



Neutral Citation Number: [2021] EWHC 2294 (Fam)

Case No: FD21P00375

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 26/07/2021

Before:

MRS JUSTICE THEIS

Between:

The Trust	<u>Applicant</u>
- and -	
Mr Y	<u>1st Respondent</u>
- and -	
Mrs Y	<u>2nd Respondent</u>
- and -	
PZ	
By Her Children's Guardian	<u>3rd Respondent</u>

Miss Nageena Khalique QC (instructed by **Trust**) for the **Applicants**
Ms Olivia Kirkbride (instructed by **Darton Law**) for the **1st and 2nd Respondents**
Mr Neil Davy (instructed by **Cafcass**) for the **3rd Respondent**

Hearing dates: 19th & 21st July 2021

Judgment: 26 July 2021

Approved Judgment

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published. The anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Theis DBE:

Summary

1. The court is concerned with an application concerning a little girl PZ, born on 8 January 2021, now 6 months. The application is made by the Trust where PZ is currently being cared for in a neonatal intensive care unit. She has been in hospital since her birth. The Trust seek a declaration that it is in PZ's best interests for life-sustaining medical treatment to be withdrawn and for a palliative care regime to be implemented.
2. Her parents, Mr and Mrs Y, who have been devoted to PZ's care since her birth, do not support this application. Their joint letters to the court sets out their position simply but powerfully; guided by their religious faith, they believe Allah will take the life that Allah gave. PZ's mother spends each week at the hospital with PZ helping care for her, working closely with the nursing team, and her father visits when he can. The parents have had the benefit of pro bono representation by Ms Kirkbride and her instructing solicitor, Ranjit Siddle. The court is very grateful to them for assisting and supporting the parents and setting out their position so clearly.
3. PZ is a party to this application through her Children's Guardian, who has had the opportunity to visit PZ in hospital, speak to the parents and the treating clinicians. She supports the application made by the Trust.
4. Tragically, PZ was born with a severe congenital condition. The impact of this condition for PZ is that she suffers significant muscle weakness, in particular she is unable to move independently, communicate, swallow or cough. It is accepted that this is a condition that will not improve, it will deteriorate and is life limiting. Although there has been some slight improvement in her limb movement she remains unable to alter her position or make facial expressions. The impact of this is that although PZ is cognitively aware it is difficult to identify when she is in distress, other than by signs such as increased heart rate or when tears are observed.
5. She is in receipt of 24 hour specialist nursing and medical care and requires mechanical ventilation, tube feeding and regular suction of secretions and drooling due to her inability to swallow or cough. She is unable to communicate. Many of these medical processes have been observed to cause her pain and discomfort and in the case of the suction procedure is required at regular intervals, usually hourly sometimes more frequently. As her father has observed one of the difficulties is not knowing how PZ feels, whilst there are some outward signs it is not known how she feels inside. Her cognitive function is likely to be normal so she has the prospect of being increasingly aware of her circumstances but being unable to communicate how she feels. Attempts to extubate PZ have been unsuccessful.
6. The parents agree with the medical diagnosis and prognosis for PZ but feel very strongly that she should continue to receive the life sustaining medical treatment as they consider, in accordance with their religious beliefs, that PZ is a gift from Allah and it is only he who can make the decision when she should go. Due to her age and her medical condition PZ has had only very limited exposure to her parents religious and cultural beliefs and values.

7. In reaching my decision I am guided by what is in PZ's best interests having regard to what her views may be, her parent's wishes and feelings, including their religious and cultural beliefs, the benefits and burdens as a consequence of her medical condition, the views of her treating doctors and having regard to the strong presumption to preserve life.
8. It is with very great sadness that I have come to the conclusion that it is in PZ's best interests for life-sustaining medical treatment to be withdrawn, and for a palliative care regime to be implemented for the reasons I have set out in more detail in the judgment below. I know this is not the decision the parents wished for and I fully understand why they would not want that. They have had to manage the most difficult situation any parent has to face. However, I have to look at the wider picture in considering PZ's best interests. Whilst I recognise the benefits she has enjoyed through her parents' loving care and attention and the importance of the presumption in preserving life, I consider the evidence demonstrates that the burdens for PZ continuing to be treated in the way that she is, with the risks of what lays ahead for her, outweigh all those considerations.
9. The invasive medical treatment she currently receives is likely to increase and cause her further distress, discomfort and pain with no real prospect of her condition changing. It is more likely that her condition will continue to deteriorate, with the very real risk of changes to her musculoskeletal position, such as curvature of the spine and dislocated hips, as well as the increased risk of infection and other complications connected to her medical treatment which are very likely to cause her further distress, discomfort and pain caused not only by those changes, but also by the likely increase in medical interventions that will be necessary. That is the very sad reality of PZ's position.
10. PZ's parents could not have done more for her. Their devotion, unconditional love and dedicated care for her will have been a great comfort for PZ in the very difficult position she is in.
11. I will therefore grant the declarations sought by the Trust.
12. I am satisfied that following the parties knowing the court's decision they will be able to have further discussions about the care plan and what arrangements that can be put in place to support everyone involved.

Relevant Background

13. When PZ was born at 36 weeks plus 3 days gestation, she was in a poor condition with a low heart rate and no respiratory effort or movements. She required resuscitation and intubation at 13 minutes of age and was transferred to the Regional Neonatal Intensive care unit for specialist investigation and management. PZ remains being cared for in that specialist unit.
14. PZ was diagnosed with a severe congenital condition and has been noted to have the following diagnoses and presentation:
 - i. dysmorphic features with low set ears, downwards slanting eyes, micrognathia (small jaw) and a cleft palate;
 - ii. slender limbs with significantly reduced muscle bulk;

- iii. no facial movement aside from eye opening;
 - iv. slight movement of her hands;
 - v. slight extension of her wrists against gravity;
 - vi. partial flexion of her elbows although not against gravity;
 - vii. slight movement of her toes;
 - viii. She can wriggle her shoulders a little and move her head from side to side but not against gravity;
 - ix. She likes having her hands up at her face but if they fall away she is unable to move them back and seems frustrated by this;
 - x. profoundly hypotonic (floppy);
 - xi. long slender fingers and no grasp reflex;
 - xii. joint contractures
 - xiii. respiratory failure, with her intubated and ventilated;
 - xiv. poor airway tone;
 - xv. significant drooling;
 - xvi. poor feeding and needing nasogastric feeds;
 - xvii. normal heart function.
15. PZ remains on mechanical ventilation. There have been three occasions when PZ has been extubated. At 5 days old a trial of extubation to non-invasive support was undertaken but she developed respiratory failure after three days resulting in reintubation with mechanical ventilation. On day 32 a further trial resulted in reintubation due to respiratory failure after 24 hours and on day 69 there was an unintentional extubation and she required reintubation within minutes.
16. Due to her condition and her inability to swallow PZ has orogastric feeding. She will need a gastrostomy to enable clinical assisted feeding and a fundoplication (surgical procedure) to help remediate her reflux.
17. PZ also has bulbar dysfunction and no ability to suck, swallow or clear her secretions which means she needs frequent suction of her mouth and pharynx. The secretions and the process to remove them are noted to cause PZ distress through raised heart rate, agitation and tears in her eyes.
18. A feature of PZ's condition is despite its severity cognition is not affected, so it is possible that PZ will be cognitively aware, although it may be difficult to gauge as at her age developmental progress and cognition is measured by her ability to acquire skills such as smiling and head control. Although, due to her condition, she is unable to develop those skills there is evidence she is cognitively aware of her surroundings to a limited degree, such as being able to enjoy interactions with her family, music and bath time.
19. There have been several multidisciplinary team meetings to discuss PZ's position, which have included her parents. There is unanimity within the neonatal consultants responsible for PZ's care that it is not in her best interests to continue ventilatory support, her condition is severe, untreatable and unlikely to improve to any significant degree. She would be unable to sustain life without ventilation support, or be able to swallow or clear her secretions. She is likely to be cognitively normal, will continue to benefit from the love of her family and the ability to listen to music. Having considered these matters the consensus of the clinical team is that PZ's life is limited in quality

and the burdens of her underlying condition produce suffering as to overcome any benefits in sustaining life.

20. The clinical team sought a second opinion from Professor M, Paediatric Neurologist at another hospital, who confirmed in an email dated 15 February 2021 that the prognosis with a child with PZ's condition was very severe and continued *'I think the directions towards palliation for a child who has such a severe condition, and who has failed extubation, is one I would support'*.
21. The clinical team also sought a further opinion from their Paediatric Intensive Care Team on 11 March 2021, who concluded they would not support tracheostomy and long term ventilation as the treatment burden, in particular suction clearance, would be considerable and there is little chance of this improving. They did not consider long term ventilation would be in her best interests.
22. On 18 March 2021 the clinical team made a referral to the Clinical Ethics Advisory Group ('CEAG'), setting out PZ's position and the treatment options for her. Having considered the matter, the CEAG concluded the withdrawal of life sustaining treatment from PZ to be in her best interests.
23. The parents have been engaged with the clinical team within these discussions and whilst they understand and accept the incurable nature of her condition they cannot support extubation on the basis that PZ would not be reintubated. As Dr C noted in her statement *'...they cannot agree to a plan that would treat her symptomatically but not intubate and allow a natural death. They feel that this decision would be wrong for them to make and is an unbearable responsibility for them'*.

The evidence

24. There are detailed written statements from Dr M (Paediatric Consultant Neurologist), Dr H (Consultant Respiratory Paediatrician) and Dr C (Consultant Neonatologist and Lead Consultant). They each gave oral evidence.
25. In his statement and oral evidence Dr M outlined how PZ will be increasingly affected by her condition. Her musculoskeletal system will be affected with it being highly likely she will develop severe curvature of the spine, dislocated hips and her bones becoming osteopenic, liable to fractures and she will not be able to feed, speak or swallow. During his observations of her there had not been any neurological improvement. Whilst he recognised there had been subtle changes in her movements, that PZ has some awareness of her surroundings, her parents' voices and music he confirmed that did not alter his overall conclusion that the burdens of her condition outweigh the benefits. Ms Kirkbride asked about the prospect of PZ being able to use eye gaze technology, he responded that to enable PZ to use such technology she would need to be able to communicate in the first place, which PZ is unable to do as a consequence of her condition. He said it was only possible to measure PZ's discomfort by physiological measures, such as increased heart rate and observed that it can be equally distressing for the child not being able to reciprocate pleasure. He described how a child developed from head to toe, head control is the first milestone which PZ is not able to achieve.
26. Dr H confirmed his view that PZ is likely to need ventilation for the rest of her life. He describes how she regularly needs suction to remove secretions, hourly and sometimes

half hourly. He confirmed there is evidence of pain and discomfort during these procedures noted by increased heart rate and tears in PZ's eyes. He confirmed there was no alternative to mechanical ventilation support due to PZ's needs. Ms Kirkbride asked about the possibility of long term ventilation through a tracheostomy and the possibility of PZ being at home. Dr H acknowledged that if PZ had a tracheostomy it would prolong her life, however this is not without complications with short and long term risks. For the reasons outlined in his statement this was not something he could support due to PZ's muscle weakness, management of the secretions, the level of support that would be required, with the risk of infections and recurrent admissions to hospital which, in his opinion, would increase and become more difficult over time.

27. Dr C is the lead consultant neonatologist who has been involved in PZ's care since soon after her birth. She describes in her statement the previous attempts to extubate PZ. She acknowledged the small changes in PZ's movement in her finger tips and her shoulders but was clear there has been no significant change in her presentation, and that is unlikely to change. Dr C acknowledged the positive things that PZ can appreciate, such as music, her parents' presence, bath time and, more recently, cartoons. Dr C described how her team had sought the advice of others to ensure there were no other options for treatment for PZ, including seeking advice from the CEAG and a specialist second opinion. Her oral evidence was clear that as a clinical team they would feel uncomfortable about continuing to provide PZ with ventilation. She did not consider PZ would be able to have ventilation at home, not only because of the risks of the tracheostomy procedure but due to her inability to swallow or cough. She described PZ needing 24 hour nursing care and can require attention to manage her secretions every 30 minutes.
28. In her discussions with the parents they have raised the concerns about what is proposed and how it conflicts with the parents' religious beliefs. The Trust have supported the parents seeking the advice of Imams, who they have discussed the situation with.
29. The Children's Guardian was able to visit PZ and talk to the parents. She set out in her report and oral evidence what she saw was PZ's reaction to music being played, which the Children's Guardian described she appeared to benefit from as her eyes seemed to be alert. In her report she outlines the benefits for PZ of being able to be loved and cared for by her parents and is likely to gain comfort from the music and singing. However, the Children's Guardian considered there were significant burdens for PZ, that outweighed the benefits. In particular, the pain and discomfort of the medical procedures that are necessary for her to be able to sustain her life, with key tangible markers that indicate her pain and distress. Second, her daily experience in not being able to respond, she is in a body that can't move. Thirdly, the trajectory of her condition, which is likely to worsen with the risks and implications for her regarding infection, and further treatment. In her discussions with the parents they said they wished to raise her in the Muslim faith and that their faith and culture is important to them and for PZ.
30. Both parents have written letters and gave oral evidence. The mother described how she spent most of the week with PZ at the hospital, caring for her with the nurses. She described what she did with PZ with obvious pride and care, and how PZ reacts to things such as music and bath time. She notes when she touches her she wakes up. She described the cartoons she plays for PZ in the parents' native language and how she wished to raise PZ in the same faith as her and her husband. She described praying for PZ and

reading the Quran to her. She was clear in her evidence she does not wish PZ to be extubated and wishes her to live for as long as she can.

31. In his evidence the father was clear that he did not support PZ being extubated. He considered she had been given to them as a gift by Allah and that he should decide when she should go. He said there is nothing visible although he recognised she sometimes suffers from pain because of the treatment. As he has described, he wished she could talk and tell us, then she could make the decision if she could stand the pain, or not. As he said, we do not know what she is thinking in circumstances where everyone is struggling to make a decision.

Legal Framework

32. There is no significant dispute between the parties as to the relevant legal framework. Miss Khaliq QC has attached to her skeleton argument an analysis of the relevant cases and guidance, which none of the other parties have taken issue with.
33. The court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place on the grounds that it is in the child's best interests. The paramount consideration for the court is the best interests of the child and the role of the court is, in effect, to step into the parents' role to give and withhold consent in the best interests of the child. In doing so the court exercises its own independent and objective judgment.
34. As Baroness Hale set out in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67 [39] in considering best interests '*...decision-makers must look at his welfare in the widest sense, not just medical but social and psychological...*'. MacDonald J in *Manchester University NHS Foundation Trust v Fixsler and others* [2021] 4 WLR 95 summarised the key principles at [57], noting at iii) '*best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations...the court must do the best it can to balance all the conflicting considerations in a particular case with a view to determining where the final balance lies*'. There is a strong presumption in favour of taking all steps to preserve life but it is not irrebuttable. It may, on the facts of the case, be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great. As part of the balancing exercise the court will need to consider the views of the parents and doctors.
35. As part of the balancing exercise as to what is in the child's best interests the court must take into account the particular religious, cultural and ethical context of the case and the religious and cultural values of the family. The extent to which PZ has experienced her parents' culture and religious beliefs and values has been limited due to her age. The child in *Fixsler* was in a similar position. At [96] MacDonald J stated as follows:

'*...absent any evidence to assist the court in determining the extent to which Alta would adopt wholesale the views of her parents, I am satisfied that the furthest the court can safely go in seeking to place itself in Alta's shoes is to acknowledge that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents. Within this context, I have held in mind at all times the strict religious credo that the parents adopt and the tenets of that credo as they*

relate to the withdrawal of life sustaining treatment. I have also borne in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that the court cannot simply assume that a profoundly disabled child will not wish to lead a life affected by disability. However, against these matters, I am satisfied that I must also have regard to the fact that Alta's likely attitude to treatment would be influenced by the fact that the prospect facing her if treatment is maintained is one of continued medical intervention that will do not more than maintain her in a moribund state with no awareness, with no prospect of improvement or recovery, the certainty of further physical deterioration and, as I have found above, in a situation of consistent pain. Within this context, in discharging the difficult task of asking myself what Alta's attitude to continued life sustaining treatment would be likely to be, I am satisfied that, in circumstances where she has not developed any understanding of the faith into which she was born, and giving due weight to the fact that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents, it is more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her.'

36. In the subsequent appeal in *Fixsler (Fixsler v Manchester University NHS Trust [2021] EWCA Civ 1018)* Baker LJ stated at [85] 'When considering the child's assumed point of view, it is difficult if not impossible to attribute any views, including religious beliefs, to a very young child who has never had, nor will have, any cognitive understanding.'

Discussion and decision

37. As has been set out during this hearing there is no dispute in this case about the medical diagnosis for PZ and the treatment she is receiving. It is accepted her condition is life limiting and requires a considerable amount of medical intervention, in particular through mechanical ventilation, assisted feeding and regular suction to remove secretions. The fact that she has been on a neonatal intensive care unit since birth, requiring 24 hour specialist nursing support is evidence of the extent of her needs and the specialist care she requires.
38. She has benefited from not only the devoted care of her parents but also the clinical team who have looked after her.
39. There is evidence that she is able to hear and show some limited response to her surroundings. The love, touch, comfort and attention of her parents and specific activities such as music and having a bath, through limited reactions by her through her eyes lighting up, or limited movement of her arms and shoulders need to be considered, although they remain very limited. She has normal cognitive function with a consequent ability to understand, the evidence demonstrated this could be a burden as well as a benefit, as she would know she is unable to respond or communicate.
40. Against these benefits the court needs to balance the burdens of her current position. PZ is going to require long term ventilation, and is unlikely to be able to withstand the procedures necessary (such as a tracheostomy) to move onto to any other type of ventilation, and, if she did, Dr H's evidence set out the ongoing difficulties in managing secretions without having the ability to cough which would mean frequent suction. This

suction procedure not only causes pain and discomfort, but has the related risk of infection and recurrent admissions into hospital.

41. Although PZ has shown some slight movement she remains unable to reposition herself and is completely dependent on others to move her to avoid discomfort. Her lack of expression and inability to communicate, coupled with normal cognitive functions means that she can understand but not express her feelings to others. As she gets older, she will become more aware of her situation. Her inability to swallow causes drooling and requires frequent suction of her mouth and pharynx, generally every hour, sometimes more frequently. The fact of the drooling and the suction procedure can cause her distress. PZ's inability to cough means she cannot clear secretions from her airway and requires suction which also cause distress, although it can be coupled with relief as the secretion is cleared. This is required every 1 – 3 hours. Due to her inability to swallow she can only be fed via a tube, and would need further procedures in the first year, such as a gastrostomy for feeding and fundoplication at the same time due to clinically severe reflux. The latter is described in the evidence as major surgery. As a result of her medical needs, PZ has the risk of infections and further hospital admissions, where she is likely to require enhanced medical intervention. Each hospital presentation would be likely to cause further deterioration.
42. The starting point of any analysis of PZ's best interests is to consider the position from the assumed point of PZ. Due to her young age and medical condition there is no evidence to assist or guide the court other than the limited evidence about what appears to bring her pleasure and what brings her discomfort and distress. Whilst, due to her age, she is likely to be influenced by the views, beliefs and guidance of her parents and may wish to continue to lead the life that she does with all its limitations. However, that has to be balanced by what her likely attitude would be to treatment that involved continued medical intervention at the level it is now, which often involves discomfort and causes her distress, with no prospect of improvement or recovery, and the likelihood of further physical deterioration. It is likely, in my judgment, when considering what PZ's attitude to continued life sustaining treatment would be likely to be, that continued life sustaining treatment would not be acceptable to her. Although she has had limited exposure to her parents' faith and culture, as described by her mother, she is unlikely, in the circumstances of this case, to have developed any understanding of her parents' faith and culture.
43. The court also has to weigh in the balance the considerable weight to be placed on the fact that there is a strong presumption in favour of taking all steps to preserve life. This is irrespective of any religious beliefs or PZ's disability as a result of her medical condition. There is a strong independent inherent value in taking all steps to preserve life, by continuing the medical treatment PZ currently receives it will prolong her life but that can't be considered in isolation and needs to be balanced with the other factors that may weigh in the balance to rebut that presumption.
44. The evidence about the burdens, pain and discomfort PZ carries with her current medical treatment and what lays ahead are set out above and will need to be carefully weighted in the balance. Whilst she may be able to survive longer with those interventions that, in my judgment, is not without the burdens of the pain and discomfort outlined and the reality that it is not going to change and is, more likely to increase. Her physical condition is likely to deteriorate in the way described by Dr M with the likelihood of major difficulties with her spine, hips and bones, as well as the increased

risks of infection. She will require long term ventilation and tube feeding with all the associated ancillary treatments and risks that come with such procedures. The reality is that intervention will not bring about any change in her position.

45. Whilst the court is not bound to follow the views expressed by the treating clinicians. in the circumstances of this case, where there is no significant dispute to their medical and clinical analysis the court is going to consider their evidence very carefully. Their evidence demonstrates that they have struggled with the severity of PZ's condition, both in terms of the day to day management of her care but also seeking the views of others about possible treatment options and alternatives for her continued care. The care they have taken is demonstrated in the papers, as is the way they have supported and engaged with the parents in talking through the difficult decision that they have had to face. They have shown compassion and understanding to PZ and her parents.
46. The views of the parents are an important part of the balancing exercise the court is required to undertake. The evidence demonstrates they have been committed to PZ's care as loving, devoted parents. They recognise their daughter will not live for as long as they would hope and accept her diagnosis and life limiting condition. Their religious beliefs prevent them from agreeing the proposed treatment plan. They believe PZ was given her life by Allah and that it is for him to take it away. Their wish is for her to live as long as she can, and for her death not to be brought about by the withdrawal of treatment. They have both shown considerable insight into PZ's position. As the father described to the Children's Guardian when she visited the hospital he can tell from the outside that she is in pain but can't tell from the inside what she is experiencing.
47. It is with very great sadness that I have decided it is in PZ's best interests for life-sustaining treatment now to be withdrawn, and for a palliative care regime to be implemented and the application of the Trust must be granted.
48. PZ's medical condition and prognosis is not going to change, it is likely to deteriorate and the continuance of the current and expected medical interventions cause her pain and discomfort and the position is likely to get worse as her condition deteriorates and ancillary complications arising from her condition occur. I have weighed carefully in the balance the benefits PZ derives from her surroundings, the love and devoted care of her parents and from the other activities she appears to enjoy, such as music and bath time. However, those benefits are significantly outweighed by the burdens of her continuing medical position as outlined above. It is likely if she was able to express a view it would be that continued life sustaining treatment would not be acceptable to her. I have carefully weighed in the balance the parents' views, in particular their religious views and values and their very understandable wish for PZ to continue to receive treatment until she is ready to go. However, those views are outweighed, in my judgment, by the very great burdens for PZ in the medical treatment being continued in the particular circumstances she is in.
49. That, with very great sadness, is my judgment.