

Care of dying children and adults. Ethics, principles and issues for law reform

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Background

The cases of Alfie Evans, Charlie Gard, Charlotte Wyatt, David Glass and Ayesha King have all hit headlines and reverberated around the world. Many have been shocked to see doctors applying to the courts in order to curtail treatment against the clearly expressed wishes of the child's parents. Fierce public debates have raged about the appropriateness of withdrawing treatment but even more strongly about also the denial of parents' wishes when plans they have made for their child do not appear unreasonable. Whilst public debate on the appropriateness of withdrawing treatment from the child has been fierce that debate has been yet more fierce on the denial of the parents' wishes to have the treatment continued even though their wishes do not appear unreasonable

My conclusion is that while limitation of treatment and withdrawal of some treatments is appropriate, the de facto removal of parental authority as a result of referral to the High Court is wrong, and deeply unjust. As well as that, I argue that, in the case of Alfie Evans, the decision by the High Court to deny transfer to other care facilities is deeply concerning and should not have happened.

Key issues in the care of dying children and adults

Underlying those conclusions and within all the complexity of the debates there are several key issues each of which I explore further in this paper.

1. The absolute and inherent worth, value and dignity of each human being, however unwell, however disabled and however soon they may be likely to die. The Church and many other religious and faith organisations loudly proclaim and set out that dignity and worth.
2. It is the God given right and duty of parents to be the primary protectors of their children and to make decisions for them. Sadly, in UK law at the moment a case is taken to court UK law removes decision making capacity from the parents and vests it in the Court. Except in circumstances when it is shown that parents are failing to meet their obligation to the child, I believe that that is unjust. Parents who are acting reasonably and making reasonable decisions for their child should not have their authority removed unless they are demonstrated to be failing to meet their serious responsibility to their child. This fundamental principle also needs to apply for decision makers in the care of mentally incapacitated adults.
3. Whether or not the law is reformed in line with point 2, parents and those responsible for decision making in mentally incapacitated adults should have access to mediators and also to legal representation in Court. It is not satisfactory for parents to face the expert solicitors and barristers of hospitals while they are not supported themselves. It is manifestly unjust for parents to face expert solicitors and barristers employed by hospital authorities without equal legal support.
4. Palliative Care for those who are suffering while they die is fully appropriate and right. Alongside that, it can also be right to withdraw treatment which is not beneficial to the

patient or which is excessively burdensome. But with the proviso that a decision to withdraw treatment should not be automatically assumed to be a decision to stop all medical treatment. That is especially strongly the case if clinicians consider that simply administered food and fluids are medical treatment. Here too, UK law (following the case of Tony Bland) is at variance with what we should consider to be good practice.

5. The principle of double effect sets out that it may be right to give some treatments which might shorten life so as to provide symptomatic relief for those who are dying. For some, appropriate treatments will include appropriate doses of morphine and sedatives.
6. In someone who is not symptomatic, treatments (including medicines such as morphine and sedatives) may be a cause of earlier death if they are given inappropriately. If that is done with the intent of hastening death that is deeply wrong.

1. The absolute worth, value and dignity of each human being.

All, people however unwell, however disabled and however soon they may be likely to die are human and fully so. Throughout history, people have championed the dignity of the sickest and weakest members of our society. In Christian tradition this was most powerfully and clearly set out by Jesus Christ with the parable of the Good Samaritan. It is anathema to think that a disabled person is less human than an able one. Or that when we are sick we become less human. To believe that, would lead to a conclusion that doctors, business men and diplomats are more human than factory workers or road sweepers. Which is clearly absurd and absolutely false. One of the great triumphs of the parents of all the recent high profile cases has been the parents' clear attestation of their child's worth and humanity. Doctors and lawyers do not always see that in the same way. In the cases of Charlotte Wyatt^[1] and David Glass^[2], doctors clearly showed their ability to get their assessment of prognosis wrong. In other cases, such as Charlie Gard^[3] and Alfie Evans^[4,5,5], parents clearly championed the humanity and beauty of their children.

The Church and many other religious and faith organisations loudly proclaim and set out that dignity and worth. Parents are to be supported and congratulated when they do it so much more effectively and well.

As with so many other parents who have done a similar thing, it has been truly humbling to see how powerfully the parents of Alfie Evans, Charlie Gard, Charlotte Wyatt, David Glass have demonstrated their children's deep and absolute humanity. We must hope that that humanity will continue to be seen for many years to come.

2. The right and duty of parents to be the primary protectors of their children and to make decisions for them.

Parents have a natural and widely accepted authority to make decisions for their children. That authority must not be unjustly usurped by the state.

As a result of the authorities taking cases to the High Court, UK law sets out that the judge becomes the decision maker in cases like Alfie Evans^[4,5,6] and Charlie Gard^[3]. That transfer of

decision making power occurs regardless of whether not the parents are acting reasonably and whether or not the authorities are acting reasonably or unreasonably. Especially in the cases of Charlotte Wyatt^[1] (see footnote¹) and David Glass^[2], (see footnote²) it is clear that expert opinions about prognosis can be seriously inaccurate.

Under the Children's Act the expectation is that parents will make decisions in the best interests of their child. In the case of "An NHS Trust v MB & Anor [2006] EWHC 507 (Fam)^[7] Mr Justice Holman stated that because "*a dispute has arisen between the treating doctors and the parents, and one [party has] asked the court to make a decision, it is the role and duty of the court to do so and to exercise its own independent and objective judgment*" In other words, merely by being taken to court the decision maker became the court. The judge stated that he was not there to determine whether or not "*the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions*" and went onto say that "*the matter must be decided by the application of an objective approach or test. That test is the best interests of the patient*". He went on to say that "*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.*"

Which means that referral to the Court removes the power of consent that parents have, regardless of whether or not the course of action they are seeking is reasonable and replaces it with a decision about the child's best interests. A decision made by a judge and not by the people closest to that child.

It is clearly right, that when parents are making decisions that are inappropriate or harmful for a child, then there must be a legal mechanism to constrain or remove their decision making authority. But it is my view that in order to take the serious measure of removing from parents the fundamental rights, duty and authority to be decision makers for their child, it should be necessary to clearly demonstrate that the parents' wishes are clearly inappropriate or harmful for that child. The current situation whereby taking the case before a High Court judge means that the judge becomes the decision maker and is expected to make that decision in the child's best interests, listening to the view of parents but not bound by them is unjust. Where parent's cannot be demonstrated to be seriously acting inappropriately or harmfully, UK law should not remove their rights and duties.

The decision that the High Court made for Alfie Evans^[4,5,6] was withdrawal of treatment (in anticipation of his rapid demise) instead of his transfer to another facility. Transfer to Rome was denied on the basis that the flight to Rome might be distressing for Alfie (despite him

¹ Charlotte Wyatt has so far lived for years following the removal of the ventilator.[1]

² David Glass was given morphine by doctors despite the refusal of his family. He deteriorated and his mother removed the morphine and resuscitated hm. While she did that, fight broke out around the patient between family and doctors.. Family members were charged and convicted of later convicted of assault and ordered to be excluded from the hospital. On 28 July 2000 their sentences were reduced on appeal. The European Court held that under Article 8 which provides that: *Everyone has the right to respect for his private and family life, his home, and his correspondence.* David lived to the age of 17 surviving for 5 years after his mother had saved his life. [2]

being described as being in a "semi-vegetative state") and because it was feared that the flight might adversely affect his epilepsy. We should note that had those risks materialised in flight, they might well have been managed by a drug such as midazolam. Evidence presented in court stated that midazolam was (appropriately and with good effect) used in December 2017 to control persistent seizures.^[4] Midazolam was also a central part of the care plan following extubation as part of the end of life plan.^[8] In a difficult to understand and unexplained contrast, when midazolam was proposed as part of a care plan for use in an air ambulance the judgement states "*In particular the Midazolam proposed by Dr Hubner was entirely contra indicated by his medical history*".^[4]

Notwithstanding all that, the Court concluded that it was in the Best Interests of Alfie to be set upon a path which anticipated the rapid deterioration and death of the patient as a result of that decision to withdraw treatment, along with provisions for both fentanyl and midazolam to be given^[8]. I find myself at least a little challenged by those contrasts, for which the judgement gives no explanation. Further, I struggle to believe that the option ordered by the judge was truly in Alfie's best interests. I think that his parents wish was not unreasonable and their views should have been respected by the Court.

Going further, we should perhaps be at least a little concerned that "Best Interests" can be too easily subverted to purposes other than the best interest of the patient. It was held in the Tony Bland case that the "*proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind.*"^[9] The withdrawal of ventilation was also considered to be in the best interest of Charlotte Wyatt and other recent key cases. Especially where an analysis of a person's best interests leads to a decision to embark upon a withdrawal of treatment which anticipates that persons early demise, great caution is required. And when parents or the key advocates have concerns and there is an alternative to that plan, especial care is needed. For Alfie there did appear to be an alternative. His parents' views were not unreasonable and it is far from clear that the course of action, taken in full opposition to his parents views, was truly in his best interests.

The reality was that doctors in the Bambino Gesù Hospital in Rome clearly thought that his life would be short, but they were willing to consider some treatment for longer. While his bleak prognosis was accepted, doctors suggested that he might be kept on the ventilator for longer and be given a tracheostomy and feeding through a percutaneous endoscopic gastrostomy tube.^[4] Which would have continued to show his worth, dignity and value, in accord with his parents' wishes. The court ordered withdrawal of treatment expecting his early death as a result of that.

Clearly when parents are getting decisions wrong and their wishes are harmful to children, the state must remain able to intervene. But where that cannot be demonstrated, I believe that a change in UK law should be enacted to empower parents in situations such as this.

With regard to mentally incapacitated adults the situation is, sadly, very similar. If a mentally incapacitated adult's case is taken to the Court of Protection then the person with decision making authority (the relevant person's representative) will find that the Court becomes the decision maker and their authority on that question is removed. Regardless (as with children) of whether or not the decision they seek is reasonable.

There is a need for reform of the law here. It is not enough, in my view, to require mediation. The test to enable the removal of parental authority should be that the parental view is demonstrated to be unreasonable. It is not enough for an elderly judge who does not know the patient and who does not have anything like the sense of humanity that a parent has for a child, to be placed in a position of final decision making authority when parents are making a decision that is not unreasonable. To do that, is a very serious injustice.

The law must also be compassionate. Parents have very clear duties towards their children. But they also have rights. All human beings are members of society and social beings. Even the smallest and most frail child gives to those around them. And it clearly accords with their humanity that they do that. For parents, that is an especially strong and vital bond and relationship. We should at least, in the light of that be willing to reconsider Justice Holman's statement that parents' *"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."*^[7] Justice Holman describes a parent child relationship in those terms as unidirectional. All healthy parent-child relationships are bidirectional. Are the parents' wishes *"wholly irrelevant"* or do children have at least some interest in the comfort and avoidance of distress for their parents at their parting.

Dame Cicely Saunders the founder of the UK Hospice movement stated that *"How people die remains in the memory of those who live on."*^[10] Alfie Evans' parents clearly suffered greatly as a result of the decision to stop treatment and to prohibit the opportunity of a transfer to Rome. Surely that reality should have, at least a little, affect judges' decisions in cases such as these.

3. Mediation and legal representation in Court

Alfie Evans father Tom had to represent himself in court in February 2018. He had parted company with his original legal team. He had hoped to ask for an adjournment so that he could find a new legal team, but this was rejected by the court.^[11] Although he was supported by Stephen Woolfe (a Member of the European Parliament), that was not adequate. Stephen Woolfe is on record stating this. On 26th April 2018 he said^[12] *"Parents' rights should neither be ignored nor dismissed as irrelevant by hospitals and courts, who believe they know best and have the power, money and resources to overwhelm families who simply want to save their child. "We demand a change in the law to restore the rights of parents in such decisions"* .

"All parents should be allowed an independent advocate to defend their case with the right legal and medical expertise and financial equality of arms. "Now is the time to act. We cannot have another baby, another family, have to go through the struggle and torment the Evans family have. It's time for Alfie's Law."

Whether or not the law is reformed in line with point 2, parents and those responsible for decision making in mentally incapacitated adults should have access mediators and also legal representation in Court. It is not satisfactory for parents to face the expert solicitors and barristers of hospitals while they are not supported themselves.

4. Palliative Care and appropriate withdrawal of treatment

Palliative care which aims to alleviate suffering in those who are dying is, of course, fully appropriate and right. In addition to that palliation of suffering, it can also be right to withdraw treatment which is not beneficial to the patient or which is excessively burdensome. For example, if antibiotics are no longer going to have an effect they need not be given. And if a ventilator is being used in a severely unwell person with little or no chance of recovery, removal of that may also be appropriate.

But there is an important proviso. A decision to withdraw treatment should not be always be assumed to be a decision to stop all medical treatment. Especially if clinicians consider that simply administered food and fluids are medical treatment. Following the Bland judgement, UK medical law has assumed that the administration of food and fluids by tube is medical treatment. That has been questioned and intuition tells us that something that can be done easily and simply while out and about shopping or on a day-trip to the beach is not the same as intensive medical treatment and ventilation. But it is clear, reading the judgment regarding Alfie Evans in February 2018 along with the care plan that the hospital had approved by the Court^[8], that stopping ventilation was also thought to mean stopping all other active treatment as well as monitoring etc. The Court hearing on 24th April heard that his parents “*begged the Hospital staff to provide some oxygen to him*”, as well as nutrition for Alfie.^[6] the Court then heard that “*The staff refused to do so for six hours on the grounds that the Court had ordered it was not in Alfie's best interests for his life to be supported.*”^[6]

The key point here is that it should be possible to withdraw or withhold ventilation, or perhaps antibiotics for infections, while still allowing and giving fluids and some nutrition. We should dispute a medical and legal view that all care is treatment and should be stopped all at once. I continue to believe that the withdrawal of simply administered fluid and food from patients, with the result that they will die is deeply wrong. Therefore, following the case of Tony Bland, UK law is at variance with what we should consider to be good practice.

5. Double effect in palliative care

The principle of double effect requires states that it can be right to give treatments which may have a harmful effect if that is necessary to enable a good effect.

The Principle of Double Effect requires that the following four conditions must apply in order for the action to be morally permissible.

1. The action itself must be good, or at least morally neutral.
2. The intention of the act must be good and the bad consequences must not be intended, though they may be foreseen.
3. The good consequences must not arise from any evil action. One should never do evil so that good may come.
4. The good result must be proportionate to the bad consequences.

Therefore, it may be right to give some treatments which might shorten life so as to provide symptomatic relief for those who are dying. For some, appropriate treatments will include appropriate doses of morphine and sedatives.

6. Double effect or the intent to kill?

But if the person is not suffering, or if the doses given are clearly excessive, and especially if death is intended as the consequence of administering drugs such as morphine or sedatives then, (even in) a dying person, giving those drugs continues to be wrong and constitutes killing. We must not kill, but we should, reasonably, sensibly and appropriately palliate.

It follows that while it is appropriate to use analgesia and sedation in a dying person who is in pain, distressed or suffering, that analysis is different where the person does not require medication to alleviate those symptoms. Such medications could (and probably would) hasten death in a child (or adult) who is already struggling to breathe. Inappropriate sedation and fluid deprivation in a child (or adult) who is struggling to breathe is incompatible with survival and wrong.

Therefore, in someone who is not symptomatic, treatments (including medicines such as morphine and sedatives) may be a cause of earlier death if they are given inappropriately. If death is intended, that is clearly wrong.

Conclusion

1. In the case of Alfie Evans, UK law removed the right of the parents to make decisions for their child. The parents' decision making authority was removed by the fact that the case went to Court. Even though there are grounds to believe that the option they sought was both viable and reasonable, the Court vested in itself the authority to decide. Parental authority was usurped. I continue to struggle to believe that the option ordered by the judge was truly in Alfie's best interests. I think that his parents wish was not unreasonable and their wishes regarding a transfer to Rome should have been respected by the Court.
2. While mediation might help these situations, the law requires reform because of the way in which UK law removed parental authority.
3. Palliative care and withdrawal of treatment can be both right and appropriate. But treatments must not be given with the intent to kill.

References

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- [6] Alder Hey Children's NHS Foundation Trust v Evans & Anor [2018] EWH 953 (Fam). Applications in respect of Alfie Evans, including that he be transferred to an alternative medical provider in Rome.
- [7] An NHS Trust v MB & Anor [2006] EWHC 507 (Fam). An application by an NHS Trust for declaration that it would be lawful to withdraw ventilation form a child suffering
- [8] The care plan was not published in the UK but was published in the USA and widely available in the UK. It can be seen at <https://www.livesitenews.com/news/chemical-suffocation-how-doctors-want-alfie-evans-to-die>
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