Neutral Citation Number: [2023] EWCOP 57

Case No: 141851504

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 14/12/2023

Before :

MRS JUSTICE JUDD

- -

Between :

THE NHS FOUNDATION TRUST	**Applicant**
- and -	
(1) K (BY HER LITIGATION FRIEND, THE OFFICIAL SOLICITOR)	**Respondents**
(2) B	
(3) F	

- -
- -

Victoria Butler-Cole KC (instructed by **DAC Beachcroft LLP**) for the **Applicant**
Jenni Richards KC (instructed by **The Official Solicitor**) for the **Respondents**

Hearing dates: 13th December 2023

- -

Approved Judgment

This judgment was handed down remotely at 10.30am on 14th December 2023 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

.....

MRS JUSTICE JUDD

This judgment was delivered in public subject to a Transparency Order made by Mr. Justice Moor on 1st December 2023. All persons, including representatives of the media, must ensure that this order is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Judd :

1. This is an application by an NHS hospital trust for declarations with respect to medical treatment for K, a young person who is currently an inpatient in intensive care.

2. K is a much loved sister and daughter who until earlier this year was living at home. She suffers from a rare inherited condition which progressively destroys the nerve cells in the brain and spinal cord. It is a condition that has affected two of her siblings who died when they were teenagers. Since May 2023 K has been repeatedly admitted to hospital with respiratory problems which have required her to be intubated and placed on a ventilator. She has also needed repeated courses of antibiotics. The view of her treating doctors is that she is reaching the end of her life, and that it is in her best interests to receive palliative care.

3. Because it has proved very difficult to engage K's family in discussions about end of life care, the trust commenced proceedings.

4. There is no dispute in this case that K lacks capacity or that she will ever gain it. There is a capacity assessment from Dr OJ in the bundle, and this is confirmed in the report of Dr. Bell. I will therefore make a declaration pursuant to section 15 Mental Capacity Act 2005 that K lacks capacity to conduct the proceedings and to make decisions about her care and treatment.

5. The issue in this case is as to her best interests.

6. This final hearing was listed by Moor J on 1st December. The family were unrepresented before Moor J and also before me. The second respondent B stated that they were unable to secure legal representation. Whilst it is never easy for anyone in this situation to represent themselves, it was not suggested that I adjourn this hearing. B drafted a number of questions for the treating expert and others, most of which were asked by Ms Richards for the Official Solicitor. B also asked a number of other questions herself, and she gave evidence and made submissions. I have a number of written documents from her in the bundle and read an email that she sent after the hearing yesterday. She has therefore been able to participate fully in the proceedings and to put forward the views of the family.

The options for K

7. There are only three options for K in her current situation. Option 1 is to continue to treat her in the intensive care unit (ICU) with oral tracheal intubation to allow her to receive continuous breathing support. Events over the last few weeks demonstrate that she is dependent upon this. Her life expectancy under this scenario is likely to be measured in weeks or months rather than years.

8. Option 2 is to extubate K and to cease any further attempts to re-intubate her in the event of respiratory difficulties. In this scenario she would continue to have full active management (suction, fluids, antibiotics) but her prognosis is unlikely to be measured in more than days. She would receive palliative care with the aim of symptom control. Although there would be the possibility of transferring K to a hospice or

home, this is likely to be burdensome and probably unrealistic given the timeframes concerned.

9. Option 3 is for K to have a tracheostomy to manage her breathing support without having a tube going into her mouth and down her throat. This would require a short operation under general anaesthetic, followed by care and treatment in the ICU. Her prognosis under this regime is very difficult to gauge, but it is likely to be measured in weeks and months rather than in years. Dr. B, her treating doctor, suggested a period of about two or three months but this is very inexact. This option is not favoured by the treating team or Dr. Bell, the independent expert instructed by the Official Solicitor but it is put forward as a possible best interests option by Dr. O the consultant who was asked by the Trust to provide a second opinion before they issued proceedings.

The position of the parties

10. The Trust's case is that it is not prepared to offer option 1, a stance with which the other experts agree. To continue the status quo is against all accepted current practice as oral tracheal intubation is only used as a temporary measure. If breathing support is clinically indicated on longer term basis, a tracheostomy is the usual treatment. The trust submits that Option 2 is the only one which is in K's best interests although it is prepared to implement Option 3 if the court disagrees with Option 2.

11. K's sister, B, has been representing the family at this hearing and throughout. For reasons which are not at all difficult to understand, she has found it difficult to focus on the issues that are before the court. It was apparent during the hearing at various stages that she finds the issues under discussion extremely distressing. She is very close to her sister and this family has suffered an enormous amount of tragedy and loss and the pain she is suffering was palpable. B clearly believes that the treating team do not have K's best interests at heart and that she needs to be moved to another hospital. In an email sent for my attention on the evening of the hearing, B asked for help and said 'with the right treatment and proper management I have full faith she will recover I have seen this'. During the course of her evidence and submissions B suggested that K was being discriminated against because of her disability and that she would not have been treated in this way had she not had the condition she does. B believes that with proper treatment K will improve and be able to manage without ventilation.

12. The family have always been against K having a tracheostomy but at the end of the hearing B made clear that their dearest wish was for K to live. At some point she noted that a tracheostomy would only give K a few months more life but my interpretation of what she said was that the family would favour tracheostomy, i.e. Option 3 over the alternative (although I should stress that this was very unclear). B does believe that settings such as the ICU only know how to deliver 'the harsh treatment of sedation'. She said that she is against there being a policy of no CPR and that her sister is strong and courageous, not NHS property.

13. The Official Solicitor's position at the beginning of the case was that she wished to hear the evidence before making a recommendation. At the end of the case, and having explored the possibility of a trial period of having a tracheostomy with Dr. O during his evidence, the Official Solicitor recommended the court follow Option 3. In

so doing she recognised that there is no real distinction between a temporary tracheostomy and Option 3 because of the time that would be needed to undergo such a trial and K's limited life expectancy.

The law

14. S 4 MCA 2005 provides as follows:

> "(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—
>
> (a) the person's age or appearance, or
>
> (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
>
> (2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
>
> (3) He must consider—
>
> (a) whether it is likely that the person will at some time have 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 to 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 for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).”

15. The Mental Capacity Act 2005 Code of Practice (“the Code”), issued under MCA 2005 s42, includes a section within Chapter 5 entitled “How should someone’s best interests be worked out when making decisions about life-sustaining treatment?” It includes the following:

> “5.31 All reasonable steps which are in the person’s best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person’s death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person’s death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.
>
> 5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.
>
> 5.33 … Doctors must apply the best interests’ checklist and use their professional Kills to decide whether life-sustaining treatment is in the person’s best interests. If the doctor’s assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be aKed to

> decide what is in the person's best interests." "5.36 As mentioned in para 5.33 above, where there is any doubt about the patient's best interests, an application should be made to the Court of Protection for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests."

16. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 at [22] Baroness Hale said:

> "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."

17. At paragraph [35]:

> "a strong presumption that it is in a person's best interests to stay alive, but this is not an absolute, and there are cases where it will not be in a person's best interests to receive life-sustaining treatment".

18. And at [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 aK what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

19. In W v M [2011] EWHC 2443, paragraph 220 Mr Justice Baker (as he then was) stated:

> "The principle of the right to life can be simply stated but is of the utmost importance. It needs no further elucidation. It carries very great weight in any balancing exercise".

20. The burden of establishing that the discontinuance of life-sustaining treatment is in a person's best interests lies with he who asserts that it should be withdrawn, here the Applicant Trust: *R(Burke) v GMC (OS Intervening)* [2005] QB 424. The civil standard of proof on the balance of probabilities applies, including in relation to any findings of fact.

The experts

21. I had reports and heard evidence from three medical experts. The first was the treating expert Dr. B. The second was Dr. O, Intensive Care Consultant, and the third was Dr. Bell, also a Consultant in Intensive Care at the Leeds General Infirmary, who was instructed by the Official Solicitor.

22. Dr B's view that it is not in K's best interests to undergo a tracheostomy was clear and firmly expressed. He said his view was one which was shared by the treating team. In his original report he recorded that the discussions that had been had with the family over the proceeding weeks and that they were opposed to the tracheostomy. Following receipt of the report of Dr O on 29th November and K's cardiac arrest following self-extubation and subsequent re-intubation on 2nd December, he prepared a further witness statement dealing with the option in more detail and on the basis of K's current condition. Dr. B explained that in addition to the operation itself (which is relatively straightforward), there is a burden of care associated with a tracheostomy, even though it is easier for a patient to tolerate than an oral tracheal tube. The nearest proxy that the treating team have in terms of K's tolerance of such is her clinical condition when intubated without sedation. She made repeated efforts to move the ET tube, successfully doing so on several occasions. Sudden and unplanned removal of a tracheostomy causes the immediate loss of a secure airway; therefore in order to practically keep it in situ she would require either sedation or physical restraint.

23. In his oral evidence Dr. B said that K would continue to require deep suctioning three times a day. If she was not sedated her arms and head would need to be restrained. He stated that physiotherapist treating her reported that K grimaces when being given treatments such as this showing that she finds this distressing. When being asked to consider the possibility of carrying out a tracheostomy as a trial he said that the process would take a significant period of time. Whilst the operation was routine it is not simply benign. There would be a full anaesthetic with muscle paralysis, surgical incision and the use of a rigid plastic tube. K would have to have some time to recover from this. K is now fully dependent on the ventilator, and her condition is deteriorating. She is becoming more distressed by interventions and it was unrealistic to believe that she could tolerate anything other than other than a level of sedation that would prevent her being able to interact with her family.

24. Dr. B did not accept B's suggestion to him that when K's oral secretions were properly managed she is fine or that any of the treatment that K is having (for example plastic tubing for ventilation, the use of propofol, management of secretions, nutrition) was contributing to her condition.

25. Dr O reviewed K's clinical notes and visited her for about 2 hours on 29th November 2023. When he saw her she had been off sedation for about 48 hours, and appeared alert. She occasionally appeared to fix her gaze on him or her sister but otherwise looked around more randomly. She appeared to reach for her ventilator tubes but this did not seem to be with intention of removing it. He concluded that K was in the final stages of her life, and that tracheostomy would provide the greatest chance of her survival to allow for her discharge from the ICU and the only chance of being discharged home with any degree of stability. Noting that she was attempting to engage with her surroundings he considered that tracheostomy represented the best option for preserving and promoting her quality of life. He took the view that this was a finely balanced decision.

26. Following Dr. O's assessment K suffered a further serious setback when she self-extubated on 30th November. For the first two days she appeared to manage relatively well and was alert. However, on 2nd December she suffered a cardiac arrest and had to have CPR for 5 minutes. She was reintubated and ventilated.

27. Dr. Bell was instructed on behalf of the Official Solicitor to conduct an independent assessment of K's overall medical treatment. He visited her at the ICU on 6th December after reading the core documentation in her case. His instruction was to consider the care she was being given and the options for her treatment, including tracheostomy. In his oral evidence he said that he formed his initial opinion quite deliberately without looking at Dr. O's report to avoid being influenced in any way. During his visit he discussed K with the nurses (including the matron) and the physiotherapist who were responsible for optimising her respiratory status. He also interviewed one of the other doctors who was engaged in K's care.

28. Once he had seen Dr. O'ss report recommending a tracheostomy Dr. Bell provided a more detailed report in answer to it. In this he set out in some detail the conversations that he had with the senior physiotherapist about K.

29. Dr. Bell was quite clear that the treatment that K is being given by her current treating team is entirely appropriate and that there is nothing they should be doing which they are not. He was also clear that she is in a terminal phase of her underlying neurogenerative condition and that this is not a case of her suffering from an intercurrent illness the resolution of which could lead to an improvement.

30. Dr. Bell identified that the key question was whether K would find the intervention of a tracheostomy tolerable once she was awakened from sedation, given her history of non-tolerance of ward-based physiotherapy and previous non-invasive ventilatory support. His belief was that she would not. His conclusion was that there would be a predictable ongoing requirement for sedation to tolerate essential interventions and a need for one-on-one direct attendance to avoid K triggering an unplanned removal of the tracheostomy. In his oral evidence he said that (having spoken to the nursing staff about how distressing the interventions are) he could not envisage 'sedation being taken away to the point that she can have any quality of life without getting distressed by all the lifesaving interventions and the medical and nursing interventions and therapies. I cannot see in that scenario the restoration of a quality of life where she can take pleasure from the environment'. He did acknowledge that she could possibly be able to tolerate some of the treatment (such as the tracheostomy tube) better because of her underlying disease, but said that other interventions were distressing.

31. Whilst it is feasible that K's condition would stabilise with a tracheostomy she would still remain in a critical care environment and is likely to succumb to an overwhelming infection at some point.

The family

32. After hearing the evidence of the doctors, I heard evidence from B. It is quite apparent that K is cherished by her family and has been lovingly and well cared for by them all her life. B said that K is strong and courageous, and a fighter. What matters to her the most is her family. She is strong willed and stubborn, and she likes to sing. B was understandably very distressed at some points, and said that she did not want her sister to die.

33. Included in the evidence I have is the statement and attendance note of KJ from the solicitor agent of the Official Solicitor. She makes a number of observations about K when she visited her, and also recorded that B told her that K loves new clothes and makeup, and that her face lights up when she is bought things. K's mother told KJ that she thinks that K knows her family are there and that she will smile when she sees them.

34. When asked if she had any thoughts about what K would want for herself, B said that K deserved the correct treatment and to be treated like anyone else.

Discussion and conclusions

35. Whilst I listed three options for the court at the start of this judgment, it is plain that there are only two. The Trust is not prepared to offer Option 1 and none of the experts considered that this is appropriate. The court cannot order treatment for someone who does not have capacity any more than it can for someone who does not. The choice is therefore Option 2 (extubation) or Option 3 (tracheostomy).

36. Both of the two options would require K to remain where she is in the ICU. Whilst Dr. B suggested that there was a possibility of a move home or to a hospice with extubation, the palliative care required and the timeframe makes this unrealistic. B is very anxious that K is not safe where she is and made a plea to the court for help for her to be moved to another hospital. I do appreciate how very distressed this family is, but there is no hospital which has offered to take her. K has respiratory problems as a result of her underlying neurological condition, and so a specialist respiratory hospital would not be in a better position to treat her.

37. In her final submissions on behalf of the OS, Ms Richards KC stated that there were three factors which tipped the balance in favour of a tracheostomy. The first was the inherent value of life itself, as K would only live for a very short time if she is extubated. The second related to what K might think if she had capacity. From the evidence we have K loved life, and she is both strong and a fighter. Her family is very important to her and so she would want to be with them as much as possible. Third are the views of the family. Although B has found it hard to advance a case she does not want her sister to die and the value to B of possible interaction with her sister is very important.

38. There is no doubt at all that the overwhelming wish of the family, as expressed so movingly by B, is for K to live. Therefore, whilst she did not say so explicitly, the tracheostomy option would be better as it gives K a longer life, albeit (as B observed at one point in her evidence, not by very much). It can also be inferred that they would support a reduction in sedation. The views of the family are not at all straightforward because they are predicated on the tragically false belief that K can recover. B went so far as to say in an email sent to the court after the hearing that the NHS team are deliberately withholding treatment from her. She said that her sister should be transferred to another hospital for her safety. I should record at this stage that there is no evidence to support this or that K has been treated differently in any way as a result of her learning disability.

39. I have given all the evidence and submissions the most anxious consideration. The factors set out by Ms Richards above, are very powerful, as are the heartfelt views of the family. There is no doubt at all that the preservation of life carries very great weight, even if it is for a short time. So too does the benefit to K of being able to spend at least some time being able to engage with her family. I bear in mind that many people would be prepared to tolerate some level of distress, pain and discomfort in order to be able to spend some precious time with loved one before dying.

40. Despite these powerful submissions I have come to the conclusion that it is not in K's best interests to have a tracheostomy. The evidence of both Dr B and Dr Bell who have both seen K more recently than Dr. O is that they do not believe that K will be able to tolerate the interventions required with a tracheostomy without sedation or physical restraint. I accept their evidence which is based on more recent and a wider knowledge of the case. Whilst I can appreciate that K is strong and courageous, the staff do have experience of how she has reacted to the current regime which is probably the best guide we have as to how she would react in the future. The truth is that K is unlikely to be able to benefit much, if at all, from being more awake. On the contrary, she is likely to suffer in a way that cannot easily be explained to her. The interventions she would require are frequent and burdensome. She would live for longer, but this would come at a heavy price.

41. In coming to my decision I bear in mind that K's deterioration has been very rapid and there has been a paradigm shift in her condition since she saw Dr. O on 28th November. At this point, only two weeks ago, her condition was such that he was able to envisage the possibility of her going home. Having heard from Dr. B, I also accept that it is not really possible to conduct the tracheostomy as a sort of trial. The operation would need to be conducted and for K to recover somewhat from it, which will take a number of days. It would only be then that the reduction of sedation could be tried.

42. In all the circumstances, therefore, and considering K's best interests in the widest sense, the prospects of K being able to obtain any benefit from a longer life and/or interaction with her family following a tracheostomy are too poor to outweigh the significant burdens that this will entail. Whilst sedation can shield her from the most distressing symptoms and interventions, this is not a case where she has no awareness at all. In her fragile state, an operation under general anaesthetic is still burdensome, as are all the sorts of treatments she will continue to have to have in the ICU until she dies. Ultimately, and unless the Trust make a successful application to withdraw

treatment it is thought she will succumb to an overwhelming infection within a few months.

43. I also bear in mind that the only other option, namely palliative care and extubation, will also carry with it the potential for distress and discomfort to K with symptoms that will require careful management. It will mean that the time with her family will be very short and realistically it seems there is no alternative to remaining in the ICU. Ultimately, however, it is my clear view, having read the care plan provided, that it is this pathway which is in her best interests, not a tracheostomy. I will therefore make the declaration sought by the Applicant Trust.

44. I would like to thank Ms Butler-Cole KC for the Trust and Ms Richards KC for the Official Solicitor for their assistance in this case.

45. Finally I want to express my deepest condolences to B and all of K's family. They have all suffered very much and I am conscious that these proceedings and this judgment will not have made things easier.