise if that was not available, the continuation of PE.

46. The risk to William of the various drugs which would be used during the transplant or later were of mood changes, hypertension and most importantly for William, behavioural changes which he had suffered in the past when on prednisolone.

47. The nephrologists agreed that if William was not subject to PE his chances of remission would be greatly reduced.

48. The question of William's ability to withstand the rigours of PE after a transplant had considerable bearing on the question of sedation and ventilation which was considered by the clinicians and the independent experts in their meeting and by the witnesses in their oral evidence.

49. The views of the professionals varied from Dr A who considered that William would be 'unmanageable' post-operatively without sedation to the independent psychologist Dr Carnaby who said that with the right support William would not need ventilation and sedation at all. In the event, Dr Carnaby fell into line with the other professionals in his evidence before me, when he said he would defer to their views on this point.

50. Professor Saleem had had experience of treating patients who fiddled with their lines but he said he had "never come across one [a patient] this difficult to manage with this behavioural level of risk" (in answer to Ms Butler-Cole QC). He was particularly concerned about William's inability to tolerate the rapid changes which would occur in a hospital setting and his attitude towards the lines. He made the obvious point that William is a large young person (6' tall) and is difficult to manage physically.

51. The nephrologists were agreed that the only way to manage the risk would be by way of post-operative elective sedation and ventilation. In his first statement Dr A had said that in the case of disease recurrence William would need sedation and ventilation for a four-to-six-week period to ensure he had PE for the optimal period (para 52(c) D36) but after the experts' discussion on 16th February 2022, the minimum period of sedation was reduced to seven days.

52. The intensivists (Dr B for the Trust and Dr Danbury the independent expert) agreed that what was being suggested was a very unusual if not unique situation.

53. In terms of the impact of sedation and ventilation the renal specialists deferred to the intensivists. To get the gold standard treatment William would need PE and that might involve 14 days sedation and ventilation. In evidence Professor Saleem said the withdrawal of PE too quickly might result in disease recurrence so he suggested PE could start under sedation and ventilation before moving to something more akin to HD as the provision of PE reduced in frequency.

54. Professor Saleem was clear that without the added complications of his ADHD, autism and learning difficulties causing the challenging behaviour, William would be offered the transplant even though there was a risk of disease recurrence (in answer to Ms Sutton).

Dr B and Dr Danbury – the intensivists

55. Dr B, the Trust intensivist who specialises in paediatrics, had listened to the evidence given by the renal specialists. He explained that the intensivist's job was to facilitate the treatment suggested by the specialist team. His view, based on what the specialist team had said about William's past and current behaviour, was that it would be impossible for him to tolerate interventions without sedation and mechanical ventilation. He made it clear that his evidence was purely from the intensivists' point of view and the risks he spoke about were the risks of sedation and ventilation and not the risks and benefits of the overall procedure.

56. Once sedation and ventilation had started, he said that it would be safer and more effective for it to continue until the essential part of PE had been received. The risks of ongoing sedation and ventilation had to be balanced with the risks of not being able to achieve the nephrology treatment because of treatment interference.

57. The risks of physical and psychological injuries and the experience that William would undergo if he was sedated and ventilated were set out in detail by Dr B and Dr Danbury.

58. Dr B said it was difficult to say what the difference in risk was between sedating William for seven days and extending that to 14 or 21 days. There were so many different types of life-threatening complications for a ventilated patient. In his evidence he stressed that the procedure was "harmful and dangerous" and that an elective use of sedation and ventilation was highly unusual.

59. He said each complication has a different time course, with some where the risk is at the beginning, and then drops such as during intubation and others where the risk is the same throughout and some where the risks increase as time goes by.

60. Dr B and Dr Danbury agreed that there were major risks in a PICU including sepsis, pneumonia, catheter related infection as well as venous thromboembolism.

61. Dr B explained the highest physical risk was at extubation but that there were risks of tracheal injury at intubation and risk factors involved prolonged intubation periods and the patient being agitated and moving his head and neck during this period. Severe laryngeal injuries may be caused and could result in lifelong problems.

62. In William's case, Dr B considered that the long period of intubation combined with the fact that he is very likely to be agitated as he approaches extubation, means that a two-week period of ventilation carries a risk of around 50% of moderate to severe laryngeal injury. In court he explained these are his best estimates.

63. Another risk Dr B set out in his statements and in evidence was the risk from mechanical ventilation. The risk that the lung could become deflated or filled with fluid is 20% if older children are ventilated for 48 hours and is "almost inevitable with a period of mechanical ventilation longer than 2 weeks" (para 20 D5). In evidence he said that if William was ventilated for five to seven days the risks were 50:50.

64. Dr B stressed the psychological impact of sedation and ventilation. There could be withdrawal issues, delirium and PTSD. Dr B said that the chance of William developing post intensive care syndrome ("PICS") was more than 50% and it was possible that the psychological manifestations post operation would make it impossible to persuade William to attend hospital ever again.

65. It is not a case that the young person who is sedated and ventilated is unconscious. Patients are aware of their environment and are only unconscious for specific treatments. Generally though, the bulk of the risks were earlier on in the admission although the intensivists were agreed that the longer the sedation and ventilation the more likely and the more severe PICS and psychological harm would be for William.

66. One of the issues for the intensivists was the drugs that would be required to sedate William. These would accumulate with time and at the end of any proposed treatment post-operatively William would need to be weaned off them to allow the tubes to be removed. The intensivists agreed that teenage boys are particularly difficult to sedate and to wean.

67. Delirium seems to develop after the first 48 hours and is more likely than not. It is an "acute neurologic dysfunction in the setting of serious illness and is characterised by a fluctuating disturbance in cognition and awareness" (para 27 D7). It can be identified in about 40% of children admitted to the PICU for more than six days and children with developmental delay are 3.5 times more likely to be diagnosed with this. William would have more than a 50% chance of suffering it if sedated and ventilated for two weeks. Dr B expressed it as more likely than not.

68. The delirium could last several days. It can start even before extubation as the patient is weaned off sedative agents. Dr B said that the patient's personality emerges once the sedation and ventilation wear off and there can be profound changes that can persist for several days. The patients lose touch with reality, they are not themselves and particularly teenage boys can become aggressive.

69. The experts were concerned that William would be disorientated on the PICU and Dr C the psychiatrist spoke about him likely feeling fear from the random noise due to the processes on the unit. Dr B said that he would be very distressed. Physical and chemical restraint is likely to be needed to keep him safe and William would not understand what was happening to him and why.

70. William's learning disabilities and autism made his post operative psychological state unpredictable, and they were concerned he would be very difficult to manage.

71. A rather sobering comment made by Dr B was when he told the court that the whole experience of sedation and ventilation is such that some children have described it to him as ‘torture’ and asked him why he had put them through this.

72. The intensivists agreed that although elective sedation and ventilation would allow William’s transplant to succeed with PE if there was disease recurrence, this would be at ‘a very significant cost to his wider health both physical and psychological’ (para 1.11.17 page E16). The shorter the ventilation the less likely he would be to suffer physical consequences.

73. In his evidence, Dr B was asked about the length of sedation, and he explained there would have to be a multi-disciplinary assessment as to where the risks are when the on-going and increasing risks of sedation and ventilation are set against the decreasing risks of pre-emptively stopping PE. What should be avoided is extubation too early and then a patient having to be re-intubated.

74. Dr B emphasised how rare it was electively to sedate a patient for five days or more, this only occurred every couple of years.

75. Importantly in my judgment, both intensivists agreed that the psychological injuries would be more severe and less predictable than the physical manifestations. It was the psychiatric impact on William of sedation and ventilation that concerned them the most.

76. Dr B gave his view that elective sedation and ventilation for five to seven days was not contrary to William’s best interests, but two weeks sedation would be because of the potential of permanent psychological harm he could suffer.

77. Ms Sutton for the Official Solicitor clarified this when she asked Dr B for his view about the risk benefit analysis when 14 days of sedation and ventilation may be required to ensure William has a period of PE. Dr B’s view was that the benefits of sedation and ventilation outweighed the risks and he suggested that when William was stepped down from daily to less frequent PE then it would be sensible to allow weaning to take place and for William to be extubated.

78. Dr Danbury had produced a detailed report dated 20th January 2022 when the proposal was that William may need sedation and ventilation for six weeks. His view was that would impose “an enormous physical and psychological burden” on him. There was a 100% chance of William suffering PICS and he would never return to the level of function prior to admission. Overall, he considered that the burdens of PICS on William with his learning disabilities outweighed the benefits of a transplant.

79. By the time he came to give evidence, the period being proposed by the nephrologists if disease recurred had reduced to two weeks. Dr Danbury said that having heard Professor Saleem and Dr B give evidence he could see that two weeks sedation and ventilation to cover PE was in William’s best interests. He was concerned about the problem of what he called ‘mission creep’ where the 14 days could become longer because the clinicians would want to give William the best possible chance of a functioning kidney but there would be the countervailing risks of the serious psychological harm such as PTSD.

80. Dr Danbury explained in evidence that if William was sedated for 14 days, then extubating would take a few days more, he said in his view up to an 18 day period of sedation and ventilation was justifiable. The various drugs would have to be cleared out of William's system before he could be safely extubated. In replying to Ms Mulholland's questions, he said there was a risk of psychological injury after about 36 to 48 hours but there was no significant difference in the seriousness of an injury between 14 days and 18 days.

Dr C and Dr Carnaby – William's mental health

81. I heard evidence from Dr C, a Consultant Child and Adolescent Psychiatrist working in the hospital and in the community for the Trust. She had been part of William's support network since July 2021.

82. She explained that her role in William's care was to work closely with the paediatric team to assist them to put together a package of support for when he is receiving HD on the ward. She said any plans put in place for William were discussed as a whole by the team around him which included his family, the clinical team and the psychiatrist.

83. In her first statement she had set out William's disabilities and explained that William likes routine and "becomes anxious if there is a change and what he had been told does not happen" (para 8 D14). Dr C set out William's behaviour on the ward which included verbal and physical aggression towards staff and his parents and disruptive behaviour. There have been times when his behaviour has led to treatment delay, and he had also tampered with the dressings protecting his central line. Dr C set out the efforts made by the hospital to try and keep him calm and settled.

84. In the light of the intensivists concerns about sedation and ventilation causing psychiatric injury to William, Dr C was asked what the injury might be and for how long it might last.

85. Dr C said it was more likely than not that William would suffer a psychiatric injury if he was sedated and ventilated for more than 48 hours. She said that the chance of developing PTSD after being in a PICU is between 35% and 80% for neurotypical children but that risk is increased in children like William who have neurodevelopment disabilities such as autism spectrum disorder.

86. Other psychiatric injuries post PICU and after sedation and ventilation for more than 48 hours were commonly PTSD, depression, anxiety and sometimes delusional memories. She said it could be a cluster of symptoms which would not reach the diagnostic threshold, such as panic attacks, flashback nightmares, low mood, lack of enjoyment, delusional memories and problems with sleeping. This was a significant risk to William.

87. Dr C said that the present situation where William was relatively settled whilst on HD had occurred after many months of rehearsal and with a lot of work being carried out with him by the staff. She said that with a transplant there would be new treatments and new demands on him, post-transplant he would be in a very different mental and physical state and William is much affected by change, things that seem small greatly upset him. She did not underestimate the demands the new treatment would place on William and his support team and said that it would have a huge impact on him.

88. In terms of William's recovery from PTSD, Dr C said it was difficult to predict but for children and young people sometimes it resolved in the first couple years. In his case she predicted that although it would take a bit longer for him to recover there would be some resolution to the symptoms.

89. Generally, she considered that the interventions that would be provided to treat the psychiatric injuries would have to be tailored to William's understanding and interaction and would have to go on for longer than one would generally expect.

90. The other interventions that could be provided to him are medical. He is currently on anti-psychotic medication and sertraline which is an anti-depressant, and these could be added to but it had to be borne in mind that William does not have a reliably typical response to medication and he is particularly sensitive to psychotropic drugs.

91. Dr Carnaby said that the hospital's recent use of Positive Behaviour Support ("PBS") was a shift in approach and was helping William by explaining to those around him the reasons for his behaviour, which is often because he is trying to communicate that certain of his needs are unmet. He said that responding and meeting William's needs before his behaviour escalates is key to him tolerating treatment. With PBS the ward staff had been recording William's behaviour during HD to be able to analyse it and form support strategies.

92. The Focused Support Team ("FST") had become involved working with William from just before Christmas. Their role is set out in an Information for Carers pack which was set out in the document bundle at F.

93. FST had provided a tool clarifying the roles and responsibilities during HD to ensure that tensions between the clinical staff who need to ensure the treatment happens in a timely way and social care staff or family members who want to delay treatment until William is ready are reduced.

94. William's treatment plan including his preparation for surgery and the strategies that the trust and others could use to manage William were considered at length during this hearing by counsel with Dr C and Dr Carnaby. Both set out a number of steps which could be taken to prepare William for the operation.

95. I set out the seven-point plan below.

    1) The provision of personalised social stories to support him whether it is with HD at home, the transplant or PICU and treatment for disease recurrence.

    2) William should meet with his clinicians and carers, although the nature of an unexpected arrival of a kidney from a deceased donor means that it is not possible to be certain about which medical staff will be available on the day.

    3) William should see the theatre and the PICU to see the equipment in situ. Dr C said she was concerned it may be anxiety-provoking and it might be better to take him to outside the PICU so he can see it is close to where he has HD and can see it is not a frightening place. She said he could then be given photographs of a PICU bed and the room.

4) Mock lines should be placed in the numerous places on his body where he will have lines post-operatively.

5) William should be provided with a 3D anatomical model, to show the operation and the lines etc.

6) William should pack a bag and have it ready for the transplant so he can associate the bag with what is going to happen, to anchor him.

7) The PBS plan should be updated after any incidents in particular if there is any dislodging of the line or dressing interference.

96. The significant evidence of Dr C was that having considered the risks and benefits to William, she said it was in his best interests to have the transplant with sedation and ventilation to follow. She accepted that if the transplant were not to be successful it would have a huge impact on William if he had to go back to HD and said it might help in those circumstances for him to be having the HD at home.

Criticisms of the Trust

97. There was some criticism of the way that the hospital had managed William's behaviour during HD particularly before Christmas. Although William's relationship with some of the security guards was clearly very positive, with others there had been occasional incidents arising out of a possible lack of training to deal with a child with William's disabilities.

98. I noted that since Christmas there appeared to be a more concerted attempt by the hospital working with the family to ensure that the right environment was provided which gave William the best chance at remaining calm and still for the required time.

99. I want to make it clear, however, that I do not underestimate the issues the hospital must have had in dealing with William's behaviour caused by his autism, ADHD and learning disabilities, when they also had a number of other children they have to care for. Just one practical problem is that William reacts better to medical staff he is familiar with but it must be particularly difficult to provide consistent medical staff when they work shifts and are caring for other children too.

100. William's PBS plan dated from May 2021 was at the bundle at F39, its aims are set out at F43. It is a comprehensive document which is reviewed every few months. I was also provided with William's Hospital Passport, which is put at the end of his bed. Both documents were impressively detailed and, as long as the information contained in them is communicated to those who treat William, would be very useful.

Second opinion, further second opinion and Ethics Committee

101. The second opinions were given by a Consultant Paediatric Nephrologist from another Trust on 10th November 2021 where the Consultant met William and spoke to his mother on 25th October 2021 and then discussed William's case with his team. He considered that it was unlikely that William would live long enough to make it to the transplant waiting list. He was concerned about how William would manage the post operative period when he would have to sit still for days when the chances of disease

recurrence were "very high". The rescue treatment would be like being back on HD but daily instead of four times a week. There was a low chance of overall success. He thought it would be useful for William to meet the palliative care team.

102. In a further second opinion dated 15th November 2021, with a summary dated 30th November 2021, yet another NHS Trust considered a number of questions posed by the Manchester NHS Foundation Trust. It considered that a kidney transplant was not in William's best interests unless active treatment was pursued then transplantation was the best option. They recommended HD should be carried out on William at home rather than in the hospital.

103. If pursuing active treatment by way of transplant, then they did not think that disease recurrence was a reason not to pursue this as "there is the possibility of no primary disease recurrence – albeit less likely than disease recurrence". If disease recurrence was estimated at 100% then they did not support a transplant.

104. The MDT Summary recommended that if there was disease recurrence after transplant, a risk assessment "regarding treatment or non-treatment options would take place again". If there was early disease recurrence leading to the loss of the kidney then a second transplant should not be offered (G8). The MDT Summary considered that long-term HD was acceptable as a bridge to transplantation, but when asked whether long-term HD was in William's best interest, said that the distress caused to William and the risks of harm to him and the effect on other patients and staff, outweighed the intended survival benefits.

105. The Manchester University NHS Foundation Trust Clinical Ethics Committee met on 26th October 2021. They considered William's case at a time when he had not begun to settle whilst receiving HD and when it was not being suggested he could be sedated and ventilated for a minimum of seven days and up to 14 or so days. The Ethics Committee shared the clinicians then views that they were doing "more harm to William than good" by continuing with invasive approaches to treatment and that the benefits to William were "substantially outweighed by the risks of harm to William" (G12).

106. Ms Butler-Cole QC was critical that the parents' views had not been taken directly by the Committee whilst a number of clinicians had attended to give theirs. It did seem to me that a better approach might be to have a meeting which is divided into two parts, one where the parents attend to give their views and the second when the clinicians attend. The Ethics Committee would then have a better idea of William's quality of life, his wishes and the position of the family.

107. It was clear from all the evidence that the Trust and the clinicians treating William have been agonising over what is in William's best interests. The mother has made one or two small criticisms of the Hospital, but it seemed to me that as the writer of the further second opinion put it "the care provided has clearly been exceptional" (G10) in what were, particularly at the beginning of HD, challenging circumstances.

Law

108. The principles the court must apply are agreed by the parties and are found in their position statements.

109. Section 4 of the Mental Capacity Act 2005 sets out the criteria to be applied to determine what is in an incapacitated person's best interests:

(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.

110. The leading case as to the application of the best interests' criteria is the decision of the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, Baroness Hale highlighted the following:

> *"[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."*

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"*

111. More recently, in *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ observed:

> *"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."*

112. William's rights are protected by the European Convention on Human Rights. In the present context, the relevant rights are established by:

a) Article 2 (the right to 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, 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)".

b) Article 3 (protection from inhuman or degrading treatment)

c) Article 8 (the right to respect for a private and family life). As the ECtHR recognised in *Burke v UK* [2006] (App 19807/06) ECHR 1212:*"the presumption of domestic law is strongly in favour of*

> *prolonging life where possible, which accords with the spirit of the Convention".*

113. I also bear in mind the observations of the then Baker J in: *Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2012] 1WLR 1653:

> *"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..."*

114. I draw the following principles from the various authorities, in particular from *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council (supra)*, *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, *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410.

115. They are conveniently set out by MacDonald J in *Kings College Hospital NHS Foundation Trust v Hasstrup* [2018] EWHC 127 (Fam) and I take from them the following approach:

a. The paramount consideration is William's best interests. The role of the court is to take over the parents' duty to give or withhold consent in the best interests of William. In doing so the court is to exercise its own independent and objective judgment.

b. The starting point is to consider the matter from the assumed point of view of William. The court must ask itself what William's attitude to treatment is or would be likely to be. His views must be considered and be given appropriate weight in light of his age and understanding.

c. The question for the court is whether, in the best interests of William, the particular decision as to medical treatment should be taken. The court must do the best it can to balance the factors for and against the proposed treatment to come to a conclusion. The court must consider the nature of the medical treatment, what it involves and its prospects of success, including the likely outcome for William of that treatment.

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

e. 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, even though the child wishes to survive.

f. The views and opinions of both the doctors and the parents must be considered. 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.

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.

Submissions

The Trust's case

116. Ms Mulholland set out what she said was the finely balanced decision for the court. The Trust acknowledged there were arguments in favour of a transplant and against. It was asking the court to make the decision based on all the evidence before it. The decision was so balanced that even a successful outcome could have severe implications for William including psychiatric injuries which could last several years. It was because of that the Trust has reservations about a transplant whilst accepting at the same time that the alternative is stark.

117. What was agreed on the evidence was that home HD ought to be implemented as soon as it was feasible and that if a transplant is carried out then there was a need for sedation and ventilation. The risk of disease recurrence was between 50% and 100%, the reality was somewhere between the two, probably 80%.

118. If William has disease recurrence after transplant and he receives the full intensive PE treatment there is a 75% prospect of success and it was the PE plus the high doses of steroids which are of particular concern to the Trust. It was agreed by the witnesses that there should be at least 14 days PE but Ms Mulholland questioned whether that amount of PE would guarantee the 75% prospect of success.

119. Ms Mulholland said that the evidence had developed and crystallised during the hearing, beforehand the intensivists were not in favour of a transplant but now they could see it was a delicate balancing exercise. The concern was of significant psychiatric injury. Dr B had spoken of children who compared sedation and ventilation to torture and had asked him why he had put them through it.

120. Ms Mulholland said that the court may well conclude that the risks of psychiatric injury are worth taking but the parties should embark on the exercise with open eyes and in full knowledge that it might fail and cause injuries to William that may affect the quality of his life in a negative way.

The mother's case

121. Ms Butler-Cole QC, on behalf of the mother, said the burden of the decision is on the court. The Trust's witnesses had made it clear that they wanted the court to make the decision. The strong wishes and feelings of William were of critical importance in the circumstances. Ms Butler-Cole QC reminded the court that the purpose of the

jurisdiction was to allow William to live life to the full which would involve the court taking on all the risks of harm for William in taking one course and not another.

122. Ms Butler-Cole QC relied on the evidence of Dr B who said in his evidence that the risks from sedation and ventilation for five to seven days were outweighed by the possible benefits from a transplant. The psychiatric harm to William was the real issue and in relation to that Dr C had said that even knowing the risks it was in William's best interests to have the transplant followed by sedation and ventilation.

123. The consequence of William not being offered a transplant was death within about 12 months. Although there are considerable risks with treatment, the alternative is much worse. Ms Butler-Cole QC questioned whether the Trust was right in their view of the manageability of William's behaviour. She pointed out that the correct autism support had only been provided in the last eight weeks and it had led to behaviour which was more manageable. The mother's view was that with appropriate tailored support it may be more manageable than the Trust thinks it is.

124. Ms Butler-Cole QC explained that the mother accepted that the treatment in the event may not work or may not be delivered. The mother is clear that she does not want William to have a poor quality of life.

125. She said that William had been prepared since July 2021 with social stories into having an understanding that he would have a transplant which would make him feel better and not have to have HD. It would be cruel to say that he could not have the procedure after all.

126. The only conclusion from the evidence before the court was that it was in William's best interests to have the transplant and post operative care provided for in the draft order.

<u>The Official Solicitor's case</u>

127. Ms Sutton contended that the tenor of the evidence made the decision easier for the court. There was no active opposition to a transplant being in his best interests. She said it was not a finely balanced decision. What was more difficult was the decision to sedate and ventilate William, but the key factor was that the presumption of taking steps which were not futile to prolong William's life, had not been rebutted.

128. The problem for William would be the speed at which the plan for a transplant may be implemented with a deceased kidney donor. William was not able to tolerate change and the changes would be sudden and intense.

129. If there was no disease recurrence, there would still be numerous lines in place and William would be in a situation he had never encountered before. Then if there was disease recurrence, there would need to be daily sessions of PE and possibly HD up to six to eight hours a day for ten days or so as well as the infusion of very strong steroids which could cause William to be verbally and physically aggressive. The Official Solicitor accepted that it would be a huge ask of William to tolerate the post-operative plan.

130. Ms Sutton said in relation to sedation and ventilation, two pieces of significant evidence for the Official Solicitor were first that Dr A was clear that it could not start at a later point and second the unanimous opinion was that although there was a slight incremental increase, it was not a significant increase in risk to William whether he was sedated and ventilated for 48 hours or 14 days.

131. Ms Sutton said there was a need for specificity to avoid what Dr Danbury called "mission creep". 14 days plus the three days for the disease recurrence to have taken place would be the limit. She said that sedation and ventilation give William the best chance and it would be in his best interests to authorise it. Professor Saleem was clear that increased sedation and ventilation would not increase the risks to the kidney.

132. Ms Sutton said that if Dr A was right and William needed four weeks of hospital stay after the sedation and ventilation is withdrawn, the witnesses were agreed that he may need continuous care and support to make sure he can tolerate his environment. The clinicians would have to decide whether the hospital was able to provide appropriate care, if not it should be provided externally, and carers known to William used.

Discussion

133. The question for the court is what is in William's best interests. I have set out the evidence at great length above as it is important, in the light of my decision, that the mother and family realise the very many risks to William of a transplant followed by sedation and ventilation.

134. I use Ms Butler-Cole QC's very helpful table which summarises the various pathways that William's care could take depending on the decision of the court. I consider her pathways below:

135. Pathway A is clear, if I decide a kidney transplant is not in William's best interests he will continue on HD. The venous access will run out in about 12 months' time and then he will die. It would be surprising, according to the nephrologists, for him to be alive in three years' time.

136. This is a decision which does not accord with William's wishes or indeed his family's. I bear in mind that what matters to William is living with his family, playing sport and doing useful things such as laminating documents, and other helpful odd jobs. He has a good quality of life which he would want to continue. He says he wants a transplant, although he does not understand what that will entail. He has been accustomed since July 2021 to the idea of a transplant. William wants to live and to continue doing the things he enjoys.

137. A continuation of HD until there is no more venous access will also mean that he will continue needing the central line which delivers the HD until his death. He will not be free of the dressings on his skin which irritate him so much or the restrictions on his freedom that regular HD demands, at present four visits a week to the hospital and HD for up to four hours at a time.

138. Even were HD to be delivered at home, which is the present plan, that will still entail the continuation of the two particular situations that William finds difficult, sitting still

for a number of hours and having a HD line in place which is protected by dressings that cause him to scratch with the consequent risks to the lines.

139. The continuation of HD does have one positive outcome which is that the severe psychological consequences of a transplant, of an extended time sedated and ventilated in PICU and heavy doses of steroids would be avoided. William will continue in his present psychological state subject to what may be a great disappointment to him when he is told that he cannot have an operation. It is inevitable that that would cause him great distress.

140. Pathway A is not a path wished for by William or his family. William lives at home. His parents know him very well. I heard evidence from his mother and she was clear that her son should be given a chance to live, he is aged 17 and if he remains on HD he may well die before the age of 18 or possibly 19. He is at the heart of his family and much loved by his parents, siblings and the extended family.

141. The family has not just sat back and let the doctors help William, they have put great efforts into ensuring he comes to HD, into supporting him there and trying to prevent him from interfering with his dressings and to calm him down when he gets agitated. Levi spent three days with William when he was unexpectedly admitted into hospital in late December 2021. The siblings therefore are involved in his care.

142. It is not the case either that the mother is not able to stand back and recognise the risks of the transplant and the post-operative care, she recognises the risks and knows that the transplant and post operative treatment could well affect William's quality of life to a significant extent but argues that the possible benefits to William outweigh the risks.

143. Pathway B is the one which gives William the best chance of a healthy future. This is the ideal situation for William. It is a pathway where the graft functions and there is no disease recurrence. William would need a seven to ten days stay as an in-patient. The various lines would be removed after about five days. He would have to be sedated and ventilated for five to seven days. This would give William a life expectancy of about 15 to 20 years after which he may need another transplant.

144. The advantage of this pathway is a life away from the lines and tubes and visits to the hospital which dominate William's life currently. There is much that can still go wrong in the years to come but he will not be facing death in about 12 months.

145. The experts agree that sedation and ventilation would prevent William from touching the dressings over the lines and tubes attaching him to the various machines and potentially dislodging them. He would have to be sedated and ventilated as it is much more of a risk to start it up after a gap.

146. The downsides of this option are the considerable risks from sedation and ventilation. The physical risks were explained by the intensivists and include risks from intubation, laryngeal injury and sepsis. The intensivists agreed that the more significant risks to William were psychological, and their particular concern was PTSD.

147. The psychological risks from sedation and ventilation are set out above in the summary of Dr C's evidence. The risks start at 48 hours. The psychological risk to William is likely to be more than to another non-cognitively impaired young person.

148. William will be conscious in PICU when sedated and ventilated and may well be very frightened as he will not understand what is going on around him. He is frightened by noise and there will be the sounds of the machinery keeping him alive which will be very hard for him to cope with. He will be aware of people around him but will not be familiar with all the staff and this will also frighten him. He will suffer from delusions from the medication he will have to take and may well have nightmarish visons.

149. In terms of the decisions I have to take, what has given me the most concern is the fear I consider he will feel when he is in the PICU, sedated and ventilated. Some child patients had told Dr B they had felt tortured in the PICU, but it will be much worse for William who will not understand what is going on.

150. William has little concept of time and in my judgment, cannot be prepared in any meaningful way for what is ahead. Although Dr C set out the many steps that can be taken to assist William to prepare for a transplant, she recognised that these would be of very limited assistance when he regains consciousness in the PICU and is sedated and ventilated there. This is when significant, in particular, psychological harm, may be caused to William.

151. William knows that if he does not have a transplant that he will continue with dialysis. Pathway C set out by Ms Butler-Cole QC in her table, shows what will happen to William if the kidney fails. In that case after all the distress he will have been caused in the PICU by the treatment, the drugs and the sedation and ventilation he will be back to HD and a 12-month prognosis. As well as the distress, he may have physical injuries as a result of the treatment and also the psychological symptoms of PTSD etc that Dr C set out in her evidence. There is a risk that he will not feel able to continue with HD such might be the level of his distress.

152. Pathway D is where the kidney function is delayed and there is disease recurrence which occurs in somewhere between 50% and 100%, probably around 80% of cohorts with William's particular SRNS characteristics. In this situation, William would be sedated and ventilated for about 14 days after the disease recurrence has been evidenced, so that PE could be administered in the optimal way suggested by the nephrologists.

153. There is a 75% success rate for PE if it is completed but on the downside for William are the physical risks I have set out above for Pathway C, along with the significant risks of serious psychological damage. If the treatment succeeds, then William has a seven and a half to a ten-year chance of survival. If the graft is not functioning HD may also have to be given and possibly the alternative approaches that were put forward by Professor Saleem.

154. If the various treatments fail then after suffering the distress and fear of being in the PICU, William will be back to HD, with a life expectancy of about 12 months. Again, his disappointment and any psychological issues may well have a serious effect on the quality of his life.

155. The risks to William are present whatever I decide. There is the risk of death in about 12 months if no transplant takes place, there is the risk of the failure of the kidney, the 50% to 100% risk of disease recurrence, the significant risks to William physically and more importantly psychologically from a lengthy period of elective sedation and ventilation and the drugs used, and the risks that PE may fail.

156. There is a risk that the transplant and treatment will fail and all the distress he is likely to suffer in the PICU will be for nothing. This may well affect his remaining months of life and destroy the quality of life he enjoys currently.

157. It is a case of what is the least bad decision for William. I must put myself in his shoes to decide what he would want. He does not understand the risks to him of a transplant and he is frightened about what it will entail but I have no doubt that he wants to have a life without HD. The only possibility of him having a longer life with an even better quality is through having a transplant.

158. I must look at his welfare in the widest sense, the choice is between a short life of about 12 months or the chance of a much longer life but which comes at a price, with a great number of serious physical and in particular psychological risks and where there is a chance that the after-effects of the procedures he will undergo may lower the quality of his life.

Conclusion

159. William and his family support a transplant and the professionals have said either that the transplant and sedation and ventilation is not in William's best interests or that it is for the court to decide.

160. In my judgment, considering the choices from William's point of view, his family and sport are important to him, he wants to be able to continue playing kerby into the future. The transplant is not futile and although the chances are it will lead to an increase in William's suffering in the short to medium term, it has the commensurate benefit which is that there is a chance for William of a long-term survival, if the transplant goes ahead.

161. I declare that William lacks capacity to conduct these proceeding and to make decisions relating to his medical treatment, including the decision to have a kidney transplant.

162. It is in William's best interests to have a kidney transplant. It is in his best interests to be electively sedated and ventilated post-operatively for up to seven days to have care and monitoring including via the numerous lines required after the transplant. It is further in his best interests for William to be electively sedated and ventilated for a period of 14 days after disease recurrence which is likely to be detected within 3-4 days of the transplant. This will enable PE to take place over ten sessions in the 14 day period.

163. Those treating William will be able to exercise their clinical judgment in relation to the weaning of William from the sedative medication and the timing of the extubation following the 14 day period of elective sedation and ventilation.

164. It is in William's best interests to be supported by carers once he is extubated, if it is considered necessary, and ideally, if it is thought appropriate, by carers he is familiar with.

165. I make the other orders in relation to home dialysis as set out in the draft order.

166. That is my decision.