[2010–12 Gib LR 273]

IN RE T (A MINOR)

SUPREME COURT (Prescott, J.): February 7th, 2012

Medicine—medical treatment—withholding treatment—strong presumption in favour of prolonging life, but may be in child's best interests (which are paramount) to withhold life-prolonging treatment when prognosis of future deterioration, if treatment painful and invasive, patient suffering irreversible medical conditions and limited quality of life

The court was asked to determine whether and, if so, in what circumstances, invasive life-prolonging medical treatment could be withheld from a child.

T was born in 2011. After a domestic violence incident in the Gibraltar hospital, the Care Agency became involved and T was made subject to an interim care order, under the terms of which parental responsibility was shared between his parents and the Care Agency. T had been born with Wolf Hirschhorn syndrome, a rare genetic condition causing him extremely serious medical problems. He was taken to the United Kingdom for treatment in 2011, returned to Gibraltar as an in-patient, and transferred back to the United Kingdom that same year, before returning to Gibraltar in 2012. His extreme disabilities and deteriorating medical condition included, *inter alia*, his small size, cleft palate, inability to feed except by gastrostomy, severe regurgitation, abnormal bowel formation, undescended testes, protruding eyes, corneal opacity, lack of visual response, congenital heart defects, pulmonary valve stenosis, reduced kidney function, minimal neurological development, structural brain defects, seizures (including West syndrome), pneumonia, respiratory infection, severe choking fits, and an inability to cough or swallow secretions. He was unable to survive without intensive medical care and his health care team, comprising the medical staff treating him, were of the view that his condition was irreversibly deteriorating. He had never been able to go home and the operations and treatment he had received had not improved his condition. It was accepted that his condition could worsen without warning and that invasive medical treatment would be required to keep him alive in the case of his being unable to maintain his breathing or of cardiac arrest. His medical health team came to the view that such treatment would not improve T's deteriorating condition, would be very painful and would not be in his best interests. His mother and the Care Agency disagreed and applied to the Supreme Court for a declaration and mandatory injunction, requiring the Gibraltar Health Authority to provide any medical treatment required to keep T alive. The father did not attend, but said that he endorsed whatever view the mother adopted. The Gibraltar Health Authority opposed the application and sought declarations allowing them to withhold invasive treatment.

The Care Agency and the mother submitted that (a) it was in T's best interests to be kept alive and the sanctity of life should be preserved, despite the pain of invasive treatment and the deterioration in his quality of life; and (b) the court should respect the views of T's family.

The Gibraltar Health Authority submitted in reply that (a) it was not in T's best interests to receive invasive and painful medical treatment in the case of his being unable to maintain his breathing or of cardiac arrest, given his extreme disability, deteriorating condition, and the irreversibility of his medical condition; and (b) although the views of family members could be taken into account, the court was required to make an independent and objective decision.

Held, dismissing the application and granting the Gibraltar Health Authority's declarations:

(1) The court would declare, *inter alia*, that it would be lawful, in the best interests of the child, for T's health care team to withhold invasive treatment from him if his condition worsened, specifically (a) in the case of his being unable to maintain his breathing, by not providing intubation and/or artificial ventilation; and (b) in the case of cardiac arrest, by not providing cardiac massage or emergency cardiac arrest drugs. The court would, accordingly, refuse the application for a declaration and mandatory injunction that the Gibraltar Health Authority should give T any medical treatment required to keep him alive. In determining the medical treatment to be given to children, the court was required to act in the child's best interests, as assessed from the assumed standpoint of the patient. That test did not simply involve an assessment of T's quality of life. Whether T's life was intolerable was a relevant factor in considering his welfare, but his welfare also encompassed the sanctity of his life, however painful it might be, which created a strong presumption in favour of continued treatment. The court would, in such cases, benefit from drawing up a balance sheet of factors for and against treatment to consider if that presumption had been rebutted. Having regard, *inter alia*, to T's extreme disability and irreversible medical conditions, his poor prognosis and limited quality of life, his dependence on intensive medical treatment, deterioration despite treatment, and the pain that invasive life-saving procedures would cause, it was in T's best interests not to receive invasive medical treatment if his condition worsened, notwithstanding the sanctity of life and the love of his family (para. 7; paras. 28–32; para. 37; paras. 60–64).

(2) The court observed that the best interests of children should usually be determined by those with parental responsibility for them and those responsible for their medical care. In cases of an impasse, such as the present, the court would intervene to make a final, independent and objective decision, albeit giving due weight to the wishes of devoted and

responsible parents. Such parents were to be identified primarily by the reasonableness of their decisions. In the present case, the mother's decision to promote T's survival naturally fell within the range of permissible decisions and had been taken into account by the court in determining that treatment should nevertheless be withheld in the event of further deterioration (paras. 33–36).

Cases cited:

(1) *J (A Minor) (Wardship: Medical Treatment)*, *In re*, [1991] Fam. 33; [1991] 2 W.L.R. 140; [1990] 3 All E.R. 930; [1991] 1 FLR 366; [1991] FCR 370, *dicta* of Lord Donaldson, M.R. followed.
(2) *OT*, *Re*, [2009] EWHC 633 (Fam), *dicta* of Parker, J. followed.
(3) *Portsmouth Hosps. NHS Trust* v. *Wyatt*, [2005] 1 FLR 21; [2005] EWHC 117 (Fam); on appeal, [2005] 1 W.L.R. 3995; [2006] 1 FLR 554; [2005] EWCA Civ 1181, *dicta* of Hedley, J. and Wall, L.J. followed.
(4) *T (A Minor: Medical Treatment)*, *In re*, [1997] W.L.R. 242; [1997] 1 All E.R. 906; [1997] 1 FLR 502; [1997] 2 FCR 363, *dicta* of Roch, L.J. followed.
(5) *Z (A Minor) (Identification: Restrictions on Publication)*, *In re*, [1997] Fam. 1; [1996] 2 W.L.R. 88; [1995] 4 All E.R. 961; [1996] 1 FLR 191; [1996] 2 FCR 164, *dicta* of Bingham, M.R. followed.

J. Fernandez for the Care Agency;
J. Daswani for the mother;
D. Conroy and *Ms. I. Armstrong* for the Gibraltar Health Authority.

1 **PRESCOTT, J.:** This judgment is being distributed on the strict understanding that in any report no person other than counsel (and any other persons identified by name in the judgment itself) may be identified by name and that in particular the anonymity of the child ("T"), the adult members of his family, the consultants, doctors and nurses of both hospitals must be strictly preserved.

2 This is an application by the Care Agency for an order in the following terms:

(a) A declaration "that it is in the minor's best interests for the Gibraltar Health Authority to provide all such medical treatment as may be necessary to keep the minor alive."

(b) A mandatory injunction that the Gibraltar Health Authority provide all such medical treatment as may be necessary to keep the minor alive.

3 The mother lends her support to this application. The father is absent from this hearing through choice, having been informed of the nature, time and place of the hearing by Mr. Fernandez, counsel for the Care

Agency, who spoke to him personally. The father's view was that he endorsed whatever view the mother adopted.

4 The Gibraltar Health Authority ("GHA") opposes this application and seeks a declaration that it be lawful for T's health care team not to administer invasive resuscitation procedures in the event that T's medical condition deteriorates.

5 The reason that the Care Agency is involved in this case is that T is the subject of an interim care order, under the terms of which parental responsibility is shared between the parents and the Care Agency. The background, as I understand it to be, is that the Care Agency has been working with this family since a domestic violence incident in hospital in July 2011. Whilst the Agency had concerns over the parents' ability to care for the child, given that T was an inpatient in hospital, a care order was considered unnecessary. By November 2011, however, the medical health care team was exploring the possibility (albeit remote) of discharging T, not because his condition had improved but because in the opinion of his doctors if his medical needs could be properly met outside hospital it would be preferable for him to be in a home environment. It is true to say that the view of the health care team, however, was that it was highly unlikely that T would be able to go home, as his care would represent too great a challenge even for the most able and dedicated of parents with the backing of a strong and highly motivated family. To provide for this eventuality, in November 2011, T was made the subject of an interim care order, unopposed by the parents. Viability studies began with a view to determining whether T's grandparents could be suitable carers and the Care Agency, in consultation with the GHA, began exploring the possibility of providing a care package for T. In the meantime, it became necessary to transfer T back to the children's hospital in the United Kingdom and he was admitted there later that month, returning to Gibraltar on January 19th, 2012.

6 At the start of the hearing I raised my concern that there was no guardian representing T's interests, and considered adjourning proceedings so that one could be appointed. Mr. Fernandez submitted that there was no legal requirement which made it incumbent upon the court to appoint a guardian in a case such as this; further and importantly there was at present no one in Gibraltar who could be appointed as guardian and adjourning the matter pending appointment would therefore cause inordinate delay which would not be in the child's best interests. I decided to hear the application so that I could determine the level of urgency and whether an adjournment was appropriate. Having heard submissions and evidence, I formed the view that this matter was of the utmost urgency, because it was anticipated that the child's condition could deteriorate substantially and without warning, resulting in a medical emergency. An

indefinite adjournment in an attempt to locate a suitably qualified person who could act as guardian would not be in the child's best interests.

7 On January 25th, 2012, I made a declaration in the following terms:

> "(a) T, as a child, lacks the capacity to make decisions about medical treatment to be delivered to himself for his physical heath-care.
>
> (b) Having regard to T's best interests and in the event that the consultant paediatrician and health care team treating T consider—
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> (i) that T's medical condition shall have deteriorated to such an extent that he is unable to maintain oxygen and carbon dioxide exchange, it shall be lawful for responsible paediatric medical consultants to reach a decision that he should not be intubated and/or artificially ventilated; and
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> (ii) that T is experiencing cardiac arrest, it shall be lawful for responsible paediatric medical consultants to reach a decision that cardiac massage and emergency cardiac arrest drugs should not be administered.
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> (c) The responsible paediatric medical consultants shall be entitled to reach a decision to use symptomatic relief (and shall do so if it is in T's best interests) which may include:
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> (i) giving oxygen;
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> (ii) suctioning the airway to remove secretions and airway opening manoeuvres;
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> (iii) positioning and chest physiotherapy to clear and cough up secretions and improve respiratory status;
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> (iv) treat bacterial infections with antibiotics given by gastrostomy;
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> (v) feed T and keep him well hydrated;
>
> (vi) stimulate and interact with him; and
>
> (vii) relieve pain and distress."

I indicated that I would give my reasons later and they are now set out below.

T's medical history

8 T is in the care of a medical health care team comprising three consultant paediatricians, Drs. X, Y, and Z, as well as various nursing staff and two doctors in the children's hospital in the United Kingdom where he

was admitted on two occasions, Dr. R and Prof. G (the "medical health care team").

9 Medical concerns were first raised during the mother's pregnancy and a detailed scan at 27 weeks gestation revealed multiple foetal abnormalities. Amniocentesis was advised, but declined because of needle phobia. Genetic counselling was offered, but was declined by the parents.

10 T was born on April 6th, 2011 in Gibraltar and is now almost 10 months old. He has remained in hospital either in Gibraltar or in the United Kingdom since birth. T was born with a rare medical condition called Wolf Hirschhorn syndrome ("WHS"). This is a genetic syndrome caused by the loss of a small part of chromosome 4. It affects approximately 1 in 50,000 babies, which given the current birth rate in Gibraltar would result in the condition arising once every 100 years.

11 The day after his birth, T was transferred by air ambulance to a children's hospital in the United Kingdom for management of his multiple medical needs. He remained there for approximately three months in the company of his mother (it is not clear to me whether his father was there), and returned to hospital in Gibraltar in June 2011, where he remained as an inpatient until his transfer back to the United Kingdom in November of the same year.

12 This little child has a plethora of medical problems. He has abnormal facies as regards head shape as well as size. He has a cleft palate. Generally he is of a small size, indicative of a failure to thrive. He is unable to feed by mouth and requires feeding *via* gastrostomy which involves the surgical insertion of a tube directly into the stomach through the abdominal wall. That procedure was effected on December 19th, 2011 in the United Kingdom, also on that date three further procedures were carried out. The first was fundoplication. This was a surgical intervention which attempted to address severe gastro-oesophageal reflux (regurgitation of the stomach contents). The second was a procedure called Ladd's procedure. This was a surgical correction of an abnormal position/formation of the bowel. The third was a stage 1 orchidopexy which was a surgical procedure to move undescended testes into the scrotum. In the report of January 24th, 2012, Dr. R stated: "We had hoped that the gastrostomy and fundoplication would, to some extent, improve his chest by preventing reflux and aspiration. Unfortunately his chest has not improved."

13 T has an abnormal pancreas. In relation to his visual system he has bilateral proptosis (protruding eyes) and paucity of eye movements and lid closure. There has been development of corneal opacity in the eyes requiring surgical closure of eyelids of the left eye and lens insertion in the right eye. Both eyes require very frequent insertion of eye drops and/or ointment. T displays very little visual responses and his visual prognosis is

poor due to abnormal development of the part of the brain that governs sight.

14 T has congenital heart defects, pulmonary valve stenosis and atrial septal defect. He has reduced function of the right kidney and persistently raised urea.

15 Since birth, T has had minimal objective neurological development and over the last few months his neurological prognosis has worsened. He has minimal, non-purposeful body movements, he is unable to communicate in any form and he suffers from generalized seizures which are controlled with medication. He has partial agenesis of corpus callosum (a structural brain defect) and in October 2011 he developed a new type of seizures called West syndrome, which is an epileptic encephalopathy. The infantile spasms resulting from this syndrome are associated with dysfunction and deterioration of the brain. Doctors are uncertain whether T can hear, although there have been no clear hearing responses noted and WHS is associated with significant hearing loss.

16 Whilst he was in hospital in the United Kingdom on his second visit in November 2011, T suffered two episodes of pneumonia. Soon after his return on January 19th, 2012, T's medical condition began to deteriorate. He contracted RSV positive bronchiolitis, essentially a viral respiratory tract infection, and suffered a very severe choking fit which was acute and life threatening. He was in visible distress—his eyes rolled back and he went blue. T has an inability to swallow secretions and is unable to cough, and because of this the risk of his suffering severe choking fits is high. T's deteriorating clinical condition caused his health care team grave concerns and plans for their future response to a further deterioration were discussed with the Care Agency at a meeting on January 24th, 2012 at 1.30 p.m. A further meeting with T's mother had been scheduled for 2.30 p.m., but T's mother failed to attend. Ultimately, T's health care team took the view that in the event of future deterioration in T's condition they should no longer administer invasive life saving procedures.

17 T's health care team became of the opinion that it was overwhelmingly unlikely that the deterioration in T's condition was reversible. He had developed long-term respiratory problems related to his underlying condition of WHS which, together with West syndrome, made his condition acutely serious. For the last two months, in order to be able to breathe, he has required a continuous supply of oxygen applied *via* nasal prongs. In the opinion of Dr. Y—"the chronic respiratory problems are likely due to multiple factors related to neurological abnormalities seizures, somnolence related to anti-convulsant medication, swallowing inco-ordination and abnormal facies."

18 In the preceding 24 hours before this application, T's condition had deteriorated significantly and after life threatening choking episodes he

was being treated with regular suction, positioning and physiotherapy, antibiotics which were being given *via* gastrostomy and a temporary reduction in feed volumes. Given T's clinical condition, the medical opinion is that the deterioration will not improve, but there is a strong likelihood that his condition could suddenly worsen without warning.

19 Should T suffer sudden clinical deterioration, such as respiratory failure, emergency invasive procedures such as ventilation and intubation would be required. These would be painful and uncomfortable, with the real potential of causing significant distress, but without the prospect of improving the clinical or neurological prognosis or changing the long-term outcome. The medical evidence is that only 5–10% of children who suffer cardiac arrest will survive, and of those a significant proportion will sustain brain damage. That T would be resuscitated to a condition even more severe than the one he has currently and with an even greater degree of brain damage is, in the opinion of Dr. Y, "unfathomable and cruel." There is a further consideration and that is that, in the event that he were to be ventilated in hospital in Gibraltar as an emergency, he would need to be transferred with urgency to a Paediatric Intensive Care Unit ("PICU"). Doctors responsible for his care would need to establish to the satisfaction of intensivists at the receiving PICU that ventilation is in the child's best interests. The medical health care team feel that it is not, and (for the avoidance of doubt) that view is shared by the two doctors who treated T whilst in hospital in the United Kingdom, namely Dr. R, the PICU consultant and deputy chief medical officer at the relevant UK hospital, and Prof. G, consultant paediatric neurologist at the same hospital.

20 In the event of cardiac arrest, cardiac massage and the administration of emergency cardiac arrest drugs would be required. Those drugs would be administered by way of intravenous line, which would necessarily entail the location and use of a viable vein. However, it is apparent from the evidence of Dr. Y that all of T's good veins "had been used up" and finding a viable vein had only the day before proved impossible. The process of attempting to find a viable vein required the insertion of a needle into various potentially viable veins. Whilst the medical health care team are uncertain about the degree (if any) of T's perception of the world around him, they are certain that he feels pain, evident from the fact that T reacted by crying at the insertion of needles. The poignant evidence of Dr. Y is that on the evening before this application, during unsuccessful attempts to find a vein, the doctor felt "under duress," being of the opinion that the infliction of pain on T was not in T's best interests. Further, and importantly, in the event of a cardiac emergency and in the absence of successfully locating a viable vein, the medical team would have to carry out an intraosseous procedure whereby a needle is inserted into the shin bone of the leg. Without anesthetic this is an extremely painful procedure and only justifiable if it would be instrumental in restoring a patient to a

basic level of health. In the opinion of Dr. Y, this procedure would cause T to feel a substantial amount of pain without altering the underlying prognosis of his condition.

21 In the opinion of Dr. Y and Prof. G, T is in the worst category of WHS and is unlikely to survive beyond the age of two years.

22 It is useful to explore the views of Dr. R and Prof. G. The report of January 24th, 2012, prepared by Dr. R states:

> "I feel I should specifically address the usefulness of re-admission to intensive care in the event of T deteriorating further. Admission to intensive care is for reversible conditions or conditions which can be treated, allowing the patient to live at home. We had a long discussion on our conference call this afternoon and it is clear that T has not been able to manage without oxygen and has problems with his airway tone and aspiration of saliva. His neurological issues were fully discussed with Prof. G. T has chronic chest problems which are secondary to his neurological problems. In this setting, admission to PICU is unable to reverse his primary underlying problem and the issue of his chest deteriorating will recur.
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> My advice would be to pursue treatment which does not involve invasive procedures; oxygen, suction and oral antibiotics may allow some improvement. I would not recommend the burden of more invasive treatment with intravenous drugs and intubation. T has a life-limited condition for which there is no effective treatment and I hope his family feel able to allow his medical team to move to a palliative care strategy"

23 The report of January 24th, 2012 prepared by Prof. G states:

> "I, like you, am of the opinion that T will continue to show very limited, if any, developmental progress. He will always be dependent on others for his day-to-day care. He is likely to continue to have respiratory problems as a result of his underlying genetic syndrome, neurological problems, aspiration and mobility problems. Children such as T often eventually succumb to chest infections and respiratory failure.
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> I am of the opinion that it is in T's best interest to now go down the route of palliative care and avoid performing invasive and distressing procedures such as intubation and ventilation on him. Such procedures may prolong his life for a short while, but will not improve his eventual outcome in terms of development and other health problems and will not improve his quality of life. In fact such procedures are likely to prolong suffering."

24 In the course of Dr. Y's evidence, reference was made to the

publication by the General Medical Council: "*Treatment and care towards the end of life: good practice in decision making*," published on May 20th, 2010. The General Medical Council is the statutory regulator for the medical profession in the United Kingdom. This publication is a guide to doctors and is based "on long-established ethical principles which include doctors' obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity; and to make the care of their patients their first concern." It is not authoritative as to the law but it "takes account of, and is consistent with, current law across the UK, including the laws on decision making for patients who lack capacity . . ."

25 Paragraphs 90–98 and 104–108 are of relevance, particularly the following:

> "92 Decisions about treatment for children and young people must always be in their best interests. This means weighing the benefits, burdens and risks of treatment for the individual child. A child's best interests are not always limited to clinical considerations and, as the treating doctor, you should be careful to take account of any other factors relevant to the circumstances of each child.
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> 93 Identifying the best interests of children or young people who may be approaching the end of life can be challenging. This is particularly the case when there are uncertainties about the long term outcomes of treatment, when emergencies arise, and in the case of extremely premature neonate whose prospects for survival are known to be very poor. Complex and emotionally demanding decisions may have to be made; for example about whether to resuscitate and admit a neonate to intensive care, and whether to continue invasive intensive care or replace it with palliative care. It can be very difficult to judge when the burdens and risks, including the degree of suffering caused by treatment, outweigh the benefits of the treatment to the patient.
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> . . .
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> 106 It may be particularly difficult to make a decision on the basis of what is in the best interests of a neonate or infant. If, when considering the benefits, burdens and risks of treatment (including resuscitation and clinically assisted nutrition and hydration) you conclude that, although providing treatment would be likely to prolong life, it would cause pain, suffering and other burdens that would outweigh any benefits and you reach a consensus with the child's parents and health care team that it would be in the child's best interests to withdraw, or not to start the treatment, you may do so."

26 The unequivocal view of Dr. Y and the medical health care team is

that whilst invasive resuscitation treatment might delay death it would not improve T's quality of life or his potential for recovery. There is the added consideration that the application of invasive resuscitation might leave the child in a worse condition than he is in at present, leading to an even poorer quality of life. Underlying these considerations is the reality that invasive resuscitation will cause T pain and distress.

27 This notwithstanding, T's mother and the Care Agency are of the view that life should be prolonged at all cost and in any event, and that T should have all available treatment, on the basis that the benefit of prolonging life in itself outweighs any pain and suffering and distress that T might be subjected to in the process. Yet, neither the mother nor the Care Agency has relied on any medical evidence in support of their view. Both have declined the opportunity to bring medical evidence in support of their submissions, both have chosen not to give evidence and, further, neither the mother, through her counsel, nor the Care Agency through theirs have sought to challenge any part of the medical evidence, indeed there was no cross-examination of Dr. Y. Curiously, the Care Agency informed the court that on the day immediately prior to this application they felt unable to form a view either way as to whether invasive resuscitation treatments ought to be administered, and indeed this was the clear impression of Dr. Y, which was not challenged. A day later, in court, their view was that life should be prolonged at all costs.

28 It is vital to define clearly what the issues in this case are. This case is *not* about the withdrawal of treatment from T in order to allow him to die, nor is it about the standard of care provided for him. T has been severely disabled from birth and has been kept alive by the dedication and devotion received from his medical health care team. Without such care and treatment he would, in all probability, now be dead. This case *is* about what should happen if T's infection worsens or he suffers some other crisis which is likely to lead to his death but which cannot be treated by non-invasive procedures and, therefore, requires him to be ventilated, intubated or subjected to cardiac arrest resuscitation measures.

29 The difficult decision facing the court must be reached having taken account of a broad spectrum of considerations to be drawn from a pool of case-law on the subject. These were helpfully set out by the Court of Appeal in *Portsmouth Hosps. NHS Trust* v. *Wyatt* (3). Wall, L.J. ([2005] 1 W.L.R. 3995, at para. 87) said:

> "In our judgment, 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 (*In re J*

> [1991] Fam. 33). There is a strong presumption in favour of the course of action which will prolong life, but that presumption is not irrebuttable (*In re J*). The term 'best interest' encompasses medical, emotional, and all other welfare issues (*In re A* [2000] 1 FLR 549). The court must conduct a balancing exercise in which all the relevant factors are weighed (*In re J*) and a helpful way of undertaking this exercise is to draw up a balance sheet (*In re A*)."

30 In determining what is in the best interests of the child, I do not need to determine specifically whether the administration of invasive resuscitation procedures would result in rendering the child's life intolerable, or whether the child's life is at present intolerable. Hedley, J., in *Portsmouth Hosps. NHS Trust* v. *Wyatt* (3), whose reasoning on the issue was upheld by the Court of Appeal put it thus ([2005] 1 FLR 21, at para. 24):

> "[I]t is in my view essential that the concept of 'intolerable to that child' should not be seen as a gloss on, much less a supplementary test to, best interests. It is a valuable guide in the search for best interests in this kind of case."

I adopt Hedley, J.'s reasoning on the point, so that the focus is not on intolerability but on best interests, although the concept of intolerability may be encompassed by the best interest consideration.

31 Any assessment of what is in this child's best interests must enshrine the principle that welfare is paramount. The concept of a child's welfare necessarily encompasses the sanctity of human life even where that life labours under a severe disability. In *In re J (A Minor) (Wardship: Medical Treatment)* (1), Lord Donaldson of Lymington, M.R., when considering the issue, spoke of the need to avoid looking at the problem from the point of view of the decider, but instead highlighted the requirement to look at the problem from the assumed view of the patient ([1991] Fam. at 47):

> "[E]ven 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."

The issue here is not so much an assessment of the quality of life enjoyed by T to date, relevant as that is, but more, given his condition and prognosis, whether the administration of procedures which will cause pain are justified when they cannot improve his quality or enjoyment of life, but will more likely worsen it. Is that a promotion of welfare or an infliction of unnecessary pain?

32 I recognize without question the presumption in favour of life, and

the sanctity of human life, but the impact of pain and suffering on the prolongation of life cannot be underestimated. In *In re J (A Minor)* (1), Lord Donaldson ([1991] Fam. at 46) said:

> "This brings me face to face with the problem of formulating the critical question. 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 even excepting the 'cabbage' case to which special considerations may well apply, it is not irrebuttable. As this court recognised in *In re B.*, account has to be taken of pain and suffering and quality of life which this child will experience if life is prolonged. Account has also to be taken of pain and suffering involved in the proposed treatment itself."

33 In an ideal situation, what is in the best interests of a child will be agreed between those having parental responsibility and those having responsibility for his medical care. When that proves impossible the court must intervene. In *In re J (A Minor)*, Lord Donaldson described the interaction between the three in this way ([1991] Fam. at 41):

> "[I]t is sensible to define the relationship between the court the doctors, the child and its parents.
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> The doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion: see *Bolam v. Friern Hospital Management Committee* [1975] 1 W.L.R. 582. This duty is, however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive treatment.
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> The parents owe the child a duty to give or withhold consent in the best interests of the child and without regard to their own interests.
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> The court when exercising the parens patriae jurisdiction takes over the rights and duties of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or withhold consent is that of the court alone."

34 It is apparent from the authorities that due weight must be given to the wishes of parents. Like Roch, L.J. in *In re T (A Minor: Medical Treatment)* (4), I will gratefully adopt the words of Bingham, M.R. in *In re Z (A Minor) (Identification: Restrictions on Publication)* (5) where he said ([1997] Fam. at 32–33):

> "I would for my part accept without reservation that the decision of a devoted and responsible parent should be treated with respect. It should certainly not be disregarded or lightly set aside. But the role of the court is to exercise an independent and objective judgment. If

> that judgment is in accord with that of the devoted and responsible parent, well and good. If it is not, then it is the duty of the court, after giving due weight to the view of the devoted and responsible parent, to give effect to its own judgment. That is what it is there for. Its judgment may of course be wrong. So may that of the parent. But once the jurisdiction of the court is invoked its clear duty is to reach and express the best judgment it can."

Roch, L.J. went on to say ([1997] W.L.R. at 255):

> "The issue then is what is in the best interests of the child? One factor in determining that issue to be taken into account by the court is the decision of devoted and responsible parents. It is, I would suggest, misleading to ask, once it is accepted that the parents are devoted and responsible, whether their decision is reasonable or unreasonable because parents who are responsible and devoted will almost certainly reach a decision which falls within the range of decisions which can be classed as reasonable. If the decision falls outside the range of permissible decisions, it is most unlikely that the parents are responsible and devoted parents who have sought only to decide in the best interest of their child."

35 It is incumbent upon the court to take account of the decision of devoted and responsible parents. In respect of parents who are thus defined it is unnecessary to decide if their decision is reasonable or unreasonable. In my view, I lack the evidence to make a determination whether these parents are devoted and responsible. I note the father's voluntary absence from these proceedings and from the decision-making process, which he has left squarely upon the shoulders of the mother. Certainly that does not strike me as devoted or responsible, but I am cognizant that I have not heard directly from the father. Whilst the mother maintains, through her counsel, that she visits the child in hospital daily, the Care Agency, through their counsel, say that visits have become sporadic. I have heard evidence from neither party and so refrain from forming a view. To her credit, and in an unequivocal show of devotion, the mother remained with her son for the first three months of his life whilst he was in hospital in the United Kingdom. It is of concern on this point, however, that despite a variation in bail conditions to which she was subject, allowing her to travel to the United Kingdom last November to accompany her son, the mother chose not to go with her son. This meant that T was in a hospital in the United Kingdom for a period of 2½ months and underwent four surgical procedures in the United Kingdom in the absence of both parents (albeit in the company of his grandparents). This could well be an indicator of lack of devotion. That said, the parents showed responsibility by their unreserved co-operation with Social Services and their consent to the making of an interim care order for the benefit of the child.

36 In all probability this mother has done the best she could for her child under some harrowing and difficult circumstances. To judge the level of responsibility and devotion she has for her child would serve little purpose given that, in any event, I find that her decision to seek to prolong life falls within the range of permissible decisions and has been motivated at the very least by a natural instinct to promote survival and prolong life. At this juncture, it is fair to mention the important role of the grandparents. Given that they were the subject of a viability study by the Care Agency, it is safe to assume they were considering taking over residential care of T in the event of his release from hospital. Importantly, they accompanied T to the United Kingdom last November so that he was not without familial support, and although I do not have evidence of the same, I do not think it unreasonable to presume that, no doubt for good reasons, his mother entrusted care of her child to them whilst in the UK hospital.

37 The Court of Appeal in *Portsmouth Hosps. NHS Trust* v. *Wyatt* (3) was of the view that the court's task of conducting a balancing act in which all factors were weighed would be made less burdensome by the drawing up of a balance sheet. I shall follow the example of Parker, J. in *Re OT* (2) ([2009] EWHC 633 (Fam), at para. 109) and conduct such an exercise, although unlike Parker, J. I am devoid of the benefit of balance sheets provided by counsel in the first instance. The balance sheet exercise I am about to conduct will necessarily involve some repetition of issues already dealt with. For this I apologize, but it is inevitable in the proper execution of the exercise.

Dis-benefits/disadvantage of treatment

38 *T has multiple medical problems caused by a genetic syndrome. This is a life-limiting condition with a predicted life expectancy not beyond the age of two years. His current clinical condition puts him at risk of a sudden clinical deterioration.* This is not disputed.

39 *T has an abnormal facies and body size, indicative of a failure to thrive. He has a cleft palate, an abnormal pancreas, protruding eyes, paucity of eye movements and lid closure, corneal opacity in both eyes and requires insertion of eye drops/ointment into both eyes. His visual capacity is thought to be poor and very little visual response has been noted. The poor visual prognosis is supported by the abnormal development of the part of the brain that controls sight.* This is not disputed.

40 *T has abnormal-looking kidneys, reduced function of the right kidney and persistently raised urea.* This is not disputed.

41 *T has congenital heart defects—pulmonary valve stenosis and atrial septal defect.* This is not disputed.

42 *Neurological development since birth has been minimal, he cannot*

hold his head up, he cannot sit up, he cannot communicate and any display of minimal body movements is not purposeful. This is not disputed.

43 *T developed a new type of seizures in October last; this added syndrome (West syndrome) is associated with a very poor neurodevelopmental outcome.* This is not disputed. Lack of neurological development and this form of epilepsy are likely to be due to a combination of his structural brain abnormalities and neurological networking problems within the brain.

44 *T has a structural brain defect.* This is not disputed

45 *There is uncertainty as to the degree to which T is able to hear, but no clear hearing responses have been noted and his condition is associated with significant hearing loss.* This is not disputed.

46 *T is unable to swallow and is fed via a tube which has been inserted into his stomach. He is unable to control his own secretions and he cannot cough. As a result he is prone to severe choking fits. When he is in respiratory difficulty, his eyes roll back and he goes blue.* This is not disputed.

47 *As a result of his significant secretion problems and respiratory difficulties, T requires regular suctioning of the upper airways, a reduction in the food volume and positioning so that secretions drain out of his mouth.* This is not disputed.

48 *Whilst in the United Kingdom, and before surgery in December 2011, T suffered two episodes of pneumonia. After surgery he developed a viral chest infection which he still has.* This is not disputed.

49 *T is unable to breathe independently and requires oxygen constantly in order to be kept alive.* This is not disputed

50 *T's respiratory problems are related to his neurological status rather than primary lung pathology and the respiratory deterioration is irreversible.* This is not disputed.

51 *There is no evidence that T responds to inter-personal contact, or that he derives any pleasure from it. Similarly there is no evidence that he derives any stimulus or pleasure from his surroundings. There is no evidence of a close bond or even a noticeable bond with any member of his family or any of the medical staff.* This is not disputed.

52 *T has recently undergone four surgical procedures.* In December 2011, some two months ago, T underwent a total of four surgical procedures: a gastrostomy, fundoplication, Ladd's procedure and stage 1 orchidopexy. It was hoped that the gastrostomy and fundoplication would improve T's chest by preventing reflux and aspiration. Unfortunately, there has been no improvement in his chest.

53 *T has suffered pain and is at risk of suffering further pain through invasive procedures necessary to keep him alive.* This is not disputed and is of some concern because whilst there is no evidence that T feels any pleasure, there is unchallenged evidence that he feels the pain of needles being inserted into him in the search for access to veins. This is relevant as the evidence suggests that invasive resuscitation procedures would necessarily involve a procedure which is painful and which T would perceive as such. By way of logical extension, this would result in causing T distress. Further and importantly, the evidence of Dr. Y was that if T went into cardiac arrest or respiratory distress, notwithstanding the fact that he might be resuscitated, he would in all likelihood suffer further brain damage. Dr. Y's view was that it would be unfair to expose T to the very real risk of being more severely brain damaged than he is already. I accept that.

54 *Invasive resuscitation procedures such as intubation, ventilation and the administration of cardiac arrest drugs may prolong his life for a short while, but will not improve his eventual outcome in terms of his development and other health problems and would not improve his quality of life.* This is not disputed nor is the opinion of Prof. G that such procedures are likely to prolong suffering.

55 *T has lived all his life in intensive care in hospital and has never been home.* This is not disputed. This is not a normal environment for a child to live in, although it is true to say that because interaction with environment is effectively non-existent it must be of little consequence to him that he is not in a home environment. In the opinion of Dr. R, the purpose of intensive care is to treat reversible conditions or to treat conditions allowing the patient to live at home. Admission to intensive care is unable to reverse T's condition, which is likely to deteriorate.

Benefits/advantage of treatment

56 *T's mother and family love and care for him.* This is not disputed, and although I have not heard from them I recognize the important role played by T's grandparents.

57 *There is no evidence that T feels constant pain.*

58 *T has the benefit of excellent medical care both in Gibraltar and in the United Kingdom.* The medical health care team are dedicated to treating and managing his condition and I am in no doubt that without that absolute dedication T would not be alive today.

59 *T has the immeasurable benefit of life.*

Conclusions

60 I find that the hospitals have done everything in their power to treat

and care for T and manage his condition. Their actions are dedicated and conscientious. Through their care and their efforts they have kept T alive.

61 T's life expectancy is short, his condition is incurable, irreversible and has worsened. His quality of life is poor. Life can be prolonged, but not improved. Further deterioration is highly likely. In the event of a serious deterioration, invasive life saving procedures will cause T pain and distress and could well result in placing T in a worse condition than he is in at present.

62 From time to time we as judges are called upon to make painfully challenging decisions; it is hard to envisage a more difficult situation than one where a child's immediate survival hangs in the balance. Mine has been a lonely and anxious task. Factoring into my decision has been an absolute respect for the sanctity of life and respect for the wishes of the parents and the Care Agency, as the parties having parental responsibility. But governing my decision and guiding me resolutely has been consideration of, and determination of, what is in the best interests of this child.

63 T is a precious little boy in a desperately sad situation, which, despite its impressive advances, modern medicine cannot cure or improve. I have no doubt that all parties—his mother, his family, the Care Agency and the medical health care team—want what is best for T. It is unfortunate that they cannot agree what that is. The natural instinct of us all is the prolongation of life, but that cannot be at any cost. To inflict further pain and distress on this fragile baby, so afflicted by extreme disability and illness, with no prospect of recovery or improvement of quality of life, is not in his best interests.

64 For these reasons, I grant the declarations in the terms set out by me in para. 7 of this judgment.

Application refused; declarations granted.