IMPORTANT NOTICE

This judgment was delivered in open court. The judgment can therefore be fully reported but there is to be no identification of ED, FD or the two clinicians from the NHS Trust, whether by name or location and this anonymity must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

IN THE COURT OF PROTECTION [2020] EWCOP 18

Case No: COP

Remote telephone hearing

Royal Courts of Justice Strand London WC2A 2LL

Thursday, 26th March 2020

Before:

THE HONOURABLE MR JUSTICE MOOR

BETWEEN:

UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST

Applicant

-and-

ED (by her litigation friend, the Official Solicitor)

First Respondent

-and-

FD

Second Respondent

MS CLAIRE WATSON appeared on behalf of the Applicant

MR PARISHIL PATEL QC appeared on behalf of the First Respondent

MS VICTORIA BUTLER-COLE QC AND MS VARSHA JAGADESHAM appeared on behalf of the Second Respondent

JUDGMENT

MR JUSTICE MOOR:-

- This is an application made by the University Hospitals Bristol NHS Foundation Trust (hereafter "the Trust") for declarations that it is lawful, if there is a deterioration in the condition of the First Respondent, Ms ED, (a) not to provide CPR or any other resuscitative measure and (b) not to admit her to the ICU Unit or provide an ICU level of care, even if, absent this order, she would meet the criteria for ICU admission.
- 2. I make it clear from the very beginning that the Trust is most certainly not saying that it will not provide a very high level of care for ED. Indeed it is clear to me that ED has had an excellent level of care from this Trust over a long period of time and that the provision that it is making for her on the respiratory ward that she is currently on is very close indeed to that which she would get in an ICU Unit. Indeed, it is perhaps as good as an ICU Unit in some other hospitals. This is not, and I repeat not, a question of authorising only palliative care. I am dealing with an application for a declaration that covers only the specific matters set out above.
- 3. I've already indicated that I am dealing with ED. She was born on 27th May 1984 and is therefore aged 35. She was born with quadriplegic Cerebral Palsy and she has severe learning difficulties. I am told she has no verbal communication. She communicates with facial expressions. The Trust's case is that she can only communicate basic feelings, such as whether she is comfortable or distressed. Her mother disagrees and believes ED communicates to a higher extent than that. ED is represented by the Official Solicitor who in essence supports the application made by the Trust.
- 4. The second respondent is ED's mother, FD. She is clearly a woman who loves her daughter unconditionally and very greatly. She has devoted enormous energy and determination into achieving what she regards as best for her daughter. She opposes the application.

- 5. I am very grateful to Counsel, their solicitors, the clinicians and FD for dealing with this case at such short notice this week. Particularly given the current Covid-19 crisis, and for preparing and presenting the case so comprehensively and ably. As a result, I am quite satisfied that I have been able to give the matter an entirely fair trial in accordance with Article 6 of the Convention.
- 6. It is necessary to give some brief history. In general, ED has lived at home throughout her life with her mother in the West Country. She was, I am told, in intensive care when she was 2 or 3 months old but, thereafter, not for many, many years until 2013 when she was admitted to an intensive care unit at a Hospital in the West Country with pneumonia and electrolyte disturbance. She was fully sedated, intubated and given ventilation. A tracheostomy was performed on discharge as attempts at decannulation had failed. Thereafter, however, she lived at home with her mother for some 6 years with the tracheostomy in place. I believe she did have the assistance of some carers, primarily overnight, but I haven't got the full details in relation to that. She did have non-invasive ventilation overnight to assist with her breathing whilst she was asleep. There have been proceedings in the Court of Protection in Bristol over a number of years, which have been dealt with by His Honour Judge Marston. Again, I do not have the specific details. I believe they primarily relate to ED's care package. On 28th October 2016, Judge Marston made an interim declaration that ED lacked capacity in that litigation.
- 7. I have also read a report from a speech and language therapist, Susan Hamrouge, dated July 2017. She says that ED uses an eye gaze as a means of indicating communicative intent, but there is no consistent repeatable response to spoken language on the assessment of her skills other than a smile. There is no evidence that she understood the information presented to her. Her responses suggested she was functioning at the age of around 12 months. The expert considered that, in view of her severe delay in understanding spoken language, she will not have capacity as identified in the Mental Capacity Act 2005 ("the Act"). Mrs. Hamrouge filed a second report on 25th July 2018 which broadly confirmed her previous report. Some investigations had been made as to whether there was a system that could assist in ED understanding language without success. I am told that final orders were made by the Judge in 2018 and there have been some further proceedings since in

2019. This means that the Judge must have been satisfied that ED lacked capacity in relation to those proceedings at that time.

- 8. In December 2018, ED's tracheostomy was removed electively. But, on the 8th April 2019, ED had to be admitted to a hospital run by the Trust with pneumonia and Type 2 respiratory failure. She was given non-invasive ventilation but then, as I understand it, she went into the Intensive Care Unit for a time and had a further tracheostomy fitted. She improved with intravenous antibiotics. The tracheostomy was removed prior to discharge, although she did have some obstructive sleep apnoea for a time, which FD says fortunately resolved itself. On 28th May 2019, she was discharged home again with night-time non-invasive ventilation.
- 9. On 6th March 2020, she was readmitted to hospital with pneumonia and her respiratory condition deteriorated. She was initially given non-invasive ventilation by a hospital ventilator almost 24/7. On 17th March of 2020, she had improved with intravenous antibiotics and she was only, at that point, having non-invasive ventilation for approximately 3 hours per day plus at night. Nevertheless, the clinicians considered that she should have the tracheostomy reestablished, but FD was not keen. On 19th March 2020, ED's position deteriorated again. She became ventilator dependent and antibiotics were again prescribed. The tracheostomy was then performed with the agreement of FD. She spent one night in the Intensive Treatment Unit.
- 10. Since then, however, there has been a significant improvement. She is back on the Respiratory Ward. I am satisfied she is getting a very high level of care there. She has improved to the extent that the ventilator was removed yesterday for 4 hours both in the morning and the afternoon. It has further been removed since about 8.30 this morning. There are, however, no plans for her imminent discharge from hospital. There is a fear that there may be a further deterioration in the future, hence this application. Indeed, it is right to note there was a significant improvement in her position in the run up to the deterioration again on the 19th March 2020.
- 11. The Trust's position is that her state of health is precarious and unpredictable. And the reasons that it advances for its application is to avoid ED from undergoing extensive and potentially invasive medical treatment that the Trust considers not to be in her best

interests. It says they would have a low prospect of success and that, if successful, would likely lead to a worse quality of life.

- 12. I have read carefully statements filed on behalf of the Trust by Dr DF, a Consultant Respiratory Physician, and by Dr HR, an ICU Consultant. Both have given evidence before me orally today over the telephone. In her statement, Dr DF deals first with the question of capacity. She tells me that ED cannot understand, retain, weigh up information or communicate her decisions. Therefore, in the doctor's view, she lacks capacity. She makes the point that FD believes that ED does have capacity. She then says that a ceiling of treatment is in ED's best interests as certain interventions would be burdensome for her. ED is incredibly frail. Her stability is precarious. The doctor sets out the history of the case. She says that ED is fed through a nasogastric tube and is incontinent. ED is very frail and weak and that there is a risk of a further deterioration the whole time. It is not clear if ED has any comprehension of language. She does grimace when she is uncomfortable. She has kyphoscoliosis. Her spine is twisted and bent forwards. As a result of that, she cannot get enough air into her lungs without help. Dr DF says that FD has no appreciation of how vulnerable and sick her daughter is, but she wants everything done to keep her alive. The doctor ends by saying she does not believe it is in ED's interests to have uncomfortable, burdensome interventions that only an Intensive Treatment Unit can provide, now or in the future. There should therefore be a ceiling of treatment on admission in the future.
- 13. The statement of Dr HR is dated 20th March 2020. It basically supports and confirms the evidence of Dr DF. He deals with the history of the last few days and says that what has happened is a sign of a poor prognosis given the optimal care that ED has had in the hospital. He does indicate that the tracheostomy has helped ED improve by enabling secretions to be more easily removed from her chest. But he makes the point that she was back in the Respiratory High Care Ward on 20th March. He says that the hospital clinicians have reached the limit of what they can do and that he does not believe it is in ED's best interests to put her through more burdensome treatment. He says that full ventilation is very uncomfortable such that she might need sedation if she went into the Intensive Care Unit. This can, potentially, cause stress on her heart and reduce her blood pressure to unacceptable levels. There would be the risk of her needing resuscitation and, if she deteriorated further, it would be unlikely she would recover sufficiently to be weaned off ICU ventilation in the future. If she developed sepsis, she might require inotropic support

which would be very difficult as it would have to be given via her neck which would give rise to a risk of stroke and a punctured lung. If there was a need for CPR, should there be cardiac arrest, the chest compressions would be extremely painful. They would risk rib fractures and be very distressing for ED. He says that he believes such treatments to be highly invasive and burdensome with the prospect of success at almost zero and giving rise to a risk of further brain injury. He says that this is not about rationing ICU beds. It is a best interests decision that he and Dr DF are agreed upon.

- 14. I have also read carefully the statement of FD dated 25 March 2020. She disputes that the decision the Trust wishes me to take is in ED's best interests. She says she does not agree that ED lacks capacity. She says she discussed the matter with ED and ED became very distressed and quite tearful about this litigation. However, ED became animated and grinning when FD said that they were going to fight it, meaning the case. This indicates to FD that ED's wish is to have these treatments because she is full of life and has plans for the future. FD says that, until 2013, she provided all of ED's care and they are inseparable. She says ED is intelligent, funny, thoughtful, caring, loving and loved. A nurse had told her that ED was the happiest person she had ever known. ED has always outperformed the medical predictions and she has flourished in the last year. She says she accepts there should not be care without limitation, but she wants sufficient care to enable ED to live a happy and fulfilling life. She does understand how ill ED is, but she has experienced ED recover and go on to enjoy her life. ED has successfully spent periods off the ventilator on 24th and 25th March. She says that ED had resuscitation in 2019 but made a full recovery. She did have an adverse reaction to an antibiotic but so have other members of the family. She does not believe that ED experiences pain or distress when undergoing suctioning when it is done correctly, although it is not a pleasant experience. It can be uncomfortable if it is done roughly or not correctly.
- 15. The Official Solicitor, at extremely short notice, instructed Dr Dominic Bell, a Consultant in Intensive Care/ Anaesthesia at the General Infirmary at Leeds and he has provided a report for me this morning. In the circumstances, for him to have done this report within the last 3 days is a tribute to his dedication and commitment. I am very grateful to him. It is fair to say that his report is almost in exactly the same terms as those of Dr DF and Dr HR. He says that, prior to admission, ED was extremely vulnerable to lower respiratory tract infections and respiratory failure. Her 2019 problems will have further predisposed

her to subsequent infection. To fight these infections, a functioning immune system is necessary. On the balance of probability, he takes the view that recurrent infection with progressively antibiotic resistant organisms is likely. He believes that it is likely that she will remain in hospital until she passes away. He considers that the time period is between 6 and 12 months, although I make it clear that FD does not accept this and says that other clinicians have given her much longer periods and that ED regularly confounds doctors' predictions. Dr Bell, however, says that, if ED deteriorates further, it will not be readily reversible. He does not believe that the return to a meaningful quality of life would be achievable if there was to be any further intensive care periods. He also considers that ED will be exposed to discomfort and distress at interventions that would not yield any ultimate benefit. It is difficult to say how burdensome these interventions are for her, but she is bound to feel, in his view, a degree of discomfort and distress. He says the nursing staff assume she is uncomfortable when she appears agitated and her body, at times, goes rigid. He takes the view that invasive devices would represent a sustained burden with no accompanying benefit. Therefore, he concludes that ICU in the future would be inappropriate unless she was making sustained progress with weaning back to her pre influenza respiratory status such that discharge from hospital was feasible and the trigger was regularly reversible. He takes the view that cardiopulmonary resuscitation would be either unsuccessful and futile or injurious to her welfare and contrary to her best interests. He takes the view that the correct approach now is for her to have a dignified death at the end of what has been a challenging life. He does, however, say that there should definitely be explicit palliative therapy to relieve discomfort and distress.

16. I must deal with two separate matters. The first is the issue of capacity and the second is the issue as to the declarations that I am asked to make. In relation to capacity, I remind myself that a person must be assumed to have capacity unless it is established that they lack capacity. A person is not treated as being unable to make a decision unless all practical steps have been taken to help her to do so without success. A person is not to be treated as unable to make a decision simply because she makes an unwise one. I remind myself of section 3(1) of the Act that 'a person is regarded as being unable to make a decision if she cannot understand information about the decision to be made, retain that information, use or weigh the information as part of the decision making process and communicate the decision by any means.'

- 17. I have listened carefully to the evidence in this respect. FD urges me to find that ED has capacity. But I am satisfied she does lack capacity to conduct these proceedings and to make decisions about what medical treatment she receives. I accept that FD believes she understands these matters, but I must always guard against any response that is dependent on the approach and apparent emotions of FD herself. I cannot ignore ED's inability to communicate. The Bristol proceedings, the reports of Susan Hamrouge and the evidence of Dr DF all point to ED lacking capacity. I have to say that I have formed the clear view that it is impossible for ED to weigh up the very detailed matters that I have to consider; the medical evidence and all the other considerations in this case. I am clear that in this regard she lacks capacity. I make such a declaration.
- 18. I now turn to consider the law on medical treatment. It is extremely helpfully set out by counsel in their respective case summaries. I remind myself that it is well established that a doctor cannot be forced to undertake medical treatment with which he or she does not agree (see <u>Re J (A Minor)</u> [1993] Fam 15, at 26H 27F). Further, the law requires a doctor only to provide such treatment and care as would be in the incapable patient's best interests (<u>Re F [1992] AC 1 at 55E</u>).
- 19. In determining the question of best interests, the Act provides that:-
 - (a) Any act done or taken in respect of a person who lacks capacity must be in his best interests [s 1(5)].
 - (b) The decision maker must consider whether the purpose for which the act or decision is needed can be as effectively achieved in a way which is less restrictive of the person's rights and freedoms of action [s 1(6)].
 - (c) The person making the best interests determination must consider all the relevant circumstances [s 4(2)]. These include a person's past and present wishes and feelings so far as is reasonably ascertainable; the beliefs and values that would be likely to influence the person's decision, if she had capacity; the other factors that she would be likely to consider if she had capacity; and, finally, the views of family members and others engaged in caring for the person or interested in her welfare.

- (d) Section 4(5) states '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 her death.'
- 20. Paragraphs 5.31 5.33 of the MCA Code of Practice provide that
 - (a) 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 [5.31].
 - (b) 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 check list should be considered, and, in particular, the decision maker should consider any statements the person has previously made about their wishes and feelings about life-sustaining treatment. [5.32].
 - (c) Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide or to continue to provide life-sustaining treatment where that treatment is not in the best interests of the person. Even where the person's death is foreseen, doctors must apply the best interests' check list and use their professional skills to decide whether the life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed and there is no other way of resolving the dispute, ultimately, the Court of Protection may be asked to decide what is in the person's best interests. [5.33]

- 21. The Courts have acknowledged that "in assessing whether it is in a patient's best interests to receive treatment that may prolong their life, the fundamental principle of the sanctity of human life, although not absolute, will weigh heavily in the balance. However, the sanctity of life is not absolute. There is no absolute duty to prolong life" (<u>Airedale NHS Trust and Bland</u> [1993] AC 789).
- 22. It is now well established that, in assessing best interests, the Court is not limited to consideration of best medical interests. "Best interests encompasses medical, emotional, psychological and social issues" (<u>Re MB (An Adult)</u> [1997] 8 MLR 217 at 225). As Baroness Hale observed in <u>Aintree University Hospitals NHS Foundation Trust v James</u> [2013] UKSC 67 at paragraphs 39 and 40:-

"39. The most that can be said, therefore, is that, in considering the best interests of a particular patient at this particular time, decision-makers must look at her 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 her attitude to the treatment is or was likely to be; and they must consult others who are looking after her or interested in her welfare, in particular, for their view of what her attitude would be.

40. ...it was correct to consider whether the proposed treatment would be futile in the sense of being ineffective or being of no benefit to the patient...He was also correct to say that 'recovery does not mean a return to full health but the resumption of a quality of life which Mr James would regard as worthwhile.'...he, (the first instance judge), was also correct to say the assessment of the medical effects of the treatment was only part of the equation. Regard had to be had to the patient's welfare in the widest sense, and great weight to be given to Mr James' family life which was of the closest and most meaningful kind."

23. Ms Butler-Cole QC on behalf of FD also asked me to look at further paragraphs in the judgment:-

"In my view therefore, Peter Jackson J was correct in his approach. Given the genesis of the concept used in the Code of Practice, he was correct to consider whether the proposed treatments would be futile in the sense of being ineffective or being of no benefit to the patient. Two of the treatments had been tried before and had worked. He was also correct to say that recovery does not mean a return to full health. But the resumption of a quality of life which Mr. James would regard as worthwhile. He clearly did consider that the treatments in question were very burdensome. But he considered that those burdens had to be weighed against the benefits of a continued existence. He was also correct to see the assessment of the medical effect of the treatment as only part of the equation. Regard had to be had to patient's welfare in the widest sense and great weight to be given to Mr. James's family which was of the closest and most meaningful kind.

41. Perhaps above all, he was right to be cautious about making declarations in circumstances which were not fully predictable or fluctuating. The Judge was invited to address the question whether it would be lawful to withhold any or all of these treatments. But if he had been asked the right question, whether it would be in the patient's best interests to give any or all of them should the occasion arise, his answer would clearly have been to the same effect. He would have said, as he was entitled to say that, on the evidence before him it was too soon to say that it was not. The conclusion is quite consistent with his statement that 'for what it's worth''' he thought it unlikely that further CPR would be in the patient's best interests.'

43. ...Thus it is setting the goal too high to say that the treatment is futile unless it has 'a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering'... Given its genesis in Bland, this seems the more likely meaning to be attributed to the word as used in the Code of Practice. A treatment may bring some benefit to the patient even though it has no effect upon the underlying disease or disability. The Intensive Care Society and the Faculty of Intensive Medicine, who have helpfully intervened in this appeal, supported the test proposed by Sir Alan Ward. But this was because they believed that it reflected clinical practice in which 'futility would normally be understood as meaning that the patient cannot benefit from medical intervention because he or she would not survive with treatment.'... 44. I also respectfully disagree with the statement that 'no prospect of recovery' means 'no prospect of recovering such a state of good health as will avert the looming prospect of death if the life-sustaining treatment is given'. At least on the evidence before the Judge, this was not, as Sir Alan Ward put it, a situation in which the patient was actively dying."

24. I was also asked to look at the judgment of Peter Jackson J at first instance, and, in particular, paragraphs 81 and 82 where he said:-

"81. In relation to DJ's medical condition and his prospects, the experience of the doctors is persuasive. The family's hope is for a miracle, but where medical matters are concerned, the court must have regard to the unanimous expert advice. In particular, the evidence of the burdens of this kind of treatment must carry heavy weight.

82. Even so, that advice is bound to be based on an assessment of probabilities, and there will be a very small number of cases where the improbable occurs. Moreover, the assessment of best interests of course encompasses factors of all kinds, and not medical factors alone, and reaches into areas where doctors are not experts."

25. I have considered with great care all of the law and the approach that I must adopt in deciding this application. I heard from 3 doctors; Dr HR, Dr DF and then Dr Bell. I also heard from FD. Dr HR effectively repeated his evidence in his witness statement. He said in answer to questions by Ms Butler-Cole QC on behalf of FD that 'it was impossible to say that there was no chance in this case.' But he took the view that there was a very low likelihood and he considered the need for comfort and dignity was of extreme importance. He said that something should not be done if the burden of doing so was out of proportion to the benefit. There was what he viewed as 'such a poor chance of recovery.' He said that, if ED's condition was to deteriorate, she would be unlikely to benefit from the increased level of treatment that they would offer. And he thought that it was unlikely that she would be able, in such circumstances, to return to even a base line of functioning. In reexamination, he was asked by Ms Watson on behalf of the Trust about paragraph 4.13 of Dr Bell's report in which he gave the caveat to a ceiling of treatment if a new deterioration was readily reversible. Dr HR thought that this was referring to the position if it had been possible to remove the tracheostomy, but he considered it would be very difficult, in these

circumstances, to get the tracheostomy removed. If that had happened, it would be appropriate to revisit the matter.

- 26. Dr DF was asked in her evidence in chief about discharge home. She did not think it was imminent, but she did think it unlikely that they would consider discharge home without the tracheostomy in place. It had been removed twice already and she thought that, if it was removed for a third time, there was a significant chance that ED's position would rapidly deteriorate again. It would be extremely risky to remove it and it should therefore stay in place. When asked questions by Mr Patel QC on behalf of the Official Solicitor, she said that the NHS Trust would, even if the orders and the declarations that I am asked to make are made, still offer a very high quality of care on the Respiratory Ward. They would offer ventilation through the tracheostomy. They would offer antibiotics. What they would not be doing was taking the matter to the next level, because of matters such as the risk of renal failure; the potential need for resuscitation; problems with blood pressure; with heart failure; and the like. Other than in those regards, she said there was not very much difference between what the ICU Unit could offer and what the normal Respiratory Ward was able to put in place. She was concerned about putting tubes into ED's neck to support dialysis. Those are the things she did not think were in ED's best interests.
- 27. In terms of the doctors, I heard last from Dr Bell. He again, supported and repeated his written document. He said, in answer to questions from Mr Patel QC, that he was concerned that the cumulative episodes were attritional. He was referred to his paragraph 4.6 and he said that he was talking about a sustainable return to a meaningful quality of life. In other words, getting back to close to where she was prior to this episode. He had to balance harm and discomfort against the likelihood of achieving that. In answer to a question from Ms Watson, he told me that the NHS Trust was continuing to provide advanced care on the Respiratory Ward. He was asked what else they could do and he responded that the doctors would have to make a best interests decision if ED returns. It is too simplistic, he said, to say she could never go back to the Intensive Care Unit as he pointed out that there are some hospitals that can only provide in an ICU Unit what ED is getting now on her Respiratory Ward. So, he said, he is not being absolutist. But he did not think there should be any fresh best interests decision and said that the court should be taking a final decision today on the basis that I have the information before me. He did accept that the clinicians would have to exercise a judgment on admission. But he took the

view that it was unlikely that anything would have changed if there was a new admission within a short period of time of ED being discharged from hospital. And if she did not respond, he took the view that the principles that he had set out would remain an active consideration.

- 28. Finally, I heard from FD. I pay great tribute to her for the commitment and determination that she has given to support her daughter and care for her daughter. I have already referred to the love that they undoubtedly have for each other. She told me that she was convinced that, if and when the time comes, it should be ED's decision as to whether or not to give up fighting or to carry on the battle. She took the view that there would come a time when ED probably would give up, but, she said, ED is not doing that at the moment. She is fighting. She told me that it amazes her that she gets better. She said that ED's life is worth living.
- 29. I accept all that. I accept that ED has been fighting, but, of course, she did get better last week and then she deteriorated again. I accept the evidence of the doctors that the progress of her condition, unfortunately and very regrettably, tends to be a downhill one in which matters do not improve and every time, the treatment becomes more difficult to be successful and, potentially, gives rise to the sort of issues that I am now concerned with.
- 30. In her closing submissions, Ms Watson urged me to make the declarations that have been sought. She said that, in particular, it was not appropriate to put ED through the sort of ICU treatments that would involve, for example, vasoactive drugs, renal replacement therapy, ICU level ventilation, treatment that requires central venous access, or cardio-pulmonary resuscitation. She said that the Trust will continue to provide the highest level of treatment that they can give in the current Respiratory Ward, but they should not have to give treatment that is burdensome, unpleasant and painful. This should ensure that, when the time comes for ED to pass away, it should be in a dignified manner with all appropriate palliative care at that point. I accept that submission. I take the view that the Trust's position is correct. I endorse the position.
- 31. Mr. Patel QC for the Official Solicitor agreed and adopted the same position. He said that there was quite compelling medical evidence of the trajectory downwards. The position is diminishing episode by episode and that, at some point, a line has to be drawn. He accepted

the evidence of the three doctors that the line should be drawn from now on. And that any further treatment should be in the Respiratory Ward and there was, he submitted to me, compelling medical evidence behind that position. I accept those submissions.

- 32. Ms Butler Cole QC asked me to take into account the other factors in ED's life. And, of course, I do so. I entirely accept that she has had a good quality of life with her mother over the years. I have read with great care of the trips to various festivals that she has made. I have seen the pictures of her with what might be described as celebrities. I understand the enjoyment that she and others have had out of her life. And of course, I as the Judge very much want her to get better from this current infection that she has had. I am pleased to have heard of her improvement in the last few days. I hope that it will be possible for her to return home. I accept entirely that she should continue to have a good level of treatment as is provided to her in the Respiratory Ward. I am quite sure that that is in her best interests.
- 33. What I do not agree, and I come to this with something of a heavy heart, is that it is in ED's best interests to have the far more invasive treatments that are involved usually and regularly by ICU admission. In particular, I cannot see that it is in her interests to have CPR or such other resuscitative measures at this point of time. In the healthy, such measures are extremely painful, distressing and difficult to administer. In somebody with ED's conditions, I consider it would be quite intolerable and burdensome. And I am absolutely satisfied that I should indeed make the declaration that I have been asked to make as to CPR and any other resuscitative measures.
- 34. I have also come to the conclusion that I should make the declaration about future admission to an ICU Unit. I make it clear, and have already done so, that by making this order, I do not consider it to be obligatory. I am saying that it is permissory. It will be up to the doctors on the ground to decide what to do in each particular circumstance. But assuming that there has been no significant change of circumstances, I take the view that it is right that I should authorise no future such admissions. It is quite clear to me that many of the things that would be involved in that, such as the renal treatment or the treatments via the neck, are likely to be extremely burdensome to ED and to provide no significant benefit to her whatsoever.

- 35. It is of course sad to come to that conclusion. I very much hope that she will not get ill again and that we will not have to get to the point of needing such treatments. But I am clear that, if she does so, the treatment that she should have, all other things being equal, is on the Respiratory Ward. It will be the best possible treatment on that ward. It will include ventilation. It will include antibiotics. It will include physiotherapy. But it will not include the extra active involvements of the ICU Unit. That in my view will not assist her, will harm her and cause her pain and is likely to be entirely futile.
- 36. I have come to the conclusion, having considered the evidence extremely carefully, and recognising the distress that this will cause to FD, that I should accept the NHS Trust's application and make the declarations that it seeks. I very much hope that it will be possible for ED to go home to recover from this current bout of illness and I very much hope that in the future she has the best possible life at home. Having said that I am clear that I should make the declarations that are sought.
- 37. Ms Butler-Cole QC then submitted to me that I had not addressed at all the matters in relation to s4(6) of the Act concerning not just the expressed view of the person or wishes and feelings but also the beliefs and values that would be likely to influence their decision if they had capacity and the other factors they would be likely to consider. She said that those were matters that she in her submissions about the evidence or lack of it as to whether ED was the sort of person who would take a less than 10% chance of survival or not.
- 38. This is already a very long extempore judgment, but I entirely accept that I did not deal directly with the point in relation to section 4(6). I take the view that ED would recognise that the treatment she is getting on the Respiratory Ward is excellent treatment and that for her to have to go through the additional invasive treatments of the ICU and CPR would not be in her best interests because it would be futile in the long term and it would be likely to cause her pain and suffering and not achieve any advantage. And that is the reason why I have come to the conclusion I have.
- 39. Although I did not make the point at the time, I add, when approving this note of the judgment, that it is not as though I am authorising only palliative care going forward. I am approving these declarations on the basis that ED will continue to get a very high level of care on the Respiratory Ward. I take the view that this makes this case entirely different

from other cases referred to by counsel and that this is something that ED would undoubtedly take into account pursuant to section 4(6).