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Neutral Citation Number: [2021] EWHC 2613 (Fam)

Case No: FD21P00293

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 24/09/2021

Before :

**MR JUSTICE PEEL**

Between :

**Nottingham University Hospitals NHS Trust**

**Applicant**

- and -

M

and

F

and

**Z (A child, by his Guardian)**

**Respondents**

**Victoria Butler-Cole QC (instructed by Browne Jacobson) for the Applicant**

**Rosie Scott for the First Respondent**

**Arianna Kelly for the Second Respondent**

**Christopher Osborne for the Third Respondent**

Hearing dates: 20-21 September 2021

**Approved Judgment**

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

**Mr Justice Peel :**

1. Z was born in January 2005 and is 16 years old. He has microcephaly, and severe cerebral palsy as a result of a hypoxic brain injury sustained at birth. Tragically, his twin died at birth. His parents have been separated for 10 years. Sadly, there remains a great deal of mistrust and outright animosity between them as I have observed at previous hearings when they acted in person. However, on one matter they are utterly united; they both want the very best for their son. Z is deeply loved by them, and wider family members. He is very much part of the family unit. He has a lovely personality and brings joy to those around him; not just his parents, but carers and, when she met Z, the Guardian. From the evidence shines through a boy who enjoys life. He takes pleasure in the company of his family. When at school he enjoyed being with friends. Like other children, his interests include TV and music, and he particularly enjoys going outside into the fresh air. There is no question but that he derives real benefit from life, notwithstanding the far-reaching limitations on his life brought about by his condition.
2. The NHS Trust applies for determination of the ceiling of medical treatment for Z. The application was brought for clarity in anticipation of a likely severe deterioration in Z's health at some point (possibly in the near future), and thus to avoid the potential of legal challenges at a critical time when Z is likely to be in intensive care.
3. Since the issue of the application, certain matters have been agreed. It is common ground that it is contrary to Z's interests to receive long-term mechanical ventilation, in circumstances where he would be permanently reliant on such treatment to breathe permanently. It is also common ground that neither CPR nor a tracheostomy would be in Z's interests. The remaining issue can be stated as follows:

“Is it in Z's best interests to be provided with invasive mechanical ventilation in hospital for a short period, in the event of an acute deterioration in his condition which was due to a potentially reversible cause”?

The suggested example of such a scenario would be a chest infection requiring antibiotic treatment. A short period is not categorically defined, but was suggested during the evidence to be up to 2 to 3 weeks.
4. The Trust's position is that short-term invasive ventilation would be deeply distressing and painful for Z, and has little prospect of success. The parents consider that even if the prospects of successful short-term mechanical ventilation, enabling Z to recover from an acute illness, are small, the potential benefits to him of being restored to his pre-admission state of health outweigh the undoubted burdens. The Guardian, acknowledging and understanding the parents' wish to explore every avenue for Z, nevertheless supports the Trust's application.
5. If the application is granted, and MN deteriorates to a point where invasive ventilation would be the next step, the Trust's care plan is for Z to remain at home under the care of his mother (“M”) and community care team, and receive palliative care so as to achieve as dignified and calm a death as possible.

**Law**

6. There is no dispute on the law. The legal framework for decisions of this nature is well established and was most recently set out by the Court of Appeal in **Fixsler & Anor v Manchester University NHS Foundation Trust & Anor** [2021] EWCA Civ 1018:
11. As McFarlane LJ observed in Yates v Great Ormond Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410, [2018] 4 WLR 5 at para 112:  
"As the authorities to which I have already made reference underline time and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."  
This Court having very recently traversed this ground in Re Pippa Knight [2021] EWCA Civ 362, it might be thought unnecessary to consider the legal principles again in any detail. But the challenge to the judge's interpretation of the law in this case has focused on a different argument. Further discussion of the principles is therefore unavoidable, even if it involves an element of repetition.
14. The jurisdiction to make orders authorising the withdrawal of treatment from a child, and the centrality of the best interests principle within that jurisdiction, were established in a series of cases in the latter decades of the last century, culminating in Re J (A Minor) (Wardship: Medical Treatment), [1991] Fam 33. At p 44 D to E, Lord Donaldson of Lymington said, when summarising how a decision whether or not to continue treatment was taken:  
"The choice is that of the patient, if of full age and capacity; the choice is that of the parents or court if, by reason of his age, the child cannot make the choice and it is a choice which must be made solely on behalf of the child and in what the court or parents conscientiously believe to be his best interests."  
At p46 D to F he stated:  
"there is a balancing exercise to be performed in assessing the course to be adopted in the best interests of the child .... This brings me face to face with the problem of formulating the critical equation. In truth it cannot be done with mathematical or any precision. There is without doubt a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrebuttable. Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself."
15. At 46 H to 47 B he continued with this observation which contains an element of substituted judgment:  
"We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life. As explained, this formulation takes account of this and also underlines the need to avoid looking at the problem from the point of view of the decider, but instead requires him to look at it from the assumed point of view of the patient. This gives effect, as it should, to the fact that even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's, desire to survive."
16. The approach to be followed by a court faced with an application to withdraw treatment was succinctly summarised by this Court in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 where the judges, having considered various earlier authorities including Re J (A Minor) (Wardship: Medical Treatment), supra, and Re A (Male Sterilisation) [2000] 1 FLR 549, observed (at paragraph 87):

"the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (Re J). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (Re J). The term 'best interests' encompasses medical, emotional, and all other welfare issues (Re A). The court must conduct a balancing exercise in which all the relevant factors are weighed (Re J)."

17. These passages demonstrate that the test is best interests but it includes an element of substituted judgment in the form of a requirement to look at the question from the patient's assumed point of view. It is important to emphasise, however, that the element of substituted judgment is no more than that. The fundamental test remains the best interests of the child and the responsibility for carrying out that evaluation lies with the judge.
7. The Court of Appeal in Fixsler went on to consider whether the approach to best interests decisions under the MCA 2005 in respect of incapacitated adults was any different to that in respect of children. The court concluded that:
  28. ...Whilst in an individual case, the child's values and beliefs may attract the most weight, in all cases they start with an equal value to that of all other relevant factors. To use ss.4(6) and 4(7) of the Mental Capacity Act 2005 to add a gloss to s.1(3)(a) of the 1989 Act risks imputing to a young child matters beyond their comprehension. I add one further observation. The fact that the welfare checklist in s.1(3) does not expressly refer to a child's values and beliefs does not mean that her culture and religion plays no part in the welfare assessment of a young child. On the contrary, s.1(3)(d) requires the court to have regard to the child's "background and any characteristics of his which the court considers relevant". In doing so, the court must in an appropriate case take into account the religion and culture into which the child is born, and the likelihood of the child following the practices and tenets of the religion. Those factors are part of the child's background and characteristics.
  29. I see no inconsistency between the provisions of the welfare checklist in s.1(3) and the proposition clearly established in the case law that a judge considering an application concerning a child's medical treatment has to look at the question from the assumed point of view of the patient. But neither the ascertainable wishes and feelings of the child nor the child's background and characteristics carry any presumption of precedence over any of the other factors in the welfare checklist. The weight to be attached to the child's wishes and feelings, and to her background and characteristics, will depend on the particular circumstances of each case.
8. At paragraph 78 the court set out the list of 5 principles that a judge must apply, taken from Wyatt v Portsmouth Hospital NHS Trust:
  - (1) The judge must decide what is in the child's best interests.
  - (2) In making that decision, the child's welfare is the paramount consideration. The term "best interests" encompasses all welfare issues.
  - (3) The judge must look at the question from the child's assumed point of view.
  - (4) There is a strong presumption in favour of the course of action which prolongs life, but that presumption is not irrebuttable.
  - (5) The judge must conduct a balancing exercise in which all the relevant welfare factors are weighed.
9. The Court of Appeal also stated that "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" (paragraph 85).

10. I also have well in mind the compendious list of relevant principles and considerations set out by MacDonal J at paragraph 57 of the first instance decision in the **Fixsler case**, which was not disapproved by the Court of Appeal:

[57] As I have observed in previous cases, the legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not '*Gillick*' competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

- i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.
- ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.
- iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term '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 test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:  
"This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."
- iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.
- v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.
- vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
- vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.
- viii) Each case is fact specific and will turn entirely on the facts of the particular case.
- ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v*

*MB Holman J*, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

"The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship."

x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

11. I am invited to exercise caution when being asked to make an anticipatory order before the moment of crisis has crystallised, in circumstances where it is said that the facts may change, and the outcome risks being open-ended.

12. In **An NHS Trust v Mrs H [2012] EWHC B18 (Fam)**, Mr Justice Peter Jackson (as he then was) considered a treatment plan in respect of KH, and specifically, a number of declarations that it was in KH's best interests to withhold certain types of treatment from him. KH was approximately 3.5 years old at the time of the application, and the judgment describes his condition as follows:

"On 24 June 2009, when he was five weeks old, KH was admitted to hospital. He was very unwell and the cause was found to be a Herpes virus infection which caused viral encephalitis. This resulted in devastating and widespread brain destruction. As a consequence he has made no developmental progress and functions below the level of a new born baby. He is totally and permanently dependent on his carer. He has a number of major physical disabilities including severe dystonia (a condition whereby muscle contractions cause twisting and repetitive movements or abnormal postures), severe and progressive scoliosis (twisting of the spine) and deformity of the rib cage, gastric reflux and frequent vomiting, severe visual impairment, inability to communicate and a disturbed sleep cycle. He is fed through a jejunostomy tube."

13. The Trust had brought the application in a time at which KH was 'relatively well' which had 'enabled the issues to be investigated in a way that is impossible in a crisis.' [42] However, the court noted that, '[t]he trade-off for these advantages is that the medical situation has not crystallised, as it would by definition have done in a crisis. Accordingly, the range of issues is the greater and the timescale may be indefinite.'

14. The court considered how it should proceed in respect of making a prospective care plan, in the absence of the specific facts which may give rise to the health crisis in which such a care plan would be utilised:

44. "The Trust has invited the Court to declare that it is lawful and in KH's best interests "To have medical treatment withheld in the circumstances as described in the attached Advanced Care Plan". There are in my view difficulties with this apparently sensible request. These were noted by Wall LJ, giving the judgment of the Court of Appeal in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 at paragraphs 117 and 188 (emphasis added):

117. We would, however, as a matter of practice, counsel caution in making declarations involving seriously damaged or gravely ill children which are open-

ended. In the same way that this court said in R (Burke) v GMC that it is not the function of the court to be used as a general advice centre (see paragraph 21 of this court's judgment), it is, in our view, not the function of the court to oversee the treatment plan for a gravely ill child. That function is for the doctors in consultation with the child's parents. Judges take decisions on the basis of particular factual sub-strata. The court's function is to make a particular decision on a particular issue.

118. As a general proposition, therefore, we have reservations about judges making open-ended declarations which they may have to re-visit if circumstances change. But all that said, we came to the clear conclusion that Hedley J had indeed thought through the implications of what he was doing, and was entitled both to make and renew the declarations.

45. From this, it can be seen that declarations should only extend to matters where the factual basis is known. This makes it unwise to endorse aspects of plans that may change in their details, as the plan in this case may. The plan also contains provisions for which legal endorsement is unnecessary, or which are matters of detail.
  46. The approach that I take is to identify the treatment issues that need to be determined and that are not likely to change over time.”
15. The court considered that in KH’s situation, the treatment issues were clear, but ‘[h]ad there been a major issue over which there was uncertainty, it would not have been possible to resolve it in theory ahead of it crystallising in reality. Fortunately for KH, that does not arise in this case. His condition is well understood, the scope for improvement is almost nil, and the prospect and manner of deterioration is sadly inevitable.’
  16. I do not join issue with any of these dicta. None of them suggest that the court is prohibited from making an anticipatory declaration. Although there may, in some cases, be a disadvantage in attempting to pre-empt a fluctuating situation, there are many cases where the facts establish, to the requisite civil standard of proof, not just what the current circumstances are, but what future circumstances are likely to be. Medical prognosis almost always involves an assessment of the future which by definition cannot be guaranteed, but the court will ordinarily have the benefit of expert evidence to assist in making findings to the requisite civil standard. The court is entitled to weigh up such medical prognosis as part of the totality of the evidence and, if the factual foundation is made out, and the evaluative exercise so justifies, I see no reason why an anticipatory declaration should not be made. Further, there are good reasons for thinking that to clarify the permissible level of medical treatment before the patient reaches a critical condition may avoid urgently instituted proceedings, fraught disputes and rushed decision making while the patient is in intensive care. That is the very situation which M in this case has said that she wishes to avoid. To my mind, it is therefore essentially a question of fact and evaluation. In my judgment, I am entitled to make an anticipatory declaration provided that (i) I have a factual basis on which to do so, (ii) those facts enable me not just to assess the situation as it is now, but also to form with a degree of solidity a prospective view, and (iii) the proposed anticipatory declaration, viewed in the context of best interests, is justified.
  17. Finally, in my judgment, the evidence in cases of this nature should be looked at holistically. Albeit in a different context the dicta of Dame Elizabeth Butler-Sloss P in Re T [2004] EWCA Civ 558, [2004] 2 FLR 838 at 33 resonate:

"Evidence cannot be evaluated and assessed in separate compartments. A judge in these difficult cases must have regard to the relevance of each piece of evidence to other evidence and to exercise an overview of the totality of the evidence....."

### **Representation and attendance**

18. I am grateful to counsel for their focussed and helpful written and oral submissions. I particularly acknowledge the assistance of those who act pro bono on behalf of the parents, Ms Scott and Ms Kelly. I have remarked in other cases that it seems to me to be little short of scandalous that in these cases where the subject matter is serious medical treatment for children, frequently involving issues of life and death, many parents have little option but to rely upon the goodwill, availability, and dedication of members of the Bar acting for free.

19. I was informed before the hearing started that M would not attend, nor give evidence. Her counsel's position statement said this:

"She finds it deeply distressing to contemplate her son's illness, the treatments that may cause him distress and death in such detail and so many different possible circumstances. She does not wish to listen yet again to discussions that she has heard before, when she has a representative to advance her position and test the evidence on her behalf. She is satisfied that, between the evidence she has already provided (at [8] and [102]) and her explanation of her views to counsel, the Court will be thoroughly aware of her position.

With the greatest respect to the Court and its role in determining MN's care, RN has therefore determined that she does not wish to attend the hearing next week."

I understand and entirely respect M's position. Her case has been fully advanced. Her position is clear from the written material. Her non-attendance has not in any way adversely affected my perspective of her written evidence, views, and submissions.

### **The medical evidence**

20. I heard oral evidence in the following sequence from:

- i) Dr R, consultant paediatrician (expert);
- ii) Dr T, consultant paediatrician (treating clinician);
- iii) Dr P, consultant paediatrician (treating clinician).

These experienced professionals were clear, moderate, sensitive, and understanding. Their opinions command the utmost respect. I found the evidence of Dr T particularly valuable, she having treated Z for some 13 years and, so it seemed to me, having great insight into not just his medical needs but the wider perspective of his quality of life, family, and social circumstances.

21. I propose to set out the history, condition, treatment, prognosis, and views on the proposed ceiling of treatment in a certain amount of detail. There was, in practice, no real dispute as to the medical evidence.

22. At birth, Z's APGAR scores were 1, 2, 4, 4 and 6 at respectively 1 minute, 5 minutes, 10 minutes, 15 minutes, and 20 minutes. A subsequent MRI scan showed global ischaemic changes. In addition to microcephaly and cerebral palsy, he has epilepsy, progressive scoliosis since the age of 6, inoperable kidney stones, right kidney



hydronephrosis, hypertension, reduced respiratory reserve and a beta ketothiolase deficiency. He has increased tone and associated spasms. His bones are fragile and at risk of fracture. Dr T says that “Z’s needs are exceptionally high and complex even for a child with severe cerebral palsy”. His provision of equipment and 24-hour care at home have been described as being akin to a High Dependency Unit.

23. Of these, it is the respiratory status which principally determines Z’s life expectancy, but, as Dr T told me, it is important to view this in the context of the entirety of the conditions affecting Z. Respiratory status in turn is partly dependent upon his bodily structure, and in particular the progressive scoliosis which impacts upon the size and functioning ability of his lungs.
24. Z has significant skeletal deformities. Both hips are dislocated, and his hands and wrists are contracted. His spine is severely curved to the right with the rib cage pressing on his right hip bone and squashing his right lung and abdomen. The scoliosis has progressed rapidly (currently it is at over 100 degrees affecting the thoracic and lumbar spine) and will continue to do so. He can no longer easily tolerate being laid on his left-hand side. He is more comfortable lying down than in a wheelchair. Spinal surgery has been ruled out as unsafe to perform.
25. The consequence is that the left lung is compressed, and there is an extremely elevated hemi-diaphragm leaving a very small apical portion of lung on the right that is aerated. The right lung cannot expand fully when he breathes, so he is in respiratory failure and struggles to clear secretions.
26. In early 2020, Z’s condition significantly deteriorated due to progression in the scoliosis and in his respiratory state, with persistent under ventilation of the right lung and instability of the airway. Up to August 2020, he required 3 prolonged hospital admissions totalling 14 weeks, much of it in intensive care, but none of which involved invasive ventilation. In August 2020, he was started on non-invasive ventilation via a mask and his 24-hour care package began. Since then, he has received continuous overnight breathing support via the mask, with an increase in the pressures in that time. This change in treatment and care has undoubtedly brought about improvement for Z in his daily life; he is more comfortable, has added weight and has had fewer hospital admissions. In other words, the management of his needs has improved. He currently has no need for invasive ventilation. But that time is approaching as the progressive scoliosis continues to compress the right lung, reducing its capacity. The very fact of requiring a mask indicates the decline. The underlying condition continues to worsen and as a result the pressures within the mask have had to increase. There is now only limited scope for further increasing the pressures. Respiratory failure will worsen, and the risk of infections will increase.
27. In September 2020 he was re-admitted for 1 week with further respiratory problems. There was a further short admission on 21 April 2021 due to respiratory deterioration caused by infection. On 14 September 2021, Z was again admitted to hospital, and remained there during this hearing, before being discharged on 24 September 2021.
28. Because his airway protection is poor, Z almost certainly aspirates oral contents when feeding. He cannot suck or swallow safely and is fed by a PEG-J feeding tube into his

stomach 3 times a day, as well as a continuous pump feed overnight. He receives suctioning 2-4 times per day to assist with aspiration. All of this is uncomfortable.

29. Z has dystonic presentation which manifests itself in stiffness, contracture of his muscles, and painful muscle spasms. Sedation helps relax the muscles but that in turn adversely affects his breathing by reducing the muscular drive to breathe. When agitated, he experiences dystonic episodes.
30. Z's sensory perceptions are severely impaired. He is registered blind, although he can recognise faces. He can hear voices and music. He is able to vocalise, but not verbalise. I was told that he has good awareness of atmosphere and surroundings. His ability to respond to the world around him enables him to derive pleasure. The other side of the coin is that, if the experience is negative, he can become distressed.
31. Z can, and does, smile, and cry, and communicate emotions. Unsurprisingly perhaps, he is notably anxious when at hospital, and relaxed when at home. At home, where he lives with M, he has a comfortable room in a well appointed and well adapted house. There is no doubt that he enjoys, and derives pleasure from, his lived experiences. He recognises familiar people by voice and touch. He enjoys interacting with people. He enjoys music, vocalising, and fixes his gaze even though his eyesight is limited. Parental touch and voice reassure him. He has family, including wider relations, who love and cherish him. He enjoys going outside. He has excellent 24-hour care.
32. All doctors consider that Z is coming to the end of his natural life. The scoliosis, chest deformity and respiratory functioning will continue to deteriorate. It is the view of Dr R and Dr T that his life expectancy is now no more than 1 year, which has come as a shock to the parents who have in the past been told it could be rather longer. "Life expectancy" as a term can sometimes acquire the status of mathematical exactitude. That is not the case here. It is used by both doctors in the sense that death could come sooner, or it could perhaps come later. It is impossible to say exactly when it will occur, but the progressive nature of his conditions means that severe deterioration is highly likely to cause death within months rather than years.
33. Both doctors and the Guardian agree (as, now, do the parents) that long term invasive ventilation would not be appropriate for a number of reasons:
  - i) Principally, it would do no more than prolong life, permanently attached to a mechanical ventilator in hospital, with minimal quality of life, and likely extreme pain and discomfort. The suffering would far outweigh any, negligible, benefit.
  - ii) His small head and mouth opening, poor neck mobility, and scoliosis, would make an intubation challenging. He would be sedated and paralysed for a time; there is a risk that he would then be unable to maintain his upper airway which would make it difficult to ventilate him during intubation. This would be a high-risk intubation, where stabilisation may be difficult, and carries a heightened risk of death during the procedure.
  - iii) There is a real risk of barotrauma, the process by which high pressure damages the lungs and accelerates the deterioration.
  - iv) It would be very uncomfortable, distressing, and painful for Z in a number of respects:

- a) Primarily, suctioning would be required multiple times per day (perhaps multiple times per hour), which would cause severe pain. I suggested the word “excruciating” to Dr R, with which he did not demur. Dr T preferred to use the word “severe”. It would be far more painful than the present community-based suctioning because it reaches far deeper.
  - b) Dystonic episodes would be triggered by unpleasant or stressful events, including suctioning. Dr T told me that such episodes would be very painful for Z who would experience involuntary muscle contractions.
  - c) The need for multiple IV drips which would require regular replacement.
  - d) The discomfort of positioning and turning, and increased risk of pressure sores.
  - e) Z would be under sedation leaving him on the edge of consciousness during the intubation and ventilation, with a degree of awareness of events, and associated distress.
- v) The risk of secondary infections would escalate.
- vi) The prospects of success (in the sense of being able to extubate from invasive ventilation and move to non-invasive ventilation and independent breathing) are very limited, put by Dr R at no more than 10-15%. That was a percentage figure with which two of the treating consultants at the hospital (from whom I did not hear evidence) agreed. In oral evidence, Dr R told me that because it is now agreed that tracheostomy is not an option, which would normally be available to assist in weaning a patient off mechanical ventilation, that 10-15% chance is probably “moderately lower”. Dr T put it at about 5-10%.
- vii) Dr T says that “It is very unlikely that we would be able to get him back to a level of health and stability that he would be able to manage on a home ventilator and ever be able to leave hospital. The likelihood is that he will die in hospital. There is a significant risk of barotrauma to the lungs. To wean him off ventilation would require a tracheostomy for the rest of his life, and even then, he may need invasive ventilation through the tracheostomy”. As already mentioned, all parties agree that a tracheostomy would not be justified.
- viii) If unsuccessful, Z would probably die either in the emergency room if during the process of intubation, or after a period of time attached to a mechanical ventilator at hospital.
34. Dr R was asked a number of questions about the issue before me, namely short-term invasive ventilation intended to address an acute bout of ill health. I summarise his evidence on this as follows:
- i) Z requires very substantial respiratory support via non-invasive ventilatory support and additional oxygen levels which have been steadily increasing and are now close to the maximum level.
  - ii) Z is therefore approaching the limits of non-invasive support. The next step in the progression is long-term mechanical ventilation. A minor perturbation could “tip him over the edge” to require invasive support. There is very little further decline possible before he becomes ventilator dependent.
  - iii) The need for more invasive and aggressive ventilation is likely to happen in the near future.
  - iv) Z’s likely life expectancy is about 1 year.
  - v) Long-term invasive ventilation is unjustifiable for all the reasons set out above.

- vi) Conceivably, there could be a short-term attempt at intubation and mechanical ventilation in the hope that the admission is as a result of a single acute infection which is reversible; in other words, in the hope that it would lead to swift extubation and a return to pre-admission health. The purpose of this would be to try everything before the inevitability of death occurs. It was clear that he did not in fact favour this option, but as a responsible expert was putting it forward for consideration.
- vii) Expressing his opinion with an appropriate degree of caution, he thought it highly unlikely that mechanical ventilation beyond a period of 2-3 weeks would be appropriate for a short-term attempt to address an acute medical problem. He thought that it would become apparent reasonably quickly whether the episode is an acute one or part of a long term, progressive and irreversible deterioration.
- viii) If the short-term option were successful, Z could return to his pre-admission quality of life. It is feasible that, if successful, such a limited scope of invasive ventilation could be repeated, although in reality each intubation would reduce the prospects of success of a subsequent intubation.
- ix) If the short-term option were unsuccessful, Z would either die reasonably swiftly, or would remain, possibly for a prolonged period of time, on a ventilator in a state of chronic non-improvement.
- x) Despite having mentioned short-term intubation and mechanical ventilation as an option, Dr R is against it for 3 reasons: (a) the chances of success are low, (b) significant pain and discomfort is unavoidable and (c) because of the reduced short life expectancy, prolongation of life would be short, and possibly reduced further by the very fact of a demanding intubation. He describes the option as “rather a forlorn hope”.

35. I summarise Dr T’s oral evidence on the specific issue before me:

- i) The burden and suffering of invasive ventilation is high. She particularly referred to suctioning and dystonic episodes, both of which could occur multiple times a day. She considered that the pain would be particularly severe as Z’s sedation is gradually reduced as part of the process of weaning him off mechanical ventilation.
- ii) She felt very strongly that even for a short period of invasive ventilation, the small potential for success is outweighed by the high level of pain and suffering involved.
- iii) She had considered Z’s best interests holistically, and not merely from a medical standpoint, having known and treated Z for 13 years.
- iv) If invasive ventilation is carried out, there is a possibility that during treatment, Z’s condition will become uncontrolled, and he will die in the throes of emergency without his family by his side. In less extreme circumstances, there are facilities at hospital for his parents to be with him at the moment of passing. Either way, she felt that it would be preferable for Z to die in calm and planned circumstances, ideally at home, rather than in potentially chaotic and uncontrolled circumstances.

36. Dr P, who has been treating Z during the current admission, gave brief evidence. He said very clearly that in his view Z should not be mechanically ventilated under any circumstances for the reasons given above. If the court concluded that some short period of ventilation should be tried, it should be limited to 7 days and only extended by a

matter of hours or a few days if recovery was clearly on the cards. He was anxious to avoid an open-ended scenario.

### **The Parents**

37. M elected not to give evidence. I have been able, however, to discern her views from her witness evidence and that which she has said to others. I heard directly from F.
38. Both love Z dearly. Both believe (and this is not disputed) that he enjoys pleasure and benefit in his life, and I have commented on some of the ways in which he enjoys himself. He is awake through the day and engages in a range of activities. He spends time with both parents. He is extremely well cared for by them, and by his carers pursuant to the funded care package. He is doted upon by his family. He has his own personality, has defied expectations to date, and brings joy to others. He has a happy and positive life.
39. Both are Muslims and through their faith have a profound belief in the sanctity of life. Both find it difficult to conceive that it is right to take steps which have the effect of shortening a life.
40. Essentially, they believe that Z should be given the opportunity to receive invasive ventilation, limited to a relatively short period, in order to address and, hopefully, reverse a bout of temporary ill health, and allow Z to continue living his life. It should be viewed as a potential bridge to recovery. They are both, of course, torn between loving him, wanting him to live and enjoy his life, and not wanting to see him suffer. A small but real chance of recovery should be countenanced, and the benefits to Z would be substantial in permitting him to continue his life for as long as possible with his family.
41. F, who gave oral evidence, was very dignified. Nobody who listened to him could fail to have been touched by the poignancy of his words and presentation. He publicly thanked all clinicians, the expert, the lawyers and the court for the care, time and attention devoted to Z. He has listened carefully to all the evidence and remains of the view that Z would wish to have the chance of continuing to enjoy life, and it is in his best interests to be permitted to do so. He was sensitive, thoughtful, and careful. These are extremely difficult circumstances and his composure spoke volumes for his love and care towards Z. His view can be summed up by his belief that a 10% chance of success represents good odds.

### **The Guardian**

42. The Guardian observed in her report and oral evidence that the parents are devoted to MN who interacts delightfully with them (particularly with M). She commented on their religious beliefs, which are clearly important to them. She remarked on how Z's personality shines through, describing him as an impressive young man. He gets obvious pleasure from life, supported by his family, with high quality care, in a comfortable family home. He leads as full a life as possible. I was struck by her obvious understanding of, and empathy for, the parents' viewpoint, describing them also as impressive.
43. The Guardian's view is that invasive ventilation (even if only short-term and designed to address a specific episode of ill health) would be distressing and painful. Z would be

in in hospital away from home. There would be only a small chance of return to pre-admission life. Much more likely, he would ultimately die in hospital on a ventilator. The burdens on him, coupled with the slight prospect of success, outweigh the benefits of a possible return to pre-admission health. Having heard all the evidence, she remained supportive of the Trust's application.

### Conclusions

44. I have had in mind throughout this case, in particular when coming to my conclusions, the best interests of Z. I have re-read the authorities cited above. I have viewed the totality of the evidence in the round and have not compartmentalised it. I have well in mind the need to consider best interests in the widest possible sense, including, but not limited to, sensory, medical, instinctual, cultural, religious, emotional, psychological, familial, social, and environmental factors. I have borne in mind that these matters should be looked at from Z's assumed point of view. I have also taken fully into account the views of his parents, who know him best.
45. It is impossible in this case to form an assessment of Z's own views. He does not have, and never has had, the cognitive ability to understand the issues and weigh up the competing factors. Like all children, he would surely want to lead a happy life in the company of his loving parents, but he is unable to consider and evaluate the application before me, encompassing as it does so many factors which are beyond his comprehension. I cannot attribute to him any views as to the approach to this application.
46. The benefits to Z of his present life are not in dispute. They are many and varied. He has a happy and positive personality. He derives joy from his family, his surroundings at home, his interests, and the world around him. He brings joy to others. He is exceptionally well cared for, and his general health had improved greatly in the past year due to changed management of his condition. I accept also the submission that for Z an additional 1 year of life would be a significant period of time. To my mind, also, the parents rightly point to the presumption of life while acknowledging that the presumption is capable of being rebutted.
47. There is no dispute, and it is self-evident in this case, that all forms of treatment below invasive ventilation should be explored wherever possible. Z is approaching the maximal limits of such treatment at home, and it seems probable that additional non-invasive treatment at hospital may be required shortly, although the doctors fairly acknowledged that, as has happened in recent times, the excellent care provided at home and in hospital may delay the tipping point.
48. I agree with the consensus that long-term, permanent invasive ventilation, CPR and fitting a tracheostomy would be contrary to Z's interests. They would serve to increase and prolong pain and suffering with no gain in Z's quality of life; on the contrary, they would all, in different ways, contribute significantly to a marked reduction in his quality of life. Z would receive no tangible benefit from procedures and treatment which would, instead, be likely to condemn him to a life of great pain and discomfort. Having experienced the pleasure and joy of being at home with his family, and being able to breathe independently (albeit with non-invasive ventilatory support), it would be intolerable to subject him to further pain and suffering which would only serve to reduce him to a state of likely permanent mechanical ventilation in hospital, continuing to

deteriorate, and deprived of those happy experiences and pleasures which he derives from the familiar comforts and social interactions at home.

49. What, then, of a short-term limit on invasive ventilation to reverse something such as an acute infection? It is, in my view, important to note that it will not necessarily be possible for treating clinicians to know instantly whether the immediate medical problem is a one-off acute issue or part of a general, long-term progression. On the evidence, that is likely to become clearer within a few days, but up to 2 weeks for the clinicians to be confident about the prospects, and even longer to complete extubation and recovery. In other words, to embark on short-term ventilation would necessarily incorporate a trial period, and the consequent pain and discomfort could prove to have been futile if in fact the illness turns out to have been irreversible.
50. The medical evidence is that, even if it is a specific, treatable issue, the prospects of successfully using invasive ventilation, extubating Z, weaning him off the invasive ventilatory support and returning him to his pre-admission health level is no more than 10-15%, and probably less in the absence of a tracheostomy procedure. These are not negligible odds, but nor are they substantial odds, and they must be weighed against the advantages if successful (particularly the return to a quality of life), the disadvantages if unsuccessful (for example, the likely process of unplanned and, potentially, prolonged death in hospital) and the pain and discomfort to be endured by Z during the ventilatory procedure.
51. There is no doubt in my mind that the process of invasive ventilation would in itself generate considerable additional pain and distress for Z. In particular, in my judgment, suctioning would be physically very painful, and would additionally trigger dystonic episodes which would also be at the severe end of scale of pain. Given that suctioning would take place multiple times per day, and possibly multiple times per hour, the combination of pain directly caused by the experience of suctioning, and the additional dystonic pain triggered by the suctioning, would cumulatively generate a very significant degree of suffering. Based on the evidence I have heard, and experience of other cases, the combination would be likely to be at a very severe level, and perhaps close to excruciating. On the available evidence, the entire process of admission, intubation and ventilation for a short-term ventilation would be measured potentially in weeks. Indeed, I wondered at times whether “short-term” is an accurate description, in this case, for a procedure potentially lasting weeks, and suffering similarly lasting weeks. I judge that this aspect alone (suctioning and associated dystonia) would likely be close to agonising during this period, particularly as sedation is lightened.
52. Although less significant, other physical aspects of the process would be onerous and painful for Z; they include the process of inserting a tube, the invasive lines, difficulty in being moved, likely pressure sores, and the general discomfort of intensive medical care.
53. Further, in my judgment Z would be likely to experience significant emotional distress during this period. He would be subjected to far more invasive treatment than he has had for many years, which in my view would be likely to be frightening for him. I was told that sedation would initially be at a level whereby he would be minimally conscious and aware, and as it reduces, so his awareness would increase. The very perceptions that allow him to experience pleasures in life are why he would also experience pain in

hospital, and his awareness of such pain, at a level far beyond that previously felt by him, would in my judgment be intensely distressing. The fact that he is unable to verbalise his pain would contribute to his distress.

54. The high degree of pain and suffering to which I have referred must of course be balanced against Z's quality of life, but also against the likelihood of successful implementation of short-term ventilation. Whilst wary of mathematical precision, it seems to me that the probability of success lies around the 10% mark (at its lowest, per Dr T, 5% and at its highest, per Dr R, 15% albeit before allowing for the impact of non-availability of tracheostomy).
55. If the short-term ventilation is not successful, on the evidence Z would likely die either in the emergency treating room, or after a prolonged time supported by mechanical ventilation. There was a considerable amount of debate about where Z would want to die. It seems to me that it will ordinarily be in a child's interests to be cared for, and to pass away, at home, rather than in hospital. Given that he has shown signs of distress in hospital before, I am of the view that, all other things being equal, it would be in his best interests for him to be cared for and loved by his family at home as he passes away, rather than have them by his bedside in hospital. Of course, this factor is bound up in the balancing exercise between quality of life, prospects of successful short-term ventilation and concomitant pain and suffering. It seems to me that the issue in fact is less about where the place of death may be, and more that death may take place in unplanned, and potentially uncontrolled circumstances at hospital. In other words, the distress felt by Z during critical last hours and days is likely to be accentuated by the lack of planning and preparation. However, I make plain that this is just one of the many factors which go into the mix and does not by itself preclude short-term ventilation intended to secure a continuance of quality of life.
56. Some concern was expressed on behalf of F that I am being asked to make a declaration before the anticipated event (admission to hospital with severe respiratory crisis requiring invasive ventilation) has occurred and in circumstances where the limits of non-invasive ventilation have not yet been reached. Thus, it is submitted, it is appropriate to authorise short term invasive ventilation to enable the parties to see whether the crisis is acute and reversible.
57. I accept that the fact I am being asked to make an anticipatory declaration requires me to exercise caution when considering the evidence. The events which are posited before me (life expectancy, the time when invasive ventilation is required and, if so, whether any admission is part of a general deterioration or a consequence of a reversible issue) have not yet crystallised. However, the evidence in this case is clear and largely undisputed. Z's current, baseline condition cannot improve; it will deteriorate over time, probably leading to death within a year. The benefits which he currently enjoys from life are there for all to see. The likely pain and discomfort associated with mechanical ventilation are comprehensively set out. I have a clear picture of (i) Z's current condition, (ii) his prognosis and (iii) the benefits and burdens of invasive ventilation. In such circumstances, I am satisfied that I am able to make an advance declaration, not least so that all parties have the clarity of a future framework, rather than the risk of urgent and fraught legal proceedings when the moment arises.



58. During closing submissions, the parents proposed a modified conditional declaration whereby invasive ventilation would be authorised for 2 weeks, with points of review by clinicians after 7 and 10 days. In the event of disagreement between the parents and the clinicians, there should be a mediation overseen by Dr R. At 14 days (on M's proposal), the clinicians would have the final say whereas (on F's proposal) the matter would return to court.
59. I accept that in principle it is possible to include conditions, particularly where they are agreed by the parties (in **An NHS Trust v S and L [2017] EWHC Fam 3619** agreed guidelines were attached to the declarations), but in doing so the court must be very wary of (i) requiring clinicians to act in a particular way, which is not generally open to the court, (ii) micromanaging the implementation of a best interests decision, (iii) interfering with clinical decisions, and (iv) inviting, or at least leaving open, the possibility of disagreement which requires resolution, including potentially by the court. That is particularly so where, as here, there is disagreement between clinicians and parents as to the way forward. Usually, in my view, the court must draw the boundary, and the clinicians must be left to act as they think fit within that boundary. The proposal of the parents, well-intentioned and thoughtful as it is, risks, at least partially, deferring the best interests decision to another day and opening the door to further uncertainty for Z. That said I emphasise that the decision I propose to make is on the principle of the application sought by the Trust, and it seems to me that, if I reject the Trust's application, it may be possible, without trespassing on clinical duties, to frame declaratory relief in such a way as to make clear the intentions behind permitting, or refusing the withdrawal of, short-term ventilation so that the clinicians can be in no doubt as to where the ceiling of treatment is drawn. Indeed, during the hearing some such forms of wording were canvassed in a general, exploratory way.
60. I accept that in the best interests analysis, Dr R looked at it mainly from a medical point of view (as, it seemed to me, did Dr P), but Dr T, with her long experience of Z and his family, looked at matters holistically and took into account a wide range of matters. Further, the Guardian, looking at it from Z's viewpoint and representing his interests, supports the application. This is a considerable weight of clinical, expert, and objective opinion, all of which supports the application. The parents' views, of course, differ. I do not think they are clinging unreasonably to hope; their opinions reflect the option offered by Dr R's short-term ventilation suggestion. They accepted his advice on CPR, tracheostomy and long-term ventilation and have shown themselves to be very child centred. Inevitably, and understandably, they are bound to be motivated by a wish to explore every possible avenue. I have taken the views of all of the clinicians, the expert, the Guardian and the parents into account.
61. Having carefully reviewed all the evidence and submissions, I judge that the presumption of life, powerful as it is, is rebutted in this case. Weighing up all the factors, the magnetic ones appear to me to be (i) Z's undoubted existing quality of life, (ii) the very severe degree of pain likely to be caused by invasive ventilation for a period measurable in weeks and (iii) the low (10%) prospects of success. These have not been considered by me separately from all other factors. I have taken full account of all matters referred to in this judgment, all the written material placed before me, the oral evidence, and the oral submissions. With considerable sadness, and acknowledging the immense dignity of the parents who have conducted themselves towards Z in an

exemplary manner, in my judgment the potential benefits to Z of short-term invasive ventilation are outweighed by the likely burdens.

62. Accordingly, the application of the Trust is granted.