

Do Parents Have a Right to Determine Where a Child Patient Dies?

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I. Introduction

In a most unusual chapter, it will now be discussed whether parents have a legal right to take their gravely ill children home to die. After four unsuccessful public appeals, there were two additional private hearings for baby Charlie Gard to focus solely on the time and place of his death.¹ Chris Gard and Connie Yates, his parents, tried to control his ending to spend “precious time” with their son but the High Court, after hearing arguments from Great Ormond Street Hospital (GOSH), refused to grant their wishes. On what legal ground might the parents have argued a case for taking their son home to die?²

Four potential legal avenues will be explored: (i) the current law on parental autonomy will be studied in the narrow context of death to reveal if there is a right to take a child home to die; (ii) the common law of best interests will also be studied to reveal if a home death could be in the “best interests” of a child; (iii) a new avenue will be explored in “care” law under the Children Act 1989 (if ventilation is removed in a hospital setting first); and (iv) it will be debated whether attempting to control the

¹ On Tuesday, 25th July 2017, and Thursday, 27th July 2017, in the High Court (unreported).

² The main legal issue for Alfie Evans was international travel to the Vatican after his brain, due to an unknown progressive disorder, had all but wasted away: *Evans & James v Alder Hey Children’s NHS Foundation Trust & Evans* [2018] EWCA 984 (Civ), but for Charlie Gard, the legal fight went one step further to control the time and place of his death. This chapter will therefore focus on Charlie Gard.

death of a child is simply a “preference” or “desire” that, owing to its impractical nature, could not be enforced in court.

It will be concluded that notwithstanding a peaceful environment, parents do not have an absolute legal right to control the death of their child, particularly when the plan involves futile treatment at home to “buy more time.” However, if palliative care is viewed as “care” rather than “treatment” it may be administered at home under the Children Act 1989 as long as it does not cause significant harm to the child.

II. “A Mother’s Promise”

We start from the final public appeal hearing dated Monday 24th July 2017 – *Great Ormond Street Hospital v Yates, Gard & Gard*³ - whereby Charlie’s parents accepted after fresh scans that their son was beyond medical help and discussions turned to taking him home to die.⁴ GOSH attended the first of two private hearings the next day to draw up an end-of-life plan for Charlie, and outlined in a position statement the wishes of the parents in clear terms: “Charlie’s parents want him to be with them and ventilated at home for several days before receiving palliative care.”⁵ Their barrister Grant Armstrong described it as “their final wish” to experience “tranquillity outside the hospital” with their son, to have a choice in “the circumstances in which Charlie’s passing will be conducted” before he died, and to spend the “maximum amount of time

³ [2017] EWHC 1909 (Fam).

⁴ For a discussion on the issues raised by the Gard appeals, see: D. Wilkinson and J. Savulescu. “Hard Lessons: Learning From the Charlie Gard Case,” *Journal of Medical Ethics*, published online: 2 August 2017, doi: 10.1136/medethics-2017-104492; J. Bridgeman. “Gard and Yates v GOSH, the Guardian and the United Kingdom: Reflections on the Legal Process and the Legal Principles,” *Medical Law International* 17:4 (2017): 285-302; E. Cave, E. Nottingham. “Who Knows Best (Interests)? The Case of Charlie Gard,” *Medical Law Review* 26:3 (2018): 500; J. Lombard. “Navigating the Decision-Making Framework for Patients in a Minimally Conscious State,” *Medico-Legal Journal of Ireland* 22:2, (2016): 78-87; and A. A. Sheikh. “Medico-Legal Issues at The End of Life: Recent Highlights,” *Medico-Legal Journal of Ireland* 23:1 (2017): 2-7.

⁵ Great Ormond Street Hospital, statement dated 25th July 2017, at paragraph 3. <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> (accessed November 3, 2018).

they have left with Charlie.”⁶ The High Court was called upon to approve a plan because the hospital would not let Chris and Connie take Charlie home for a further week of futile intensive care, causing talks with palliative care consultants at the hospital to break down.⁷ GOSH felt that a dignified death was at risk:

Charlie is a child who requires highly specialised treatment. His care cannot be simplified. It must be provided in a specialist setting by specialists. It is in Charlie’s best interests that the risk of a precipitate, distressing or disordered death is removed so that he may be assured of a peaceful and dignified passing.⁸

GOSH put a suggestion forward - a family-friendly hospice - but time would be limited because it was not licensed or insured to deliver intensive care overnight.⁹ Mr Justice Francis gave the parents two days to find an intensive care team for their flat or the hospice who were willing to provide futile intensive care, but hinted that a hospice, with removal of ventilation shortly afterwards, was the realistic option.¹⁰ Chris and Connie were unable to do so. Mr Justice Francis therefore ruled in the final private hearing on Thursday, 27th July 2017, that Charlie was to be moved to a hospice the next day and extubated within a few hours of arrival. Connie Yates expressed her sadness when leaving the High Court:

[GOSH has] denied us our final wish. We just want some peace with our son – no hospital, no courts, no media – just quality time with Charlie away from everything to say goodbye to him in the most loving way. We’ve had no control over our son’s life and no control over our son’s

⁶ R. Mendick, D. Boyle. “Charlie Gard’s Parents Accuse Hospital of Blocking ‘Final Wish’ for Baby to be Allowed Home to Die,” *The Telegraph*, 25th July 2017. <https://www.telegraph.co.uk>.

⁷ See GOSH statement dated 25th July 2017, at paragraph 2. <https://www.serjeantsinn.com/news/charlie-gard-position-statements/> (accessed November 3, 2018).

⁸ *Ibidem*, paragraphs 1-5.

⁹ *Ibidem*, paragraphs 8-9.

¹⁰ M. Holden. “Parents, UK Hospital Clash Over Taking Baby Charlie Gard Home to Die,” *Daily Mail*, 25th July 2017. <https://www.dailymail.co.uk>.

death. I'm shocked that after all we've been through, they won't allow us extra time...we promised Charlie every day we would take him home. It seems really upsetting, after everything we've been through, to deny us this.¹¹

GOSH responded in a statement that it had

tried absolutely everything to accommodate their final wishes...including exploring the unprecedented step of delivering intensive life support away from a hospital intensive care unit [but] there is simply no way that Charlie, a patient with such severe and complex needs, can spend any significant time outside of an intensive care environment safely. The risk of an unplanned and chaotic end to Charlie's life is an unthinkable outcome for all concerned and would rob his parents of precious moments with him.¹²

On the morning of Friday, 28th July 2017, hospice staff transferred Charlie and his parents to a hospice 45 minutes away and they had a few hours to say goodbye. They took him into the garden, made casts of his hands and feet, and took plenty of pictures with him. The ventilator was disconnected at 15:12 PM and he died twelve minutes later. Charlie was given a temperature-assisted "Cuddle Cot" so his parents could take him home (the equivalent of lying in state) for a few days.

On the face of it, the final wish of the parents does seem understandable in the circumstances. So, were they right? Did they have a legal right to take Charlie home to die? The answer is, it depends on whether medical treatment is involved in the plan as to how much control is enjoyed. Chris and Connie did not only wish to take Charlie

¹¹ Press Association. "Charlie Gard's Parents Prepare for Final Farewell After Hospice Move," *Daily Mail*, 28th July 2017. <https://www.dailymail.co.uk>; "Charlie Gard's Parents Denied Final Wish After Judge Approves Hospice Plan," *Daily Mail*, 10th August 2017. <https://www.dailymail.co.uk>; and M. Robinson. "Charlie Gard's Anguished Parents Concede He Must End His Days in Hospice – Yet They Still Cannot Agree with Doctors How He Should be Cared for in his Last Hours," *Daily Mail*, 28th July 2017. <https://www.dailymail.co.uk>.

¹² Great Ormond Street Hospital, 27th July 2017. <https://www.gosh.nhs.uk/news/latest-press-releases/latest-statement-gosh-patient-charlie-gard> (accessed November 3, 2018).

home to die, but they wished to administer futile intensive care for an additional week in their ground floor flat, without a specialised team, to say goodbye to their son in their own time and on their own terms. This plan caused legal difficulties because of its futility. The four potential legal avenues for parents in this unusual situation are now explored below.

A. Avenue 1: Does the Existing Law on Parental Autonomy Support Control Over Death?

The definition of “parental responsibility” under section 3(1) of the Children Act 1989 is very wide, including: “the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.”¹³ It is also a criminal offence to fail to provide “medical aid” to a child under section 1(2)(a) of the Children and Young Persons Act 1933. The common law regarding parental authority, however, is also clear that even though parents must make decisions about medical treatment, parental authority is subservient to the inherent jurisdiction of the High Court.¹⁴ So, can parental authority be extended to cover the death of a child? There are flickers of support for this idea in the case law. Lord Bingham MR in *Re Z (Identification: Restrictions on Publication)*¹⁵ noted that: “I would 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.”¹⁶ A unique scenario occurred in *Re T (A Minor) (Wardship: Medical Treatment)*¹⁷ whereby the parents of a young boy refused a liver transplant for their son and the court supported this decision:

¹³ Parents have a “large measure of autonomy in the way in which they discharge their parental responsibilities” according to *R v Secretary of State for Education and Employment and Others* [2005] UKHL 15, per Baroness Hale of Richmond at paragraph 72.

¹⁴ *Re A (Children) (Conjoined Twins: Surgical Separation)* [2000] Fam 147 at 178-179; and *Re W (A Minor) (Medical Treatment: Court’s Jurisdiction)* [1993] Fam 64 at 78.

¹⁵ [1997] Fam. 1.

¹⁶ *Ibidem*, pp. 32-33.

¹⁷ [1997] 1 WLR 242.

The welfare of this child depends on his mother. She will have to comply with the court order, return to this country and present the child to one of the hospitals. She will have to arrange to remain in this country for the foreseeable future. Will the father stay in country AB and work or come with her to England, giving up his job and having to seek another job? If he does not come she will have to manage unaided. How will the mother cope? I believe that the best interests of this child require that his future treatment should be left in the hands of his devoted parents.¹⁸

The decision in *Re T* allowed the parents to reject a life-saving liver transplant for their son due to lifestyle, stress, travel, and employment factors. It was also confirmed in *Glass v United Kingdom*¹⁹ that to treat a child without the consent of the parent interferes with the human rights of the patient (Article 8) and that in the event of a disagreement, court approval is required.²⁰ *Glass* concerned treatment rather than withdrawal, but it places parents in a position of authority whereby their consent (or lack thereof) is the gateway to medical treatment, rendering doctors powerless until the court intervenes.²¹ Parental autonomy is also supported by section 31(2) of the Children Act 1989 whereby a court's jurisdiction is limited to making care or supervision orders if a child is likely to suffer "significant harm" through unreasonable parenting. On the face of it, the ambit of parental responsibility appears to be wide enough to include death.

However, the question of whether parents have authority over the death of their child ultimately rests on whether medical treatment is part of the plan and the doctors agree with it. Lord Oliver stated in *KD (A*

¹⁸ *Ibidem*, pp. 250-255. For a detailed critical analysis of this case, see: M. Fox and J. McHale. "In Whose Best Interests?," *Modern Law Review* 60 (1997): 700-709.

¹⁹ [2004] 39 EHRR 15.

²⁰ *Ibidem*, paragraphs 70 and 75. It was also confirmed in *Lambert v France* [2016] 62 EHRR 2 that court is the best option when doubts arise as to the best interests of the patient (at paragraph 143).

²¹ This was supported in *Re B (A Minor) (Wardship: Sterilisation)* [1988] A.C. 199; *Re W (A Minor)* [1993] Fam. 64; *Re J (Specific Orders: Child's Religious Upbringing and Circumcision)* [2000] 1 FLR 571; and *B (Child)* [2003] EWCA Civ 1148.

Minor) (*Ward: Termination of Access*)²² that: “the natural bond and relationship between parent and child gives rise to universally recognised norms which ought not to be gratuitously interfered with and which, if interfered with at all, ought to be so only if the welfare of the child dictates it.”²³ In *Gard*, the court ruled that it did not support the welfare of Charlie to continue his ventilation,²⁴ meaning that when Chris and Connie proposed to continue the futile intensive care at home, the court was entitled to intervene. The hospital was also under no obligation to support the ventilation once it was rendered futile.²⁵ It could also be said that the decision in *Re T* was wrongly decided because it placed a greater weight on the lifestyle of the mother than the grave predicament of her son. It has not been followed by any other case since.

The parental autonomy avenue is therefore unavailable to parents wishing to take their child home to die if their wish includes futile treatment: the court can simply override their wish to ensure that the child is spared treatment that is not in his best interests.

B. Avenue 2: can it be in a child’s “best interests” to die at home?

A second possibility is whether the best interests test can be interpreted to include a home death. This may offset the futility of the treatment, for example, if there is some form of benefit to be gleaned.²⁶ This route may be phrased as follows: “is the continuation of treatment at home with the ultimate aim of ending life surrounded by family in the best interests of the child?” The case law on best interests supports a comprehensive test which could include a home death. For example, the case of *Re A (Male*

²² [1988] AC 806.

²³ *Ibidem*, pp. 824-825.

²⁴ *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 972 (Fam).

²⁵ Indeed, the case of *Portsmouth NHS Trust v W* [2005] EWHC 2293 confirms that a doctor need not act if it is against his “professional conscience, intuition or hunch” per Hedley J at paragraph 56, following on from Lord Donaldson MR in two cases: *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at 41; and *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507 at 516.

²⁶ The best interests test is only applicable if medical treatment is involved in the home death, so if the parents agree to withdrawal in a hospital and *then* take their child home to die, there may be no need for a best interests test. This option will be discussed below as “avenue 3.”

Sterilisation)²⁷ interpreted “best interests” to include “medical, emotional, and all other welfare issues.”²⁸ *An NHS Trust v MB*²⁹ also interpreted best interests “in the widest sense” to form a balance sheet of benefits and burdens, including “medical, emotional, sensory and instinctive considerations.”³⁰ *Aintree University Hospital NHS Trust v James*³¹ added that: “decision makers must look at welfare in the widest sense, not just medical but social and psychological.”³² These judgments support the idea that a gravely ill child could die at home surrounded by family if this provides him with an emotional benefit.

However, should that child be unconscious and any emotional or physical benefit be removed, the question then boils down to simply: “is the continuation of futile treatment in the best interests of the child?” The cases cited above are not so supportive when read in the context of futility. *Re A*, for example, stated that “speculative benefits” are not part of the best interests test,³³ and in *Gard* where the court confirmed that there was “nothing to be put on the other side of the balance in favour of preserving life,”³⁴ it is highly unlikely that a child would glean any (even a speculative) benefit from being taken home for futile treatment so as to fulfil the desires of his parents. The court in *MB* also rejected the “wholly irrelevant” wishes of the parents, meaning that the home death would have to confer an actual benefit to the child to be considered.³⁵ The court in *Portsmouth NHS Trust v Wyatt*³⁶ raised concerns that the parents were “projecting [their] intuitive feelings” onto their gravely ill daughter and found that prolonging her life to allow her parents to

²⁷ [2000] 1 FLR 549.

²⁸ *Ibidem*, per Dame Elizabeth Butler-Sloss P at p. 555.

²⁹ [2006] EWHC 507.

³⁰ *Ibidem*, per Holman J. at paragraph 16. See also: *An NHS Trust v A* [2007] EWHC 1696, per Holman J. at paragraph 40.

³¹ [2013] UKSC 67.

³² *Ibidem*, per Lady Hale at paragraph 39.

³³ *Re A* (n 27) per Dame Elizabeth Butler-Sloss P at p. 555.

³⁴ *Yates & Gard v Great Ormond Street Hospital* [2017] EWCA Civ 410, 23rd May 2017, per Lord Justice McFarlane at paragraph 48.

³⁵ *NHS Trust v MB* [2006] EWHC 507, per Holman J. at paragraph 16.

³⁶ [2004] EWHC 2247 (Fam).

control her death was not in her best interests.³⁷ *Re L (A Child) (Medical Treatment: Benefit)*³⁸ - with remarkably similar facts to *Gard* - also determined that even though the term “medical interests” included the emotional need of the baby to bond with his mother, the medical treatment was futile, rendering the balance sheet in favour of withdrawal.³⁹ Therefore, the best interests test when applied to a home death leads to the same negative result as seen in *Gard* if medical treatment is involved: the continuance of futile treatment will not be in the best interests of the child. The only benefit is to the parents. It is a well-established principle going back to *Re J (A Minor) (Wardship: Medical Treatment)*⁴⁰ that futile treatment must be withdrawn, as per Lord Donaldson MR: “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.”⁴¹

It is worth noting that substituted judgment is also not an option. Desperate parents may use phrases such as: “he would have wanted it” or “this would have been his wish if he were awake” to substitute the consent of the child, but the idea of a substituted judgment was removed from minors in *Airedale NHS Trust v Bland*⁴² and removed from incompetent adults in *Re F (Mental Patient: Sterilisation)*.⁴³ A best interests test is now deemed more appropriate.⁴⁴ There is a glimpse of substituted

³⁷ Per Hedley J. at paragraph 34. For further discussion, see: M. Brazier, “An Intractable Dispute: When Parents and Professionals Disagree,” *Medical Law Review* 13:3 (2005): 412.

³⁸ [2004] EWHC 2713.

³⁹ *Ibidem*, per Dame Elizabeth Butler-Sloss P at paragraph 26.

⁴⁰ [1991] Fam. 33.

⁴¹ *Ibidem*, p. 47.

⁴² [1993] AC 789, per Lord Goff and Lord Mustill at pages 871-872 and 894-895 respectively.

⁴³ [1990] 2 AC 1, per Lord Brandon at 55.

⁴⁴ For further discussion on the inappropriateness of substituted judgment on minors, see: L. Cherkassky. “Children and the Doctrine of Substituted Judgment,” *Medical Law International* 1 (2015): 1-23; D. Tomkin, P. Hanafin. “Medical Treatment at Life’s End: The Need for Legislation,” *Medico-Legal Journal of Ireland* 1:1 (1995): 3; and C. Somers. “Deciding Obliquely and by a Side

judgment in *Aintree* whereby Lady Hale said: “[the doctors] must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be,”⁴⁵ but this was an incompetent adult case whereas the statutory best interests test under section 4(6) of the Mental Capacity Act 2005 requires the medical team to ascertain the wishes and feelings of the patient during his competent years. It does not substitute his judgment - it tries to ascertain his actual judgment - and so it would not be applicable to children who had not yet lived a full life. The best interests’ avenue is therefore closed to parents if futile treatment is involved in the home death.

C. Avenue 3: a new approach under Care Law

Let us now remove futile medical treatment from the equation and simply pose the legal question as follows: “do parents have a right to take their gravely ill child home to die?” The answer appears to be “yes.”

Parents who agree to withdraw ventilation at the hospital before taking their child home remove any medical element from the equation, leaving the Children Act 1989 to govern their parental responsibility under “care” law. This requires a welfare test under section 1(1) which stipulates: “when a court determines any question with respect to the upbringing of a child, the child’s welfare shall be the court’s paramount consideration,” but a court can only intervene and apply this test if there is a risk of “significant harm” to the child under section 31(2), which states:

A court may only make a care order or supervision order if it is satisfied that the child concerned is suffering, or is likely to suffer, significant harm and that the harm, or likelihood of harm, is attributable to the care given to the child, or likely to be given to him if the order were not made, not being

Wind: Substituted Judgment and End-of-life Decisions for Minors,” *Medico-Legal Journal of Ireland* 19:1 (2013): 11.

⁴⁵ *Aintree* (n 31), paragraph 39.

what it would be reasonable to expect a parent to give to him.⁴⁶

A home death has not yet been debated within the context of care law, nor has a court yet ruled on it, but perhaps it may offer a legal avenue for future cases like Charlie Gard?⁴⁷

Chris Gard and Connie Yates did try to exert their parental authority using section 31(2) to argue that taking Charlie abroad for innovative treatment did not breach the threshold of significant harm and therefore the courts had no place to intervene. This was successful in the earlier case of *Re King*⁴⁸ whereby Baker J said:

it is a fundamental principle of family law in this jurisdiction that responsibility for making decisions about a child rest with his parents. In most cases, the parents are the best people to make decisions about a child and the State – whether it be the court, or any other public authority – has no business interfering with the exercise of parental responsibility unless the child is suffering or is likely to suffer significant harm as a result of the care given to the child not being what it would be reasonable to expect a parent to give.⁴⁹

Nevertheless, Lord Justice McFarlane in the Court of Appeal in *Gard*⁵⁰ quickly rejected the idea that care law could govern medical treatment and restated the importance of the common law of best interests:

Best interests is the established yardstick which applies to all cases... Mr Justice Baker's words provide no basis for saying that he was holding that any test based on significant harm

⁴⁶ For further discussion, see: C. Auckland and I. Goold. "Defining the Limits of Parental Autonomy: Charlie Gard, Best Interests and Risk of Significant Harm Threshold," *Law Quarterly Review* 134 (2018): 37-42.

⁴⁷ It should be noted, however, that pain relief (palliative care) may be considered medical treatment, so there might still be medical interference with parental autonomy. This is unclear without existing case law.

⁴⁸ [2014] EWHC 2964.

⁴⁹ *Ibidem*, paragraphs 31 and 34.

⁵⁰ *Yates & Gard v Great Ormond Street Hospital* [2017] EWCA Civ 410.

is to be applied to cases relating to the medical treatment of children.⁵¹

However, should Chris and Connie have agreed to withdraw ventilation at the hospital and *then* take Charlie home to die, the need for a best interests test would have dissolved, paving the way for the 1989 Act. The legal question would then be rephrased as follows: does taking Charlie home to die carry a risk of significant harm under section 31 of the 1989 Act? One can only imagine that, with adequate pain relief, and notwithstanding his inevitable natural death, the answer would be “no.”

There may be a potential barrier to this legal avenue. No common law exists at present, but a local authority may disagree with the parents that taking their child home to die will not cause him significant harm. This impasse would result in the High Court invoking its inherent jurisdiction to rule on the matter under section 100(4) of the 1989 Act, which states that the court must have “reasonable cause to believe” that if its inherent jurisdiction is not exercised, a child will suffer “significant harm.” The courts may find it harder to overrule parents in a “death only” scenario if the parents have already agreed to withdraw futile treatment in the hospital.

The recent case of *Re C (Children)*⁵² demonstrates how the law works in practice and how the courts might deal with a home death scenario. A mother wished to name her daughter “Cyanide,” so the local authority sought the inherent jurisdiction of the High Court under section 100(4) of the 1989 Act. The three legal questions to be answered at appeal were: (i) whether the local authority had the statutory power to prevent the parents from naming their children; (ii) whether the local authority, if they did have this power, needed to ask the court to sanction its authority, and (iii) whether the naming of children was serious enough to come under the inherent jurisdiction of the court. All three questions were answered affirmatively, allowing the court to explain in detail why certain “unusual, bizarre, extreme or foolish” parents required court intervention.⁵³

⁵¹ *Ibidem*, paragraphs 74 and 104.

⁵² [2016] EWCA Civ 374.

⁵³ *Ibidem*, per King LJ, paragraph 105.

In answer to the first question, the local authority did have the power under section 33(3)(b) of the 1989 Act to determine how parents meet their parental responsibility, which states:

while a care order is in force with respect to a child, the local authority designated by the order shall: (a) have parental responsibility for the child, and (b) have the power to determine the extent to which [a parent] may meet his parental responsibility for him.”

Lady Justice King described this provision as a “trump card” allowing a local authority to intervene with the “rights, duties, powers, responsibilities and authority” of parents under section 3(1).⁵⁴ There are limitations to this power listed under sections 33(6) and (7) whereby the local authority cannot act without a court order (such as taking a child abroad) but nothing is listed about forenames, allowing the local authority in *Re C* to: “exercise its parental responsibility under section 33(3) in order to prevent the mother from giving her twins the forenames of her choice.”⁵⁵ A home death would come under the ambit of section 33(3)(b) because it is not carved out as an exception under sections 33(6) and (7) requiring a court order. The local authority has the statutory authority to intervene with preventative measures.

In answer to the second question, the local authority was right to ask the court to sanction its statutory power owing to the potential breach of the human rights of the parents (per Lady Justice King):

the mother has a safety net in that she may apply for an injunction under section 8 of the Human Rights Act 1998 ... such a decision involves such a serious invasion of the Article 8 rights of the mother that I am satisfied that the court should invoke its inherent jurisdiction in order that it may either sanction the local authority’s proposed course of action as in the interests of the child.⁵⁶

⁵⁴ *Ibidem*, paragraphs 59 and 64.

⁵⁵ *Ibidem*, per King LJ, paragraphs 61, 65 and 66.

⁵⁶ *Ibidem*, per King LJ, paragraphs 75, 77 and 98. King LJ also confirmed that the court was there to “limit, circumscribe or sanction” the existing power of the local authority under section 33(3)(b), not “confer” the power onto the local authority (at paragraph 97).

A home death is also a private and family matter, so an action by the local authority to prevent it may constitute an unjustifiable interference of the right to respect for the private and family life of the family (both the parents and the child) under Article 8 of the European Convention of Human Rights.⁵⁷ The local authority, therefore, notwithstanding its statutory powers under section 33(3)(b) to prevent the home death to avoid significant harm to the child, may still have to invoke the inherent jurisdiction of the court to sanction its preventative measures. It would then be for the court to decide whether there is an unjustified interference under Article 8 and whether there is a risk of significant harm to the child. There is no indication as of yet as to how the court would decide this matter.

In answer to the third question, and notwithstanding the potential human rights breach, naming a child “Cyanide” was deemed by Lady Justice King to be serious enough to invoke the inherent jurisdiction of the court. The “significant harm” test under section 31(2) was applied at this point to answer the pivotal question posed by section 100(4): “whether there is reasonable cause to believe that if the court’s inherent jurisdiction is not exercised with respect to the child [she] is likely to suffer significant harm.”⁵⁸ Lady Justice King concluded that:

in my judgment, although it will only rarely be the case, there is every reason to believe that if the court’s inherent jurisdiction is not invoked in order to prevent the girl child from being named Cyanide, she is likely to suffer significant harm.⁵⁹

King LJ then carved out a “special category” of cases for future reference that could be applicable to home deaths:

I have reached the conclusion that there is a small category of cases where, notwithstanding the local authority’s powers under section 33(3)(b), the consequences of the exercise of a particular act of parental responsibility are so profound and have such an impact on either the child or the Article 8 rights

⁵⁷ *Ibidem*, per King LJ, paragraph 75.

⁵⁸ *Ibidem*, per King LJ, paragraph 101.

⁵⁹ *Ibidem*, paragraph 102.

of those other parties, that the matter must come before the court for its determination.⁶⁰

It is highly probable in a home death scenario that taking a child home to die falls within the “special category of cases” that requires court approval. This is because, first, the child may suffer intense pain or distress once his life-sustaining treatment has been removed. Secondly and conversely, the consequences of not letting the parents do this would almost certainly interfere with their rights under Article 8.⁶¹ It is also fair to say that, if the name “Cyanide” is deemed by the courts to cause significant harm, then taking a gravely ill child out of hospital will almost certainly attract the attention of the law.

The first home death case, therefore, may decide the following: (i) the local authority has the statutory power to prevent parents from taking their child home to die under section 33(3)(b) because it is not listed as an exception requiring a court order under sections 33(6) and (7) of the 1989 Act; (ii) the local authority will need to ask the court to sanction its preventative measures because a home death falls into a special category of cases whereby the human rights of numerous parties may be interfered with; and (iii) a home death is serious enough to fall within the inherent jurisdiction of the court because of the risk of significant harm to the child. It is very difficult to predict how the court will answer this final and pivotal question, but the complexity of the grave illness and the level of pain relief will be decisive factors. In favour of the parents, palliative care is easier to administer at home than intensive care, and once the medical treatment of a child ceases, the hospital has no legal grounds upon which to further detain the patient. This would be a deprivation of his liberty under Article 5 (a theory also unexplored by the courts in the context of home death thus far).⁶²

⁶⁰ Ibidem, paragraph 104.

⁶¹ It was confirmed in *Lambert v France* [2016] 62 EHRR 2 that relatives who were also victims of a human rights breach may have scope for an action under human rights law.

⁶² It should be noted, however, that this section is underpinned by the assumption that “medical treatment” stops when ventilation is withdrawn. If palliative care (pain relief) is considered to be medical treatment too, we have a completely different scenario: we return back to the “doctors versus parents” scenario under the common law of best interests as per the *Gard* case. There is

D. Avenue 4: it is not a legal right but a fanciful whim dependent on practicalities

Chris Gard and Connie Yates asked to take Charlie home for an extra week of futile intensive care before withdrawing his ventilation. This idea has now been explored and it is clear that parents do not have a legal right to continue futile medical treatment in order to create an “ideal” death for their child. The cases of *Re King*⁶³ and *Re C (Children)*⁶⁴ presented a more viable option, which is to take a child home to die *after* futile treatment has been withdrawn, but this may only be viable if the doctors are supportive of palliative care (pain relief) in a private dwelling under “care” law (the Children Act 1989). The courts have not ruled on this matter yet, but should a disagreement arise in future and the courts agree with the doctors that palliative care is to be administered in hospital to avoid significant harm to the child, the parents have no legal avenue left except to plead that it is their “wish” to take their child home.

How unreasonable is this wish? Two days after the European Court rejected their appeal, Chris and Connie posted devastated video messages on YouTube describing how they felt unable to control their son’s death (on Thursday 29th of June 2017):

We’re not allowed to choose if our son lives and we’re not allowed to choose when or where Charlie dies. We know what day our son is going to die but don’t get a say in how that will happen.⁶⁵

The public did not feel that Chris and Connie were being unreasonable. On the morning of Mr Justice Francis’ decision to send

no legal authority yet on whether palliative care is regarded as “treatment” or simply “care.”

⁶³ [2014] EWHC 2964.

⁶⁴ [2016] EWCA Civ 374.

⁶⁵ D. Boyle. “Charlie Gard’s Parents Endure ‘Worst Day of Our Lives’ as Doctors to Switch Off Baby’s Life Support Within Hours,” *The Telegraph*, 30th June 2017. <https://www.telegraph.co.uk>; and M. Robinson. “Outpouring of Grief Worldwide for Baby Charlie Gard as his Parents say their Last Goodbyes to their Son as Doctors Switch Off his Life Support after Eight-month Battle,” *Daily Mail*, 30th June 2017. <https://www.dailymail.co.uk>.

Charlie to a hospice, a family friend of Connie Yates posted on Facebook (on Thursday, 27th July 2017):

the hospital has set the bar so high that in terms of [a] clinical team for Charlie's end of life nothing seemed good enough for Great Ormond Street ... Connie and Chris have conceded a hospice but it was not their first choice. They will be devastated they have not been granted their final wishes as parents.⁶⁶

This message reflected a wider sense of public anger that Chris and Connie's final wishes were not respected. However, the public misunderstood three vital issues. First, it was simply not practical to administer futile intensive care in a ground floor flat. GOSH provided a number of reasons for this, including bulky equipment, no qualified experts, and the risk of an "unplanned and chaotic" death which would have been "unthinkable" for the parents.

Secondly, and most importantly, the courts had already ruled that Charlie's ventilation was futile, so it was not appropriate to continue it any further. It is here that the motives of the parents changed too: when they conceded on Monday, 24th July 2017,⁶⁷ that Charlie was beyond medical help, their priorities switched from what was "best for him" to what was "preferable for us," indicating that the best interests of Charlie had expired.

Thirdly, and in a general moral sense, parents cannot control the natural death of their child. They can try to prevent death with proper parenting (e.g. road safety or good diet), and they can try to chase away the threat of death with medical treatment (e.g. chemotherapy), but when these options fail, and natural death is imminent, no parent has the luxury of asking for "one more week." The crux of the two additional private hearings on Tuesday, 25th July 2017, and Thursday, 27th July 2017, was for Chris and Connie to control the time and location of Charlie's death, but parents who tragically lose their children to grave genetic diseases do not have this luxury. Chris and Connie were ultimately playing God when a hand had already been dealt. They were attempting to postpone his

⁶⁶ Press Association. "Anguish of Charlie Gard's Mother as Judge Sets Timetable for End of his Life," *Daily Mail*, 27th July 2017. <https://www.dailymail.co.uk>.

⁶⁷ In *Great Ormond Street Hospital v Yates, Gard & Gard* [2017] EWHC 1909 (Fam).

natural death. The “right” so revered by the public would be better termed as a “preference” or a “desire” that is ultimately relegated by nature.

III. Conclusion

The answer to the opening question: “do parents have a right to determine where a child patient dies?” is that it depends. A request to continue futile intensive care at home (as per Charlie Gard) will not be in the best interests of the child. However, palliative care may be administered at home under the “care” provisions of the Children Act 1989 if it is not considered to be “treatment” (the courts have not yet ruled on this matter but *Re King* and *Re C* provide good guidance as to how the “significant harm” test would apply). Ultimately, however, it is still not an absolute legal right as much as it is a “wish” that is subservient to nature taking its own course, the seriousness of the illness, and the complexity of pain relief required.

There is one final theory to be considered: perhaps Chris and Connie attempted to control the death of their son because their control over his *life* had been removed? Was it a way of “repossessing” their own child? Their frustration was clear after the Court of Appeal ruling (Chris Gard): “When we got the appeal papers they said Connie Yates and Chris Gard against Great Ormond Street Hospital and Charlie Gard and yet he’s our son. It broke my heart when I saw that because how can that be right?”⁶⁸ Connie published an interview after Charlie had died, and the peaceful way she describes those few days at home suggests that all they really wanted was to be his parents again:

Once home, it was lovely to sit and watch him, lying there like any other baby, not surrounded by equipment and machinery, without anything obscuring his lovely face. To just see our Charlie, at home, sleeping in his cot where he should be...it felt perfectly natural to leave the hospice with Charlie and take him home with us. We had got our last wish to bring him home, but Charlie was no longer alive.

⁶⁸ S. Bell. “Charlie Gard Parents to Keep Fighting,” *BBC News Online*, 1st June 2017. <https://www.bbc.co.uk/news>.

Although it was upsetting, at least he was home – finally back where he belonged. It felt like he was ours again.⁶⁹

It is submitted that, if the myriad of legal actions and the adversarial legal documents had been replaced by non-technical mediation (e.g. no medical jargon or intimidating specialists) and a stronger emphasis was placed on the option of taking Charlie home to lie in state for a few days, perhaps Chris and Connie would have been more open to the idea of letting him die in a hospital or hospice, and would have had a glimmer of peace to look forward to in a world of chaotic darkness.

⁶⁹ A. Smith-Squire. “Our Last Hours With Our Son: Charlie Gard’s Parents Emotionally Reveal How They Finally Brought Their Baby Home After he Died in a Hospice and Spent Several Days Saying Their Last Goodbye,” *Daily Mail*, 4th August 2017. <https://www.dailymail.co.uk>.